

# *Patterns of* Supported Living A Resource Catalogue

Developed for:  
California Department of Developmental Services  
1600 9th Street  
Sacramento, CA 95814  
D.D.S. Contract No. Hd290099

by:

*Allen, Shea & Associates*  
1040 Main Street, Suite 200B  
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and  
Claudia Bolton

*Patterns of*  
Supported Living  
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6/93

# Acknowledgements

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This catalogue of resources represents the experiences and thoughts of people throughout California, the United States and Canada. We drew upon the work of people who have been pioneers in helping people with developmental disabilities achieve supported lives and in developing supported living services. In leading us forward and for starting it all, we express our appreciation to Angela Amado, Bruce Anderson, Pat Beeman, Dale Dileo, George Ducharme, Cathie Duchesne, Sharon Gretz, Kathy Bartholomew-Lorimer, John McKnight, Beth Mount, Robert Perske, Julie Racino, Bonnie Schoultz, David Schwartz, Judith Snow, Jeff Strulley, Steve Taylor, Colleen Wieck, and Joe Wykowski. We spoke with many of these people in the process of creating this resource and you'll recognize the presence of their work as you read on. Their contributions have challenged, taught and guided us in understanding supported living. We want to acknowledge Paul H. Brookes and Brookline Press for publishing the work of many of our teachers. Also, thanks to Responsive Systems Associates for permission to reproduce copyrighted materials attributed to John O'Brien.

We especially want to thank our Project Advisors who are also pioneers leading us down this new path: Becky and Joe Donofrio, Charles Galloway, Debra Tweit Hull, Gail Jacob, Jay Klein, Hector Mendez, Mark Rice, Richard Rosenberg, Connie Saverino, and Mary Ellen Sousa. They gave of their precious time and contributed examples, ideas and resources. We especially want to thank Connie Saverino for developing an extensive listing of community and generic resources. In addition, the support and encouragement we received from Julia Mullen, Rebecca Sandoval, Dale Sorbello and Randy Ferguson at the Department of Developmental Services made this all possible.

A modest man of great wisdom, John O'Brien, deserves special mention. John has been the mentor for many of us doing this work, he has helped us, as he would put it, *to find truth through reflection on our experiences and the experiences of others*. He has a way of helping us figure out and realize that which we already know.

# Preface

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**W**e must also acknowledge people with disabilities who in the end have been our ultimate teachers. We appreciate the many people who were willing to share their lives with us and to let us include their personal stories.

# Preface

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We all lead supported lives and that support comes from all over. It might be a doctor, mechanic, or a friend. We all need to remember that while some of us might need supported living services, they are just one of the means to a supported life, not the end.

Charles Galloway, 1993

At one point in completing this work, we were overwhelmed by how it could easily go wrong. That is, we could just paint a picture called *Supported Living* and hope for the best as people tried to reproduce it. Instead, we've opted to tell you about a number of patterns of supported living. Patterns that represent unique individuals and how they've developed a life pattern that works for them. Sometimes you'll notice that it includes *supported living services* and sometimes it does not. What you will notice is that these patterns always include relationships among people in communities all over California.

Claudia Forrest  
John Shea  
Bill Allen



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# Introduction

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I started out with the idea that I, as a human service worker, should be as invisible as possible. I've come to believe that sometimes this is true and sometimes it's not. Again, there was no one answer. The challenge became to discover what our role might be, finding the ways to not impose or change the natural flow of communities but to still somehow guide them in finding and being open to the contributions their members with disabilities could make.

David B. Schwartz  
*Crossing the River*  
*Creating a Conceptual Revolution*  
*in Community and Disability*

A *conceptual revolution* (Schwartz, 1992) is occurring in the way people with disabilities are perceived and the ways in which they are supported. People with disabilities have been teaching us that they have unique gifts to offer and that we need to listen to them to figure out how to support them. People in the social service professions are starting to recognize that building effective services starts with building relationships with people who have disabilities. A shift from the traditional isolation and segregation of the residential service system to supported living services is just one indicator of the conceptual revolution. There are parallel shifts occurring in the education and employment fields as well. Common to all of these changes is a commitment to the value and dignity of each person and the value of diversity in our world.

Supportive living services allow us a channel for participating in and benefiting from this conceptual revolution. Supported living services are creating exciting opportunities for all of us. An opportunity to recognize people's gifts, to stand by others and to help them build a supported life. An opportunity to build relationships based on mutual trust and respect. An opportunity to be a bridge for people with

# Introduction

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developmental disabilities returning or becoming part of the community. Perhaps the greatest challenge and the most significant opportunity of all is in joining the national movement to rebuild a *psychological sense of community ... a readily available, mutually supportive network of relationships [on which we can] depend* (Sarason, 1977). People with disabilities teach the community to be more responsive to its members and to remember, that as John O'Brien phrased it, we are *members of each other*.

As with other revolutions, this one has the ingredients of enthusiasm, contrast and resistance. You can depend on encountering resistance from people and agencies who are comfortable with the current ways services are provided to people with developmental disabilities. You can also depend on seeing old ways of doing things under new names. This creates tension for all of us and a responsibility to let others know about the ducks as in *if it walks like a duck, and quacks like a duck, it's a duck*.

Our challenge in developing this resource was to help people understand the values of supported living and the process of implementing supported living services. The difficulty we had was that the *how to do it* comes from figuring things out with each person. That will mean that you've got to be comfortable with knowing only what needs to be figured out and not knowing how it will look in the end. People and agencies who do this work must be comfortable with the chaos and uncertainty of not having the answers. They must thrive in the unfolding process of trying to figure things out. We hope we've given you a good idea of the kinds of things that have to be figured out.

While we have presented several examples of people who lead supported lives, we have to caution you not to consider these examples as *models*. The same is true for any of the agencies we have used as examples. Each supported living agency must go through the process of identifying their own distinct mission, values, and ways of working with people. People and agencies can't be replicated.

# Introduction

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We want this resource catalogue to benefit everyone who wants to know more about supportive living services. There are no experts because we are, all of us, beginners. As beginners, we all have a chance to: start with the basics of listening and organizing support based on what we hear; give up on the control that we may be used to as professionals; and, throw out the assumption that someone will give us a model or an answer for how to do things. Most of all, we have a real opportunity to learn about something in collaboration with people with disabilities.

We hope that we've successfully told you how these services differ from familiar residential and independent living programs. We also hope that we've told you how with creative and flexible support, people can live in their own homes. Finally, we hope that we've made the point that a supported life is what we all value and that supported living services are one way that people with developmental disabilities can achieve that goal as well.

In this resource catalogue, you'll find:

*Values, Philosophy and Definition*

A brief history of the service system; and, values, philosophy and definition of supported living services.

*Patterns of Supported Living Services*

Getting to know someone; identifying support needs; finding a place to live; formal and informal support; community participation; choice and risk; and, supporting diversity.

*Community Resources*

A guide to generic and specialized community health, social, legal, transportation, housing, and education resources.

*Community Employment*

A basic guide to supported employment with information on Social Security and the Americans with Disabilities Act.

# Introduction

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*Stories of People's Lives*

Stories of supported lives with an emphasis on individual differences.

*Other Resources*

An annotated bibliography of books, videos and other interesting materials on supported living.

*Words and Terms*

Weaving your way through the jargon.

*References*

Sources of information for this guide and possible additional resources for you as well.

## Before You Read On

You may have already noticed that we have used both supported and supportive in this introduction and we will use the terms interchangeably throughout the catalogue. While *supported living* is commonly used around the country, after many discussions of values, beliefs, and common meanings attached to words, the Department of Developmental Services has decided on *supportive living*.

While we have devoted a part of the catalogue to describing how ethnic and cultural diversity must be honored in developing patterns of supported living services, we feel that it needs to be mentioned here in the introduction. The bottom line is that we must all be aware of the cultural and ethnic values of our communities before we consider ways to provide support to people with developmental disabilities and their families. However, it's clear to us that awareness of those differences is just not enough. Cultural competence should be viewed as a goal towards which individuals and agencies must strive. Precautions should be taken not to isolate cultural competency as a separate area of focus but rather needs to be integrated into all areas of supportive living.

Well it's time to read on. As you do, try to remember to go slowly on this journey and to give yourself time to learn from your experiences. You'll find others on this same path, make sure that you seek them out and that you support each other.

# Using this Resource Catalogue

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There are a number of ways to use this resource catalogue:

- you can sit down and read it cover to cover (although we don't recommend it);
- you can pick out something that you're particularly interested in and read that section;
- if you're looking for information in a hurry and you only want to read a summary, look for *Quick Starts*;
- if you want more than a summary, look for *Information Packs*;
- if you're interested in testing yourself about the material you've read, look for *Check Your Understanding\**;
- if you want to go beyond your basic understanding, then look for *Reflections\**.

We encourage you to add your own stories, examples and resources. Each chapter is page numbered separately (using initials and numbers like *VPD 13* for page 13 of the *Values, Philosophy and Definition* section) for your convenience when adding pages. Also, each section contains a *Directory* of the things you'll find there and we have reprinted all of them on the next several pages for your convenience. Finally, you'll find an *Index of Key Concepts* on pages WT 13-WT16.

\* *Check Your Understanding* and *Reflections* are best used in group settings. The sharing of thoughts, beliefs, and experiences will often heighten a person's understanding of ways of providing support. If you're using this Catalogue on your own, we suggest you talk with others about what you're feeling and thinking. Since there is no one way (or recipe for) supporting someone, we provide no "Answer Sheets." Some exercises are experiential (e.g., developing a person-centered plan), and understanding will come by watching others or by actually doing. A sympathetic partner can be helpful, even if you both are embarking on a new experience.

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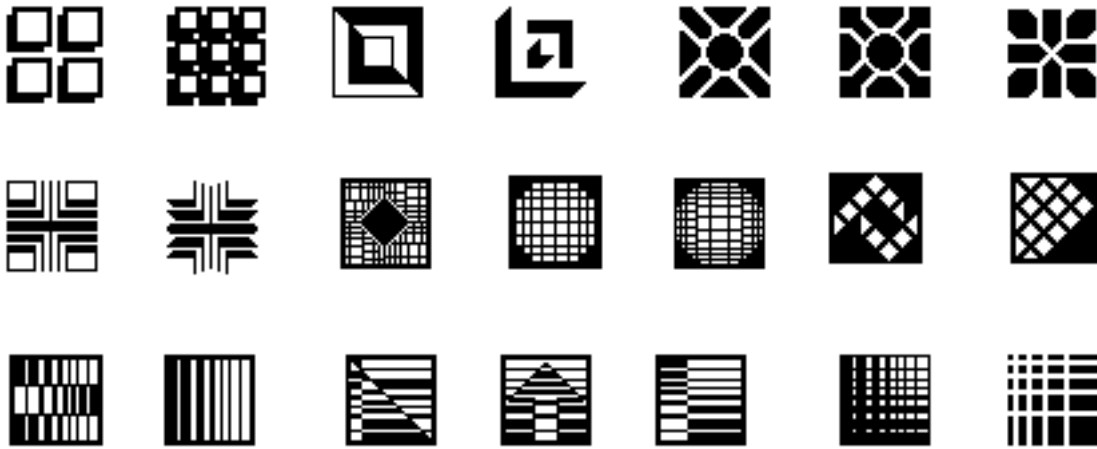
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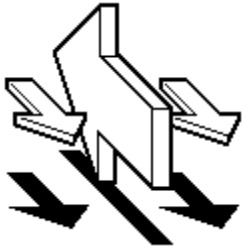


*Patterns of Supported Living*

Values,  
Philosophy  
and Definition



# Values, Philosophy and Definition



## Directory

### Introduction

It's important right up front to have a sense of history and an idea of the value base of supportive living services. This gives you a chance to think about your own values and decide if this is really something you want to do. Remember, when you're thinking and talking about values, things can get very spirited and emotional. That's all right! *Values, Philosophy and Definition* includes:

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# Values, Philosophy and Definition

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## Snapshots

### Mary

#### Can You Make Jello To Stand Up?

Four years ago, Mary lived in a group home designed to help people get ready to live on their own. It was expected that people who lived there would receive intensive training over two years, and then be ready to move to their own apartments -- a goal Mary had long sought. A prerequisite to being able to learn to cook was being able, independently, to make jello that would stand up when removed from its mold. Mary was not able to measure ingredients accurately, and was unable to achieve the objective. After two years, her interdisciplinary team recommended that Mary's goal of living in her own apartment be dropped from her Individual Program Plan (IPP).

Mary's parents, who had just completed a course on residential service options, objected. They knew that there had to be another way for Mary. Since age 16, Mary had been dating Stan who lived an hour away. Mary's parents called Stan's mother to see if she could help. Coincidentally, Mary's parents had intended to move near the town Stan lived in to be closer to her father's work. Sherry, Stan's foster mother checked with some friends, and one agreed to rent a room to Mary. Mary's mother would help her with budgeting and shopping, as she had done when Mary lived at home.

Armed with this opportunity, Mary's parents requested another meeting with her team, but again they refused to support her plans. Mary and her parents went ahead with their plan for Mary to move out of the group home and into a home she could

# Snapshot of Mary

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call her own. Mary continues to live quite well with very little paid support. Occasionally she has used the services of an independent living skills instructor. And, she spends much more time with Stan than she was able to do when she lived an hour away.

Stan lives in his own place -- with a housemate -- and Stan and Mary get together as often as they can. Mary enjoys the two women she moved in with and they have a lot in common. Mary was finally able to get the services of a supportive living agency to help her manage her money, cook and develop more relationships in the community. With their assistance, Mary is participating in a country western dance class. She has become good friends with another person in the class and they go out quite often to listen to country western music.

# Values, Philosophy and Definition

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## First, Some History

Since supported living services haven't always been available, you might be wondering about the kinds of living services which have been available to people with developmental disabilities in the past. As in other fields, an historical perspective gives you some idea of how we got to here and what the future might hold.

Starting way back when, the creation of state institutions (also called state hospitals, colonies, training schools or developmental centers) for people with mental retardation and related challenges was widely accepted as a progressive, reformist step in the mid-1800's. The public concern for health and safety in crowded, impoverished families and inner city neighborhoods drove this transition to asylum living. These institutions were typically located in small-town, rural America, away from public view. However, reality quickly diverged from this idyllic value of caregiving in a quiet setting as it proved difficult to train and motivate compassionate caregivers. In addition, despite well-intentioned efforts at supporting institutions through farming and other work, budgets were skimpy and uncertain and conditions were unfavorable at best.

During the early post World War II period, parents began to organize and form coalitions to insist on community alternatives to institutional treatment. In the early 1960s, the civil rights movement and a 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.

So, in the late 60's and early 70's, the *hostel*, or group home concept caught on -- for

# Values, Philosophy and Definition

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economic (cost efficiency) and other reasons as well. In addition, significant improvements occurred in teaching learners with disabilities which was based on scientific work completed at universities and in the field. Systematic instruction became the rage and soon, men and women -- long warehoused in state institutions -- learned (and learned quickly) new skills (like using the bathroom rather than depending on diapers) 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 similar needs would live together in what seemed reasonable and cost effective (6 to 15-person) homes. Then, with intensive teaching, they would be able to move on to lesser-restrictive places to live as they developed more skills and achieved greater independence.

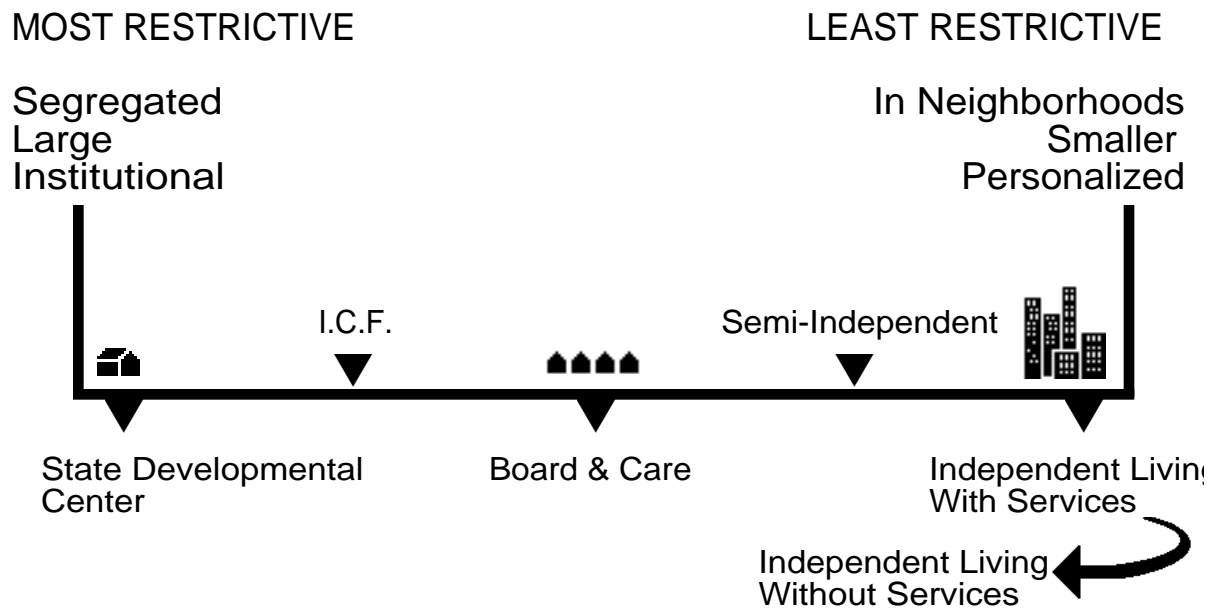
If everything went well, it was expected that someone would move from a large, state institution to a well-staffed group home, and then (depending on their development) on to a less expensive board and care home. If the person learned enough to live independently, then moving into one's own apartment would be the final step toward independence. A similar logic gripped the way people thought about vocational training and employment as well. For example, someone might start in a school for children with handicaps, move to a class for children with disabilities on a regular campus, hopefully develop to a point of being able to spend some time with children without disabilities, graduate and attend a training or activity center of some kind, move on to a sheltered workshop, and finally transition to a paid job in the community. This way of organizing the service delivery system was referred to as the continuum model. People moved from home to home, class to class, and job to job as they became more *ready*.

In the early 1980's, the logic of the developmental and readiness models as well as



# Values, Philosophy and Definition

## The Residential Continuum Model



continuum of services was questioned. It finally occurred to many that no matter how talented a teacher or caregiver 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 for managing 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 supposed to be ready and without knowing certain developmental skills like reading or writing.

At the same time, new social movements involving senior citizens and people with physical disabilities also had an impact. Individuals in these self-advocacy groups began asserting their rights to equal access to services in local communities. This right *to be where I want to be* began to energize individuals and groups of persons with developmental disabilities and their families towards *full inclusion* in schools, *supported employment* in community work, and now *supported living services*. While

# Values, Philosophy and Definition

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these three pages briefly summarize 140 years of service history, they do not begin to account for the difficult and heroic struggles that people have faced in working towards a time when services are guided by choice, preferences, and personal support needs. We've all come a long way!

## Things Are Changing

[Our] mission . . . is to join with others to offer the necessities with which all people with developmental disabilities have a full chance to:

- Be included in . . . community life.
- Make increasingly responsible choices.
- Exert greater control over their life circumstances.
- Establish and maintain relationships and a sense of belonging.
- Develop and exercise their competencies and talents.
- Experience personal security and self-respect.

-- Mission Statement from  
*Colorado Department of Institutions*  
*Division for Developmental Disabilities*  
1996

As stated earlier, in about the mid-1980's civil rights movement and consumer self-advocacy really started to affect the service system for people with developmental disabilities. That is, people with developmental disabilities started to advocate for themselves and to assertively express their preferences and choices about their own lives and the support services they were receiving. In the 1990's, these voices have started to influence policy and practice at the federal, state and local level of service. For example, look at the mission statement above from Colorado. As you can see, community participation, choice, relationships, and self-direction are important parts of that statement.

You've probably also noticed that California is changing as well. On the previous page (VPD 11), you'll find a summary of some recent changes to the Lanterman Act

# Values, Philosophy and Definition

## A Summary of Recent Changes in the Lanterman Act

The following is a summary of statements (in easy to understand language) that have been added to the Lanterman Developmental Disabilities Services Act. The Lanterman Act is the California law which set up the service system for people with developmental disabilities and their families.

### **Rights**

- People have the right to make choices in their own lives-

where to live

who to have friendships with

how to spend their time

choices in leisure

who to live with

who to have relationships with

choices in employment

choice in directing the future

### **Sharing the power**

- People with developmental disabilities and their families should figure out what services should look like now and in the future.

### **Living in the community**

- Regional centers have to develop ways to support people so they don't have to move when something happens.
- Regional centers have to develop ways to help people be regular community members.

### **The way that regional centers must do this**

- Work on ways that people can live in their own homes and have supported living services.
- Support people in finding a home, keeping it fixed up, having a circle of support, and advocating for themselves.
- Help people get special equipment and keep it in working order.
- Help find, train and hire people who provide personal care like in-home support workers, paid neighbors and roommates.

### **Individual Program Plan**

- The IPP must mention people's needs and preferences, ways to get involved in the community and ways to lead a healthy life.
- Services that are written into the plan should be ones that help people develop relationships with others, be a part of their community, live, work and go to school where they want, have fun, and be in charge of their life.

### **Regional centers**

- Regional centers should help persons with developmental disabilities and their families get services which support them in making choices for living, working, learning, and having fun in the community.

# Values, Philosophy and Definition

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(the law that set up the service system for people with developmental disabilities in California). As you may know, these changes came about as a response to public testimony all over the state about what was going well and what could be better in the service system for people with developmental disabilities and their families. You can see that the values of choice, community participation and self-determination are very evident.

## The Value Base for Supported Living Services

This shift in values that is so evident in current federal and state legislation has *driven* the effort to develop supported living services. It's important to know about these shifts or changes in order to understand how supported living services are different from other services.

### ***A Shift from *Getting Ready to Choice and Support****

People don't get ready for supported living the way they had to get *ready* or prepare for more integrated living based on the continuum model discussed on page *VPD 8* and *9*. The basic idea of supportive living is that if a person wants to live in their own home, it's up to the person, family, supported living program 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.

### ***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 people live in a home of their own. 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. The opportunity of supported living is to help people become rooted in their homes, neighborhoods and

# Values, Philosophy and Definition

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communities. In our society, having control of the lease or mortgage says *this is my place*.

## **A Shift from Professionals Having *Power Over People* with Developmental Disabilities to People with Developmental Disabilities *Having Power***

A shift of power to people with developmental disabilities requires that professionals let go of power. Supported living services require that professionals learn to share power with people they serve. Sharing power protects the right to choose where to live and with whom to live as well as a choice of supported living services and direct service staff.

## **A Shift from A *Program Curriculum* to *Individualized and Flexible Supports and Services***

Supported living services and supports are patterned differently for each person. Each pattern is, as Robert Perske would say, *unique and unrepeatable*. This method of providing services contrasts with programs based on the continuum model which often have a course of study or curriculum that everyone moves through regardless of their service needs. Supportive living requires a shift in thinking for programs and funding agencies from valuing time limited, measurable, instructional and behavioral goals to valuing the choices, needs, and satisfaction of people with disabilities.

## **A Shift from *Independence* to *Interdependence***

As we mentioned earlier, the developmental and continuum models were based on people moving in a step-by-step fashion with each step offering increased rights, responsibilities and independence. This 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 an isolating and depressing state of aloneness. What we missed in our efforts to help people live better lives was the importance of relationships and *interdependency* in all of our lives. Supportive living services value interdependence. The goal is not complete independence. Instead, the goal is to help people experience the interdependency or give and take of relationships within

# Values, Philosophy and Definition

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families, neighborhoods, and communities. Relationships that will support people in ways that everyone needs support, and offer friendships, and a sense of belonging, and feeling important and valued.

## **Where do You Stand?**

Regional centers and programs differ greatly in their support for supportive living and in their perception of who should be using the services. We all have to make up our own minds about what is right. The fundamental question we must ask ourselves is *What am I about and what kind of community do I want to work hard for?*

## **How has this Shift in Values Changed the Basic Mission of Service Agencies?**

### **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 tea  
That the whole damn thing is a bore

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

# Values, Philosophy and Definition

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On the previous pages, you read about some of the core values that are commonly embraced by people who are involved with supported living. While each agency must define its' own *mission*, here are two examples of value statements from agencies providing supported living services:

The purpose of Training Toward Self-Reliance is to increase opportunities for people with disabilities to lead good lives in places of their own, strengthen their communities, and enjoy a genuine sense of self-worth.

**Training Toward Self-Reliance  
Sacramento, California**

Toward Maximum Independence exists to provide the support necessary to enable individuals with disabilities to participate fully in community life. The agency is based on the belief that every person has a fundamental human right to live in a home of his or her choice and that no person should be forced to live and work in a setting which is segregated due to the nature or severity of his or her disability. It is the mission of TMI to improve the quality of life of persons with developmental disabilities through the provision of an individually determined level of support which will enable persons to live in real homes and work in real jobs, as well as enjoy fulfilling relationships with persons other than paid providers of service and support.

**Toward Maximum Independence  
San Diego, CA**

## Defining Supported Living Services

The definition of supported living services varies depending on who you ask or where you look. Although the definition may vary among people involved in providing supported living services there are commonly accepted values and principles which we have mentioned on previous pages. The California Department of Developmental Services' Supported Living Advisory Committee (1991), recommended the following definition:

# Values, Philosophy and Definition

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*Supported living services are 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.*

**How Do Supported Living Services Differ from Independent Living Programs in California?**

© 1993. John O'Brien.



# Values, Philosophy and Definition

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*Supported living is a simple concept which enables a person with a developmental disability who requires long term, publicly funded, organized assistance to join with an agency whose role is to arrange or provide whatever assistance is necessary for the person to live in a decent and secure home of the person's own*

## Supportive Living Services are about:

- X Visualizing dreams, ~~not~~ creating models
- X Supporting people, ~~not~~ fixing or changing them
- X Figuring things out together, ~~not~~ having the answers
- X Change and evolution, ~~not~~ maintenance
- X Space and openness, ~~not~~ structure and security
- X Letting go and shared power, ~~not~~ control
- X Lives, ~~not~~ models and replication
- X Focusing on gifts, ~~not~~ deficits
- X The community and citizenship, ~~not~~ the path of clienthood, isolation and disconnectedness
- X Regular and ordinary, ~~not~~ specialized and professionalized
- X Creation of gifts, ~~not~~ diagnosis of differences
- X Standing by people, ~~not~~ conditional relationships
- X Life and living as we all know and experience it!

# Values, Philosophy and Definition

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## ***Supportive Living Services Include, But are Not Limited to . . .*** **(California Department of Developmental Services, 1992)**

financial management	check cashing
purchasing activities	budgeting and bill paying
correspondence with official agencies	meal preparation
cooking	shopping
menu planning	personal health and hygiene
home and community safety	general household activities
household care and maintenance	activities essential to health
eating, bathing, dressing, grooming,	assistance with the medical care of children
assistance with the recruitment, screening,	obtaining police, fire, or emergency help
hiring & supervision of personal attendants	community resource awareness and assistance
orientation to the community	identification of and access to points of interest
mobility training	care and repair of durable medical equipment
access to leisure activities	use of leisure time
cultivating and maintaining friendship	participation in community recreation
interpersonal communication skills	adaptive social skills
self-advocacy	support for marital and sexual relationships
parenting skills	24-hour emergency assistance services
training in the selection and use of	crafting of unique technology and equipment
assistive technology & adaptive equipment	communication devices
repair & maintenance of assistive technology	home modifications
vehicle modification	canine and other animal companions
interpreters or translators	securing suitable housing
facilitating circles of support	

**Introduction.** The idea for independent living programs in California was developed during the 1970s and 1980s at the same time the continuum model was becoming a reality. 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 by regional centers, were to be time-limited.

# Values, Philosophy and Definition

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## Comparison of Service Assumptions

### Supportive Living Services

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

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

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

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

Helper, advisor, facilitator, advocate.

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

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

### Services Based on the Continuum Model

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

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

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

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

Landlord.  
Responsible for well-being and progress.

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

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

*Adapted with permission from OPT*

At the time they were developed, independent living programs were viewed as radical and ground-breaking. People who had previously been limited to group or parent living options, 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 to live in the community and some agencies were able to negotiate with their regional centers to expand their array of services and to lift time limits.

At the same time, people with disabilities and their families were advocating for more

# Values, Philosophy and Definition

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options in the residential service system. Finally, the idea of supported living grew out of a combination of forces including independent living programs willing to push themselves beyond 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. Supportive Living Services and the programs that sponsor them are funded through categories of service named Independent Living, Supported Living or CSLA (Community Supported Living Arrangements; for more information see CSLA in *Words and Terms*).

**Differences that May Exist Between Supportive Living Programs and Independent Living Programs.** The saying *you can't judge a book by its cover* represents the dilemma of identifying the differences between supportive and independent living programs. There are agencies referred to and funded as independent living programs which provide supportive living services. On the other hand, there are agencies referred to and funded as supportive living programs whose patterns of providing service don't reflect the patterns of supported living. The following questions might be helpful in trying to look at the differences between supportive and independent living. The ways that supportive living agencies would answer these questions are discussed in the chapter on *Patterns of Service*.

## *Eligibility Criteria*

- How do people become eligible for services?
- What are the entry requirements?
- Are people with significant support needs or behavioral challenges excluded?
- When is someone excluded or denied services?

## *Patterns of Support*

- How does the agency get to know the person requesting services?

# Values, Philosophy and Definition

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- How does the agency figure out the type and frequency of services and supports?
- Are people with disabilities ever grouped together to live in a home or during service provision?
- How much control or power does the person have over who they live with, where they live, and who provides direct service to them?
- What stance does the agency take if a person gets in trouble with the law? doesn't seem to be motivated to keep up their home? makes bad decisions?
- How is the program involved with family and friends?
- Are there any arbitrary time limits on length of service, number of hours of service each month, and so on?
- If the person receiving services drops out or ends their service for any reason, does the supportive living program have any say over whether or not they have to move from their home?

# Values, Philosophy and Definition

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## You and I

I am a resident. You reside.

I am admitted. You move in.

I am aggressive. You are assertive.

I have behavior problems. You are rude.

I am noncompliant. You don't like being told what to do.

When I ask you out for dinner, it is an outing. When you ask someone out, it is a date.

I don't know how many people have read the progress notes people write and even know what is in there. You got mad when your best friend read your journal.

I make mistakes during my check-writing program. Someday I might earn the money to open a bank account. You forgot to record some withdrawals from your account. I had to remind you.

I wanted to talk with the nice-looking person behind us at the grocery store, but it was inappropriate to talk to strangers. You met your spouse in the produce department.

I celebrated my birthday yesterday with 5 other residents and 2 staff members. My family sends a card. Your family threw you a surprise party. It sounded wonderful.

I am on a special diet because I am 5 pounds over my ideal body weight. You were up telling you.

I am learning household skills. You hate housework.

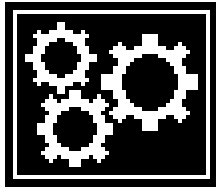
I am learning leisure skills. Your shirt says you are a "couch potato".

My case manager, psychologist, R.N., occupational therapist, physical therapist, and house staff set goals for me for the next year. I hear you say you have more goals than you want out of life.

Someday I will be discharged ... maybe. You will move onward and upward.

Elain Popovisch  
Lutheran Social Services

# Values, Philosophy and Definition



## Check Your Understanding

1. Write some one- and two-word descriptions of your view of the service system in the past and how you see it in the present.

PAST	PRESENT

2. What do you understand to be the basic *core* values of supported living services?

# Check Your Understanding

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3. What do you understand to be the basic *differences between* supportive living services and independent living program based on the continuum model?
  
  
  
  
  
  
  
  
  
  
4. What kinds of support can be provided through supported living agencies in California?
  
  
  
  
  
  
  
  
  
  
5. Write your own one-sentence description of what supported living services mean to you.



# Values, Philosophy and Definition

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## Reflections

### What About Luis?

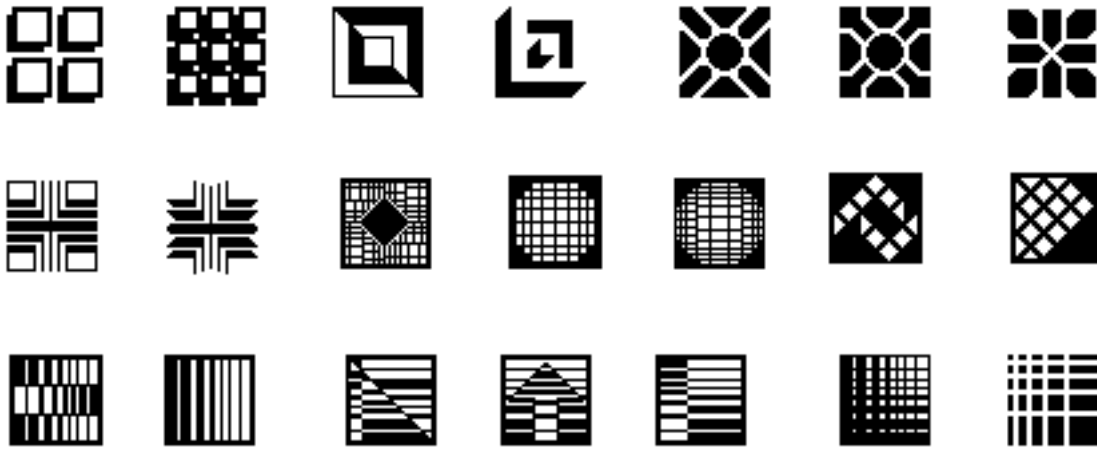
Luis has lived with his elderly parents all of his life. He comes from a family of 13 brothers and sisters and an enormous extended family. As Luis' parents get older, they depend on him for transportation and to translate for them since they don't speak English. For the past 10 years, he has worked during the summer at a cannery, but he has no health benefits and his job is only seasonal. Luis has decided that he would like a better job and a place of his own and he wants your support. What are some of the things you need to know about Luis, his family and his community to help him figure out the supports he might need to live in his own place? What about Luis' parents?

# Reflections on Values, Philosophy & Definition

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## What's Your Agency's Mission?

Look at the mission statement of your agency (or the agency that supports someone you know) and see how it fits with the values of supported living services. Write down your thoughts about how it fits and what could be better about it. If your agency doesn't have a Mission Statement, write one up in your own words. Remember, the shorter and the easier to understand, the better!



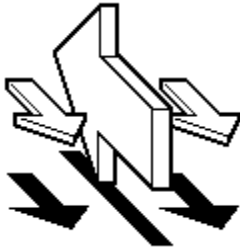
*Patterns of Supported Living*

# Patterns of Service



# Patterns of Service

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## Directory

### Introduction

To this point in this catalogue, we've written about some of the values and philosophy of supportive living services. Now it's time to offer you ideas on how people figure out individual *patterns of service*. This section includes:

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# Patterns of Service

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## Snapshots

### Maria

After two weeks of looking, Maria found a gorgeous, two bedroom apartment. The only problem was, there were two other people interested ahead of her with deposits already paid. I watched in amazement as Maria not only talked the landlord into ignoring the others, but putting the lease in her name only (not including her roommate/attendant) even though her monthly income did not cover the rent. When the manager asked for a deposit, our agency happily loaned her the money.

We're now assisting Maria in finding a roommate/attendant and we are covering those services for her until she hires someone. We have also supported her in getting involved with the community college, using the para-transit system, finding a counselor, borrowing books on tape from the library and setting up an emergency system with neighbors. Next, Maria wants a job!

Adapted from a story written by a staff member at *CHOICES*, Arcadia, California.

Maria's pattern of life includes support from:

- Supportive Living Program
- Neighbors
- Community College
- Community Resources
- Counselor
- Paratransit system





# Patterns of Service

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## QUICK START

### *On Developing a Pattern of Service*

#### **Introduction**

Developing a pattern of service with and for someone who is leading a supported life 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.

While we'll be providing you a lot more information on each of these support services in this chapter, 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 Karren 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 started 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 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

This story was adapted with permission from *Get Me the Hell Out of Here. Supporting People with Disabilities to Live in Their Own Homes*. A chapter by Jay Klein in *Natural Supports in School* by J. Nisbet, Brookes

# Quick Start On Developing a Pattern of Service

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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 Karren 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 Karren; 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.





# Patterns of Service

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## Information Pack

*on Getting to Know Someone*

### Introduction

Families and friends typically see people with disabilities they know and love very differently than professionals see them. Most professionals who diagnose or assess (like psychologists and physicians) are looking at ways that someone differs from what is *typical* or *normal* for a person of the same age (for example, not reading at grade level). When you look at someone this way, *strengths* tend to be healthy conditions or abilities that are like others and *weaknesses* are seen as things which stand in the way of fitting in like everyone else. On the other hand, family and friends tend to see each other in terms of an unfolding life story. They tend to be familiar with someone's changing moods, preferred activities, unique talents, individual quirks, and the like. While both ways of *seeing someone* can have value, information from someone you're supporting and their family and friends is critical in developing a pattern of service.

### Spending time with someone

The best way to get to know someone is to spend time with them and, if possible, with significant persons in that individual's life -- asking questions, listening, and

# Getting to Know Someone

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observing things that represent the life quality and support needs of an individual. In deciding how best to support someone, it's important to understand them well enough to change your support as you learn more. So, how do you do it? Here are some ideas (Racino, Walker, O'Connor and Taylor, 1993; see the chapter on *Other Resources* for the complete reference):

- *ask* -- which may not get you a great deal of information at first, in part because persons with developmental disabilities are seldom asked, and when asked may have had few responses taken seriously.
- *listen* -- which means not only hearing what people want, but being in tune with what works and what doesn't.
- *spend time together* -- observing, especially if the person has difficulty communicating in conventional ways (speech, sign language, adaptive communication device).
- *ask significant others about the person to be supported* -- especially individuals who are committed to the person and who have been actively involved in the person's life over a long period of time.
- *create opportunities for new experiences* -- which can be crucial, when a person faces a choice situation without any real knowledge of the options.
- *expand opportunities for communication* -- by providing an opportunity for a person to communicate through facilitation or an assistive device of some kind.
- *provide opportunities for honest expression of wants*-- many individuals may be afraid to speak up for fear of being *labeled* as uncooperative. For example, whenever possible, a person should be interviewed in his home, or in another place of the person's choice. Differences of opinion must be honored.

# Getting to Know Someone

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- *acknowledge the pace of your developing relationship* -- each new relationship contains mistakes, misunderstandings, and, ultimately trust.
- *take the initiative* -- by speaking up to make sure that others listen to the person's (or family's) concerns.
- *learn together* -- by calling together people who know the person to share and to generate ideas for getting the support the person wants and needs.

## Some things to ask about when getting to know someone

As you spend time with someone, there are a number of things that will help you get to know him or her and at the same time give you some ideas about developing a pattern of service. Options in Community Living, Madison, Wisconsin, recently developed a guide to the kinds of information they want about the people they support. We have presented an adaptation of it on the next few pages as an idea of the kinds of information that would be helpful. Remember:

- You don't have to ask all of these questions at one time
- You don't have to ask these questions the way they're written and
- You can ask others who know, if communication is difficult.

The idea is to find out more about how someone looks at issues about their income, home, health, safety, relationships and getting around.

# Getting to Know Someone

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## A Guide To What We Want To Know About People We Support

(Adapted from *Options*, Madison, Wisconsin)

### Income

How do you feel about someone supporting you in budgeting and taking care of your money

Where do you bank?

How much money do you have to live on each month?

Who makes choices and decisions made about how your money is spent?

Are there any changes you would like to make in how your money is taken care of?



# Getting to Know Someone

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## Housing

What are your feelings, preferences, comments about:  
Where you live?

Your neighborhood and nearby places (store, laundry, parks, and people)

Safety in the home/neighborhood?

Your landlord

The furnishings and belongings in your home?

Your choice of neighborhood, building, and room?

Any changes you would like to make in your home?

## Your Health

What are your personal feelings, preferences, comments about:  
Your doctor, dentist, or other people you see for health reasons?

What's your current health (like your weight, your nutrition, exercise, medication)?

What's your current mental health (happy, depressed, upset, anxious)?

Any changes you would like to make in these health related areas?

# Getting to Know Someone

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## Your Safety

What are your personal feelings, preferences, comments about:  
Your safety in your home?

Your knowledge of what to do in an emergency?

Your safety in the community?

Any changes that would make you feel safe?

## Taking Care of Yourself

What are your personal feelings, preferences, comments about:  
The way you look?

The way you dress?

Your choices of how you look or dress?

Any changes you would like to make in appearance?

# Getting to Know Someone

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## Getting Along with Others

What are your personal feelings, preferences, comments about:  
Your relationship with family members?

Your friends?

Your sexuality (intimate relationships)?

Having people to do things with?

The choices about who to spend time with?

Any changes you would like to make in your p  
relationships

## Meaningful Activities

What are your feelings, preferences, comments about:  
Your job (money, hours, type of work)?

Your recreational activities in and out of your home?

relationships?

Your choices about work and recreational activities?

Any changes you would like to make in your activities?

# Getting to Know Someone

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## Getting Around

What are your personal feelings, preferences, comments about:

The way you get around (transportation)?

Your ability to get to the places you want to go?

Adaptations (like a wheelchair) needed to get around?

The transportation choices available?

Any changes you would like to make?

## Service Provider Issues

What are the person's feelings, preferences, comments about:

Attendant, paid roommate, or other direct service staff?

Our services (choices about services, how they are provided)?

Other services you receive (like job training)?



# Check Your Understanding

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3. If you (or your son or daughter or friend) are someone who relies on paid support, how could the staff of a supported living agency get to know you?

# Patterns of Service

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## Information Pack

*on Support Needs and Desires*

Personal Futures Planning provides strategies to increase the likelihood that people with disabilities will develop relationships, be part of community life, increase their control over their lives, acquire increasingly positive roles in community life and develop competencies to help them accomplish these goals. Futures planning helps to clarify and implement these ideals, one person at a time.

Beth Mount and Kay Zwernik  
*It's Never Too Early; It's Never Too Late*

### Introduction

There are many ways that you can assist people to talk about their support needs and preferences. Recently, a lot of attention has been given to something which has been called *person-centered planning*. This method of planning goes by a variety of names, including *MAPS* and *Personal Futures Planning*. What they all share, is a common sense and systematic way of asking someone about his or her life, connections with others, likes, dislikes, hopes, fears, gifts and capacities, needs and desires. These planning processes are about: helping people and their families and friends look at hopes and dreams for the future; figuring out the support they need [from family,

# Support Needs and Desires

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friends, community and agencies] to get there; and, then writing down some first steps to take towards that plan right now.

There are at least three major problems with the ways we have usually tried to figure out a person's support needs and desires:

1. They have usually been completed with an assessment process that highlights someone's deficits. When someone is defined in terms of things they can't do, then they appear to be in constant need of services and "fixing" and will never be *ready* for community life.
2. They tend to result in goals that are already part of an existing program. In other words, the goals of the person are changed to fit the program.
3. They have relied solely on the judgment and decision-making of professionals. People with disabilities and their families and friends have been prevented from taking part in the process.

The *values* of person-centered planning are that:

- Support service options should be based on choice
- Support services vary from person to person
- The community is full of support service resources that are available to everyone
- Friends, families, neighbors and co-workers should be a part of the pattern of support.

## Three Ways to Use a Person-Centered Planning Approach to



# Support Needs and Desires

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## An Excerpt from The Challenger ARC-Napa Newsletter, October 1991

Frustrated by traditional IEP or IPP meetings? Concerned with overemphasis on Wonder why many professionals don't want to talk about the things most important to your family? Feel there must be a better way? Well, you're not alone! And, you're not alone. There is a better way. It involves person-centered planning, under a variety of models. Those indicated above, a new way of thinking about a person with a disability, and how a person can lead a more fulfilling life.

The approach is to develop a vision of a desired future, based on who the person wants to be and to do, and then to marshal resources to support the person in achieving her goals. Ideally, a circle-of-support or person-centered team seeks to develop connections, to invent and experiment with novel courses of action, and to start doing as any close friend would do.

The traditional way of planning services relies on (1) assessments that look at deficits rather than gifts and strengths; (2) using professional judgment in the place of what the person and his or her family know about themselves; (3) efforts to 'fix' people, to get ready [for life] indefinitely; and (4) opportunities, defined by what exists rather than what is desired. This is service-centered planning, and combined with high case loads, budget constraints, and restricted service menus, often produces mismatches.

We recently compared the plans generated for a young woman we support as a part of Mary's Individual Program Plan listed four objectives, as follows:

- With supervision, increase her work skills and productivity;
- With monitoring, Mary completes household responsibilities on a regular basis;
- Following a budget, Mary pays her bills and buys personal items with money allocated on a weekly basis; and
- With support services, Mary socializes in the community with peers at least once a month.

Mary's person-centered plan, worked out at about the same time, listed Mary's future as follows:

- A job at Mervyns;
- Learning communication and problem-solving skills that will help in her relationship with Stan;
- The chance to spend time with Stan, so they can find out more about each other as they move towards marriage;
- Learn about pregnancy and raising a child;
- Change her relationship with her mother from adult/child to adult/adult; and
- Make sure she keeps her apartment.

Wouldn't it be more fun to approach life this way? And, wouldn't we contribute to the well-being of those we care about? We think so!

# Support Needs and Desires

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## Finding Out About Support Needs and Desires

Again, there are many ways to find out about someone's support needs and desires. In *Getting to Know Someone*, we presented some straightforward questions that would help you start to figure out a pattern of service. However, some people will need more help in talking about their support needs. The following three examples are offered as ideas to assist people (and their friends and families) to start talking about what support they will need from others. You'll have to find out what works best for you and what works best for the people you are supporting. To learn more, we've listed a resource for each example.

### **Personal Futures Planning** (developed by *Beth Mount*)

The goals of *Personal Futures Planning* are:

- To build a circle of people who are interested in making a positive difference for and with a particular person
- To look at life patterns, interests and preferences, relationships, living circumstances, health considerations, motivating and frustrating situations, and other influencing factors
- To assist someone in developing a vision about himself or herself which includes-
  - ✓ a picture of a desirable future
  - ✓ ways that people in the 'circle' can offer support
  - ✓ some first steps.

In using the process, it's important to ask questions in a way that doesn't limit thinking about individual options. This strategy is built on the following assumptions:

# Support Needs and Desires

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1. All things are possible with the right types of support.
2. Support can come from all parts of the community (e.g., parents, family, friends, generic service agencies.)
3. Presenting a 'fixed' menu of service options will produce 'fixed' outcomes, not necessarily based on individual preferences.
4. Given lead time, support services can adapt to individual preferences or new support service options can be created.
5. Most important, we will not know how to plan for the future unless we ask people with disabilities and their families what it will look like.

This planning process has a greater chance for success when:

- The group focuses on strengths, preferences and opportunities
- The picture of the future is detailed and specific
- People commit to meet on a regular basis and stick to their commitments of support when they make them
- Someone agrees to facilitate the meeting to keep the group focused
- People participating [in the planning process] have developed a number of community connections
- Family members and advocates are in the group.

When you first look at the set of questions used in a futures planning meeting, they may not seem too unusual. However, when you get everyone together with someone who acts as a guide and someone who can record the meeting with graphics (pictures and words on butcher or flip chart paper), great things happen. It's one of those things that's difficult to describe until you go through the experience. You'll find the set of questions used in *Personal Futures Planning* on the following page. As Beth Mount once said, these questions are only tools and you should use them when they are necessary and make sense.

## Questions Used in *Personal Futures Planning*

PERSONAL PROFILE:

# Support Needs and Desires

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1. Who is this about?
2. Who helped make this plan?
3. What services do I get now from agencies?
4. How do they describe me?
5. What is my health status?
- 5A. What health supports do I use now?
6. What are the highlights of my life?
7. Who are the people I know?
8. What do people think of me? (Things that are good & bad)
9. What places do I go?
10. What things make me happy and sad?
11. What new people would I like to meet?
12. What things have I learned recently?
13. What new things would I like to do and learn? (What new places would I like to go?)
14. What scares me most about my future?
15. What jobs have I had?
16. What jobs would I like to try?
17. What other things do I know?
18. What is fun about the jobs I have had or would like to try?
19. What would I like about these jobs?

## PERSONAL VISION:

20. If I could do anything I wanted, what would my best possible future be?
21. What would I need to know, or what would need to happen to make this possible? People? Community? Systems?

## PERSON-CENTERED PLAN:

22. Moving toward that vision, what do I want to work on during the next year?
23. What would I need to know, or what would need to happen to make this possible? People? Community? Systems?

For more information on how to use *Personal Futures Planning*, you can get a copy of Mount, Beth, and Zwernik, Kay (1988) *It's never too Early, it's never too late: a booklet about personal futures planning* from the Governor's Planning Council on Developmental Disabilities, 300 Centennial Building, 658 Cedar Street, St. Paul, Minnesota 55155. Other resources include: *Person-Centered Development: A Journey in Learning to Listen To People With Disabilities* by Beth Mount, Pat Beeman, George Ducharme (1991) and *Imperfect Change: Embracing the Tensions of Person-Centered Work* by Beth Mount (1990). These publications are available from *Communitas*, P.O. Box 374, Manchester, CT 06040.

**MAPS (Making Action Plans;** developed by Marsha Forest & Jack C. Pearpoint) As in *Personal Futures Planning*, *MAPS* is a process that brings together the key people in someone's life to develop a support plan. It also focuses on finding out about someone's likes, dislikes and preferences. A *MAPS* get-together is usually

# Support Needs and Desires

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hosted by two people, one who helps guide the meeting and one who records what happens on chart paper on the wall.

To start out the meeting, the host asks everyone who they are and what is their relationship to the focus person. During the meeting, the host always asks questions of the focus person first and then turns to others. There are eight key questions that the focus person and group tackle in developing a *MAP*:

What is a *MAP* and how will it help us support someone?

What is the story of your life?

What is your dream?

What is your nightmare?

Who are you?

What are your strengths, talents, and unique gifts?

What do you need? What do we need to do to meet these needs?

What is the plan of action to avoid the nightmare and to make the dream come true?

The host, of course, uses a variety of ways to get the group focused on developing a *MAP*. In addition, at the end of the meeting, the recorder summarizes the graphic charts and presents them to the focus person as a gift. In the words of Marsha and Jack, *the MAP is more than anyone can do alone. It proves what we strongly believe - together we're better* (Forest and Pearpoint, 1992). For more information on how to use the MAPS process, you can find out about available texts, videotapes and training by writing to Marsha Forest and Jack Pearpoint at the *Centre for Integrated Education and Community*, 24 Thorne Crescent, Toronto, Ontario, Canada M6H 2S5.

**Person-Centered Interview** (adapted from *Personal Futures Planning* by Allen, Shea & Associates)

In order to bring the practices of *Personal Futures Planning* into the service agency planning process, an adaptation has been developed. It's important to note that this interview format does not take the place of either of the two strategies previously

# Support Needs and Desires

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mentioned. However, it does provide everyone involved an experience of looking at a person's life in a more *full* way than can be found in more traditional ways of looking at people's strengths and support needs. Here's an excerpt from the introduction in versions developed for Harbor Regional and Regional Center of the East Bay:

*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 to 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 (4) 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!

On the opposite page, you'll find a reduced version of the first two pages of the interview. For more information on this adapted interview format, please contact *Allen, Shea & Associates*, 1040 Main Street, Suite 200B, Napa, CA 94559.

## Moving from Getting to Know Someone to a Support Plan

Each agency will have its own way of taking the information learned from getting to know someone into a plan of support. On these two pages, we offer two ideas for you to consider. The main thing to remember is that the plan will be *bigger* than you or your agency. It will include things that people can do for themselves or with support

# Support Needs and Desires

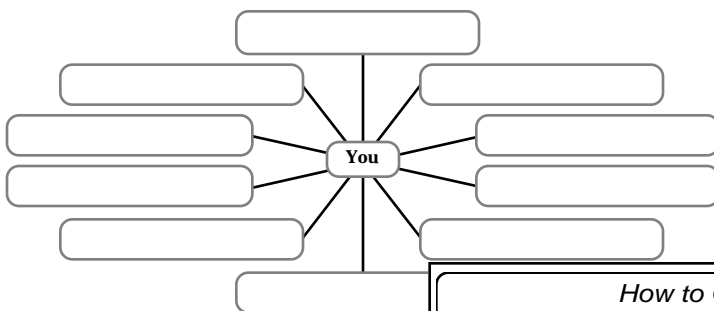
## How to Get There From Here!

### 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 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.

## How to Get There From Here!

### Things About You

4 What things do you like to do? around town? at home? for fun?

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?

# Support Needs and Desires

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from friends, families, neighbors or others.

Name of Person:	8	Harbor Regional Center <i>Bringing it All Together!</i>	UCI Number:
Moving towards your plan for the future, what do you hope will happen next?	What kinds of support will you need from:		
	Family, friends and community	Support service agencies	
How will you know if your plan has worked?			



# Support Needs and Desires

Name of Person: Bill Allen		Training Towards Self-Reliance Personal Support Plan	
What are the things that you need support in <i>learning</i> or <i>doing</i> over the next six months to one year?	What can you do for yourself?	What kinds of support will you need from:	
		Family, friends, and community	Support service agencies
<ul style="list-style-type: none"> <li>I'd like some support in using a regular doctor and dentist.</li> <li>I'd like to learn about what is the best thing to do in an emergency.</li> <li>I'd like to have some new hobbies and things to do in the evenings and on weekends.</li> <li>I'd like some support in keeping my apartment.</li> <li>I'd like to work on my temper</li> </ul>	<ul style="list-style-type: none"> <li>I can take the bus to get there when I have an appointment</li> <li>I could read a list of what to do in an emergency</li> <li>I could use the phone to dial 911 or take the bus</li> <li>I can pick one or two things to try each month</li> <li>I can keep it picked up and keep being a good neighbor</li> <li>Count to 20, take deep breaths when I get mad</li> </ul>	<ul style="list-style-type: none"> <li>I can see if other people in the building use the same doctor or dentist and share a taxi ride or drive with them</li> <li>I can see if a neighbor or my mother would be a back-up for me in an emergency</li> <li>I can ask my friends and neighbors what kinds of things they do for fun and ask if I can join them in something that sounds interesting to me</li> <li>I can ask one of my neighbors that I carry groceries for if she can help me read my mail if I don't understand it</li> <li>Talk to a counselor at the counseling center</li> </ul>	<ul style="list-style-type: none"> <li>I need Steve's support in:               <ul style="list-style-type: none"> <li>making appointments over the phone</li> <li>going to the doctor or the dentist with me for the first time</li> <li>helping me learn the best bus routes</li> </ul> </li> <li>helping me make up a list of emergencies and when it's best to get there on my own or when to dial 911</li> <li>go over with me what to say to the emergency people</li> <li>giving me ideas and encouragement</li> <li>helping me practice how to talk to people about their interests</li> <li>reading important things from Social Security and the Housing Department</li> <li>listen to me and give me ideas about how to deal with anger</li> </ul>
<b>How will you know if your support plan for the next six months to one year has worked for you?</b>			
<ul style="list-style-type: none"> <li>I'll see a doctor and a dentist when I need to</li> <li>I'll have a hobby that I like to do</li> <li>I won't get so mad and lose my temper</li> </ul>		<ul style="list-style-type: none"> <li>I'll know what to do in an emergency</li> <li>I'll be living in my apartment</li> </ul>	
Your Signature: _____ Date: _____ Your TTSR Support Service Coordinator: _____			

## Things to Think About When Using a Person-Centered Planning Approach

There are a number of things to think about if you decide to use a person centered approach to finding out about someone's support needs and desires:

- *It will take more time* than the traditional *checklist* approach, but it will reduce the time it would take if you were using observation as your only tool.
- *It takes some practice as a facilitator* to feel comfortable and effective. You may want to go as a team or even bring in another person to record.
- *Again, the plan you develop will go far beyond what you can do* as an

# Support Needs and Desires

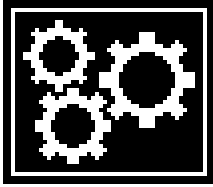
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individual or an agency, but that's all right because you're trying to develop a circle of support as well as a support service plan, and various people may choose to offer support.

- *Some things will be hard for people to talk about* and will create some emotion which you need to honor. It may mean stopping and coming back to something or suggesting that you talk again later.
- *Some people will not be able to express themselves in a meeting or at all.* This may mean talking to someone ahead of time in the case of someone who does not like to talk in a group. It means relying on the thoughts and observations of others when someone cannot communicate their basic strengths and needs.

# Patterns of Service

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## Check Your Understanding

1. What are some of the problems with the ways we usually try to figure out people's support needs and desires?
2. Why would person-centered planning provide a better picture?
3. What do you see as the biggest challenge for you in this type of planning?

# Check Your Understanding

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4. If you rely on paid support, how would you want a supported living agency to figure out the services and support you need?

# Patterns of Service

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## Information Pack

*on A Home of One's Own*

Today's service systems developed around the unspoken assumption that people could not have both severe disabilities and homes of their own.

-- John O'Brien (1991)

### Introduction

A primary value underlying supported living is supporting a person who controls -- through ownership or lease -- the place in which he or she lives. Traditionally, nearly every person with severe disabilities has had two options: (1) remain with their family; or (2) live in a licensed place owned and controlled by others.

Living in one's own home is more than having one's name on title to property, or on a lease agreement with a landlord. John O'Brien observes three dimensions in the idea:

- a sense of place (for example, security and comfort; ability to invite in guests)
- control (for example, live alone, or choice of housemate)
- Security of place (equity position or tenancy).

These dimensions are graphically presented on the next page.

# A Home of One's Own

Three Dimensions of Home Ownership		
Sense of Place	Control	Security of Place
<ul style="list-style-type: none"> <li>• Personalized space &amp; time</li> <li>• Engagement in household activities</li> <li>• Safety &amp; comfort</li> <li>• Security of tenure</li> <li>• Base for outside activity</li> <li>• Means to offer hospitality</li> </ul>	<ul style="list-style-type: none"> <li>• Choice of place to live</li> <li>• Choice of people to live with</li> <li>• Control of necessary assistance</li> </ul>	<ul style="list-style-type: none"> <li>• Individual or cooperative equity or</li> <li>• Tenancy</li> </ul>

Revised with permission from John O'Brien, 1991.

In comparison with licensed places to live, control of your own place through ownership or lease should bring (a) greater personal control of space and time (what you do every day); (b) more involvement in the activities of daily living (shopping, cooking, laundry); (c) a sense that *I belong here*; and, (d) more control of the *threshold* (who can enter, and who must leave) which, in turn, gives people the opportunity to invite guests into the home without getting permission from a *service provider*. Choice can be an illusion, however, if the items in the *Control* column above are not respected. All too frequently, for reasons of tradition or convenience, paid service providers give lip-service to choice of place to live, and choice of people to live with.

## The Ups and Downs of Owning or Renting

Licensed homes are typically owned (and controlled, by public regulation) by the people who provide services, or who hire others to provide services. Those who live there are considered invited guests, and they may be asked to leave for any number of

# A Home of One's Own

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## Would You Show Me the Keys to Your House?

Typically, in group homes, a person may not enter the house unassisted during certain hours (for example, on weekdays, when no one is home). When you're looking at who has control of a place to live, just ask the person whether they have a key to the place where they live. If so, ask to see the key. It's relatively unobtrusive and fairly objective. Recently, the authors had occasion to ask others about this *measure*. One person said that the really important questions are: *How many other people have keys to your home?* and *Who gave you the key?*

reasons, such as retirement of the service provider, personal illness, behavior that is problematic for others, or a *professionally-determined* decision that the person needs a different type or level of care. Some board-and-care homes are bought and sold like any other businesses -- and paying guests are sometimes considered as working capital in such transactions. So long as the buyer wants to continue services, the guests may be invited to stay on. While this is not an ethical or legal thing to do, it does happen!

Can a person with disabilities assume greater stability and control if they own their own place? The answer may appear obvious, but it may be wrong. As noted at a recent housing and supported living workshop, *a bank is often able to foreclose on a mortgage faster than a landlord can evict a tenant*. With ownership of a property comes a host of responsibilities, such as paying the mortgage and taxes, getting insurance, finding others to live with if the house is otherwise unaffordable, keeping the house in good repair, and getting support services (if needed). And, if the person must rely on SSI (Supplementary Security Income) to meet basic living expenses, ownership can be problematic in yet another way. While the home in which an SSI recipient resides is not a "countable resource," subject to the \$2,000 limit (\$3,000 for a couple), if the person chooses to live elsewhere -- or, is forced to live elsewhere -- he or she only has three months to sell the property and to reinvest the proceeds into another owner-occupied dwelling. This may be impossible, for example, if the person

# A Home of One's Own

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has to move somewhere (for example, to a nursing home) to get needed health-care services. All of these matters can be problematic, especially if the person does not have a family member, friend, or advocate willing and able to help.

*What about renting?* For some people, renting may be preferable to owning. Renting typically carries fewer responsibilities than ownership, such as taking care of landscaping and household maintenance. Furthermore, if the property is a multi-unit complex -- and if the local unit of government would *not* approve conversion to condominium status -- in all likelihood the property will not be turned to some other use. (The same can not be said, for instance, of rented single-family dwellings.)

## Living with others -- What about *breaking up*?

People frequently assume that *the ideal* for an adult with a developmental disability is

It seems to be engrained into the American consciousness that *most people desire to own their own home*. The following true story, the subject of a recent article in a Los Angeles area newspaper, cautions us again to ask and listen, rather than to *assume* what is good or right for other people.

### 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 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



# A Home of One's Own

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to live alone in his or her own apartment. The reasons for this assumption are not altogether clear. Some feel that a full test of one's emerging ability to be independent implies *making it* while living alone. Housing may also be the issue, since few housing authorities provide housing subsidies to unrelated individuals living together. Finally, there may be less hassle in working with someone who doesn't have to face the difficulties of living with others (for example, compatibility issues, spats and so on). The important thing to remember is that this is just an assumption until we find out first-hand where and how someone wants to live. Remember that where and how someone wants to live will change over time and that people should be supported in their decisions.

When two or more people live together, married or not, there is always a need to *get along* well. If people don't get along, a split-up (or divorce) is usually in the cards. How does this relate to supported living? It is related in two important ways. First, understanding individuals is crucial. Some persons needing support want to live with others, and this desire should be respected. The next question is *who would you like to live with?* The answer should guide the exploration of the possibilities. While pursuing *shared housing with adults without disabilities*, two of the authors interviewed a young man with cerebral palsy, living in a group home, who wanted to leave and *live on his own*. When asked about his preferences, he said that he wanted a three-bedroom house, accessible (because he uses a wheelchair much of the time), with room for a garden in the yard, no more than a mile from the community college campus, and he wanted to live with two other guys with cerebral palsy. Should these hopes and dreams be respected? You bet! The task was to network with others in hopes of finding two other young men with cerebral palsy who would like to live together.

Can you minimize squabbles among housemates? When difficulties arise, and a *divorce* is likely, how can someone intervene? There are interpersonal techniques for resolving issues and building positive, constructive relationships. Fundamentally, the skills of open and honest communication, team-building, facilitation, negotiation, and

# A Home of One's Own

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dispute resolution are useful. Some of these skills are well-developed in persons who have worked with various groups around shared housing -- particularly with senior citizens and other special groups (for example, single parents, or adults in recovery). Problem-solving house meetings, reaching consensus on house rules, dividing up responsibilities for utility payments, and allocating chore responsibilities based on preferences and aversions are good places to begin.

Even with good planning, artful collaborative team-building, and other efforts, some individuals are likely to bother others. What then? Sometimes, the matter is one of tolerance, as when a housemate insists on 'borrowing soft drinks' without asking. Brainstorming with everyone who lives in the house and a circle of support may bring about solutions to vexing problems.

## Housing controlled by a person's *agent*

An *agent* (like a friend, advocate or a parent) may play a key role in handling the housing of some individuals with significant disabilities. Some do a stellar job -- being responsive to the needs, hopes, and preferences of the person, while encouraging self-direction. Others do an okay job, not wholly respectful of the needs and wishes of the person supported, but they have the 'right idea' about support, self-reliance, and learning. And, frankly, some *agents* could do a much better job. Of course, there are realities to contend with -- as when someone can't get along with others (even with considerable support) but indicates a desire to live with others. And, if there is a falling out, who should stay and who should leave? What about pressure from people who may want a person to 'fail,' so that he or she can be placed into a group home to receive more care and supervision? These are the kinds of issues that confront agents, as they seek to do the right things for the person they represent.

# A Home of One's Own

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## Bill and Bob

Bill and Bob are brothers. They live down the street from their parents home, and get some help from a college student recruited by their father. Mom and dad are Section 8 landlords, and accept certificates from their two sons. The Housing Authority provides a rental subsidy. In return for a break on rent, the college student is directed by the father to do certain things to assist his sons.

A few years ago, when Bill and Bob moved away from home, the regional center purchased ILS training for the boys. The young ILS instructor spent a good deal of time explaining to the young men what their rights were, and questioning the degree and kind of involvement from the father. After much discussion within the family, the young men fired their ILS worker, and the contract ended.

While the brothers seem to get along fairly well, their father (who is retired and has plenty of time on his hands) designs their menu, does all the grocery shopping, and otherwise makes sure that his son's needs are met. One has the impression that while the boys would be willing (and able) to plan their menus, buy their groceries, and prepare their meals, this is not allowed by their father. Wittingly or not, he may want them to remain dependent on him as part of a larger design to assure their well-being into the future.

## Locating a Home

People receiving supportive living services should have the same housing options available to people without disabilities. Their range of options should include apartments, condominiums, houses, cooperatives, or mobile homes. They may need assistance deciding which kind of home they want because their experience may be limited.

When locating a home with someone, it helps to first choose a neighborhood they would like to live in. Some people choose to live near family, jobs, people they like, or particular places or resources. Easy access to places someone goes to on a frequent basis is often a criteria when looking for a place to live. On the next few pages you'll find a *Housing Resource Checklist* developed by Toward Maximum Independence

# A Home of One's Own

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## Toward Maximum Independence Housing Resource Checklist

Here is a way to look at the apartment where you might want to live. It will help you decide what is good about the apartment 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 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 apartment in the boxes provided.
4. Think about all of these things before you decide if you want to live in the apartment or not.
5. You may be looking at several different apartments - use this checklist to decide which apartment is best for you.

## Housing Resource Checklist

1. The apartment is close to stores, banks, places to eat and other resources.

2. The apartment is clean inside and outside.

3. The apartment is in an area of my choice.

4. The apartment is near and easily accessible to bus routes.

5. The neighborhood feels safe, and I'm comfortable when I leave my apartment.

# A Home of One's Own

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6. The rooms in the apartment are spacious and wheelchair accessible, if r

7. The apartment is in good repair.

8. I can afford the deposit required by the apartment.

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 ur

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

# A Home of One's Own

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16. The neighbors are friendly and supportive.

17. IHSS referral has been made.

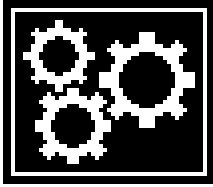
18. Everyone who lives in the apartment has agreed upon "house rules".

19. I am comfortable with the level of privacy I will have there.

20. The apartment complex, if needed, is wheel chair accessible with ramp enough space to get through gates.

# Patterns of Service

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## Check Your Understanding

1. What are the some of the benefits of having a place of your own?
2. What are some ways to minimize the *squabbles* that housemates usually have?
3. What are some ways to support people who are having problems with their housemates?

# Check Your Understanding

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4. (a) If you (or a son or daughter or friend) rely on paid support to move into your own home, how would you decide where to live and who to live with?

(b) Who would help you decide-- or would you decide on your own?



# Patterns of Service

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## Information Pack

*on Formal and Informal Support*

### Introduction

As stated in *Support Needs and Desires*, one of the outcomes of person-centered planning can be a *circle of people* who are interested in making a positive difference for and with a particular person. This group consists of the person supported and might include neighbors, friends, extended family, employers, support service providers, as well as any other interested persons.

### How do Support Circles come into existence?

There is no one way. Some *circles* (of widely varying sizes and degrees of organization) are put together by the individual, family, or friends, simply because of shared interests, mutual commitments and caring, and the joy of being aligned with each other. Other circles, especially if the center of attention (often called the person supported) is a youth or adult with severe disabilities, are consciously created in an organized way.

Organized circles may evolve from personal futures planning in which a group of people agree to come together at least once or twice to: learn more about the individual and the people in that person's life; listen to that person's hopes and

# Formal and Informal Support

## Judith's Circle of Friends -- The Joshua Committee

Judith has used a wheelchair all her 38 years, and she needs an attendant to help her meet all of her physical needs -- eating, using the bathroom, moving about, scratching her nose. As a child living at home and as a university student, she had attendant care, and she participated in the usual childhood activities, grew up, went to school, earned a degree, got a job. Then, because the system decreed that subsidized attendant care is not available for working adults, she suddenly no longer could afford to live alone. She moved to a chronic care hospital, where she lived for four years.

But because she wasn't sick, the hospital proved, in her words, "nearly fatal." Her vitality, and independence, not to mention the irritating habit of going out to work everyday, caused constant struggles with the hospital staff. A friend, Marsha, who came to visit, asked in astonishment, "how can you live here?" You who are so energetic and competent and normal. How can you stand this?" Judith found it increasingly hard to stand alone. She became worn out, suicidal, and one day in March, 1980, she collapsed.

That week, the Joshua Committee was formed. As Judith lay in a friend's house, Marsha and other people who cared about her came together. "Alone, none of Judy's friends could deal with the enormity of the crisis -- yet we had all expected Judy to do it. Now we began to see how hard she has to work simply to live." Judith dubbed this support group the Joshua Committee, "because we were going to break down walls." Each member had both general and specific tasks: budget, health and attendant care, social, professional, spiritual, rest and relaxation. Judith herself was part of the circle. "We were all friends," says Marsha. "We had many meetings. We never gave up or gave in, although we got more angry and tired. We were constantly amazed that Judith had indeed survived so long."

Judith's circle helped set up regular attendant care with a paid coordinator, and got the Ontario government to pay for it. She lives in an apartment in a section of Toronto where many other single people her age live; her attendants' schedules are flexible so that "I can now decide when I will get up, when and where I will have lunch or supper, and what time I will go to bed" -- a level of choice unthinkable for many people with disabilities but taken for granted by everyone else. Judith helped set up the Toronto Citizen Advocacy Program and works for the Canadian Association for Community Living. She travels around the United States and Canada to pursue her work of building relationships between typical and labeled citizens.

Mary O'Connell, *The Gift of Hospitality: Opening the Doors of Community Life to People with Disabilities*. (Evanston, Illinois: Center for Urban Affairs and Policy Research, Northwestern University, February 1988), p. 6-8.

# Formal and Informal Support

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dreams for the future; and, see what support each person may want to offer to move the focus person in the direction of a desired future.

A personal team seeks to develop community connections, to invent and experiment with novel courses of action, and to stand by the person as any close friend would do. The essence of person-centered planning is having the person with a disability (along with family and friends) create a vision of a desired future, identify the support needed to get there, and determine what steps to take, here and now, in pursuit of that desired future. Personal futures planning was discussed in the Information Pack on Support Needs and Desires earlier in this catalogue.

Some tips on organizing and nurturing a *circle of support* are:

1. Interview the focus person (and family and friends) and get names, addresses, 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. (See the sample letter on the next page .) 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.

# Formal and Informal Support

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Friends of Bonnie Jean McLaughlin  
c/o Milo Shea  
1571 McKinley Road  
Napa, CA 94558  
(707) 255-5871

May 15, 1991

Gretchen Oertel  
1234 Lawrence  
Napa, CA 94559

Dear Friends of Bonnie Jean:

Bonnie Jean has asked me to invite you to her house, 3912 Stover Street, on Monday, June 3rd, at 7:30 pm. You will be joined by several of her other friends, and family, to talk about how we can all support Bonnie. This will be a chance (1) to share with Bonnie the things that make her a friend; (2) to learn what she wants to do (and become) in the future; and (3) to 'brain-storm' how she can move toward her goals. The meeting should last for about two hours.

Bonnie Jean has asked me to help her get a circle-of-support started. No one is under any obligation to offer anything (e.g., advice, assistance, an occasional telephone call). We simply ask that everyone agree to come back at least once to see how Bonnie Jean is doing.

If you have any questions, please feel free to call me, or Bonnie Jean, or her mom and dad.

Hope to see you soon!

Cordially,

Milo Shea

# Formal and Informal Support

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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 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.

# Formal and Informal Support

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## 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.

# Formal and Informal Support

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For more information on developing a circle of support, consider:

*What We are Learning About Bridge–Building.* A summary of a dialogue between people seeking to build community for people with disabilities. By Beth Mount, Pat Beeman, and George Ducharme (1988).

*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).

These publications are available from *Communitas*, P.O. Box 374, Manchester, CT 06040.

## Three Types of Support

There are three main types of support or assistance that may be offered to people. The first type of support is "on demand" support. "On demand" support involves establishing some system to allow a person to obtain support only when needed. For example, this could be accomplished through a beeper, an intercom, or a call button. The second type of support is called "scheduled" assistance or support. Just as the word suggests, people simply obtain the support they need on an agreed-upon schedule. For example, an attendant may arrive at 6:00 A.M. to assist someone out of bed. The third type of support is called "immediately accessible" support. Much like "on demand" support, the person obtains this assistance when needed; however, "immediately accessible" support is always available within minutes. For example, in case of an emergency, an agreement that specifies procedures could be established between the person and a roommate or someone living across the hall in an apartment complex. Any one of these types of support can be designed for people wishing to live alone.

All three types of support described above can be obtained in many different ways. The above examples suggested a number of individuals who could provide unpaid or paid support. Support also can be obtained through generic public, private, and consumer-run personal care agencies. Many people will choose to use a combination of the above to meet their unique support needs.

Reprinted with permission by Jay Klein  
from his article *Get Me the Hell Out of Here.*

# Formal and Informal Support

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## Formal Supports

The term *formal supports* typically means work for pay, in contrast with the time, energy, and assistance provided voluntarily -- typically by family and friends -- without pay. While this distinction is typical, there is a hazy middle ground. One agency, for example, pays volunteers a stipend to cover expenses associated with volunteer work. Another agency pays a retainer fee for individuals to be on-call at certain times in case of an emergency.

The variety of paid positions is nearly endless. Indeed, being *consumer-driven* rather than *curriculum-driven*, supported living services should be tailored to the unique needs and desires of each person, and many such services can be provided quite well by many different kinds of people. Some supportive living programs use the term *Community Support Facilitator* for the person who may provide a number of services, including personal assistance, habilitation and training, helping the person access community resources, and so forth. This person may, at times, perform tasks identical or similar to those performed by skills instructors -- if the person wants to learn certain things related to activities of everyday living. If the person is moving away from home (or from a board-and-care facility), this support facilitator -- or, family and friends, or both -- may divvy up responsibilities to assist the person in finding a place to live, entering into a lease agreement, signing up for Section 8 Rental Assistance, gathering together furniture and equipment, checking out possible housemates, and so forth.

Some agencies use paid companions or attendants to provide a supplement from others (for example, through the In-Home Supportive Services program). Rather than being restricted to a limited menu of tasks, CSLA agencies can write job descriptions or contracts to get about everything done that is needed and wanted by the individual being supported. Shown on the next several pages are job applications and descriptions that illustrate this individualization of paid support.



# Formal and Informal Support

## JOB APPLICATION

Submitted to Allen, Shea & Associates, 1040 Main Street, Suite 200B, Napa, CA 94559, (tel. 258-1326), for Job as Friend/Cheerleader for Young Man with a Disability

Date: \_\_\_\_\_

Name: \_\_\_\_\_ Telephone: \_\_\_\_\_

Street address: \_\_\_\_\_ City, State, ZIP: \_\_\_\_\_

How long have you lived there? \_\_\_\_\_ Are you presently working?  Yes  No

Where do you work (or, where did you work most recently)?

Name of company: \_\_\_\_\_

Please describe your job: \_\_\_\_\_

Address: \_\_\_\_\_ How long? \_\_\_\_\_

Education:

Highest grade completed: \_\_\_\_\_ Name of school/college: \_\_\_\_\_

Years attended: From \_\_\_\_\_ To \_\_\_\_\_

Interests, knowledge, and skills?

Do you have a current first aid card?  Yes  No

Do you have a current CPR card?  Yes  No

How do you spend your leisure time? (Special interests, etc.)

Have you ever been convicted of a crime (other than minor traffic violations)?  Yes  No

If "Yes," please describe:

References:

Name: \_\_\_\_\_ Relationship? \_\_\_\_\_

Address: \_\_\_\_\_ Telephone: \_\_\_\_\_

Name: \_\_\_\_\_ Relationship? \_\_\_\_\_

Address: \_\_\_\_\_ Telephone: \_\_\_\_\_

Name: \_\_\_\_\_ Relationship? \_\_\_\_\_

Address: \_\_\_\_\_ Telephone: \_\_\_\_\_

Date: \_\_\_\_\_ Signature of job applicant: \_\_\_\_\_

# Formal and Informal Support

## Job Description Friend/Cheerleader (IHSS Worker)

1. Eat dinner with me two or three nights a week, and remind me to fix sack lunches (if next day is a workday) that are balanced and healthy.
  - a. Talk to me (without making me feel bad) about better things to eat (e.g., more fruits and veggies; less food dense in fat);
  - b. Remind me, if I seem to be making a mistake, not to eat corn, nuts, too much white bread, seeds (e.g., raisins, most grapes), etc.;
  - c. Coordinate your work with my ILS (Independent Living Skills) instructor, who will be helping me to shop.
2. Spend time with me (companionship), especially on weekends, and help me plan and follow through on other social activities.
  - a. I like to run. If you're not a runner, encourage me to do other things with you that are fun for both of us.
  - b. Help me develop a calendar of activities (for example, a low-cost date with my girl friend; movie on Saturday night).
  - c. Since my ILS instructor helps me with my money, work with us to help me get involved in social and fun activities.
3. Otherwise, work closely with me and with my ILS instructor to assist in other ways (for example, remind me to care for my feet, if my athlete's foot is a problem).
4. Keep a time sheet, which will be provided, and give it to me. My ILS instructor will help me in reviewing it and signing an invoice to be submitted to the County Department of Social Services.

*I am asking you for assistance and friendship to meet my needs, as written above.*

Date: \_\_\_\_\_  
\_\_\_\_\_ Employer

*I agree to provide these services and to work closely with you, your ILS worker, and your family and friends in ways consistent with being an IHSS worker.*

Date: \_\_\_\_\_  
\_\_\_\_\_ IHSS Worker

Date: \_\_\_\_\_  
\_\_\_\_\_ Personal Advocate

# Formal and Informal Support

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Supportive living agencies around the country use a number of job titles. The term paid roommate is common and generally means a person who shares the focus person's dwelling. A tenant support worker is often a person who provides assistance to several fellow tenants in a complex, but has his or her own apartment. A paid neighbor is typically someone who lives close to the person supported, and this person often takes care of a limited set of tasks, best performed by someone who lives close by (for example, assisting a person 15 minutes per day to get off to work on time).

In making imaginative, cost-effective use of various services, supported living agencies often *package tasks* into positions that best meet the needs of each individual. For example, if a person is expected to do IHSS work (paid for through another agency), but the person needs more support, one often finds jobs that pay one rate for certain tasks (e.g., \$4.25 per hour) for certain numbers of hours per week, plus another rate for other tasks (e.g., \$11.00 per hour) for some other number of hours. The idea is to get support needs met, and to obtain and retain the kind of personalized support the person needs.

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

# Formal and Informal Support

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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

## Relationships and Obligations

Excerpted with permission from 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...

# Formal and Informal Support

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- ... 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

# Formal and Informal Support

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- ... 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

# Formal and Informal Support

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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.

These obligations make plain an uncomfortable fact at the heart of supported living: to assist people with developmental disabilities in this way is to become vulnerable to them, to their families, and to their communities. Our success depends more on inviting and assisting people with disabilities and community members to do what we cannot do: create satisfying lives and fulfilling community relationships.

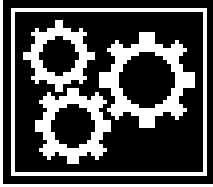
# Formal and Informal Support

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# Patterns of Service

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## Check Your Understanding

1. If someone wants your assistance in developing a circle of support, how would you go about it?
  
  
  
  
  
  
  
  
  
  
2. (a) What will be the biggest challenge for you in assisting someone in developing a circle of support?
  
  
  
  
  
  
  
  
  
  
- (b) If you work for a supported living agency, how can your agency help you meet that challenge?



# Patterns of Service

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## Information Pack *on Community Participation*

Civic life depends on citizens' willingness to recognize and support one another's membership despite apparent differences. All people will live better lives when the knowledge that we are all members of each other shapes everyday life and collective decisions.

**John O'Brien, Connie Lyle O'Brien**

If we are to have peace, our loyalties must transcend our race, our tribe, our class and our nation. Injustice anywhere is a threat to justice everywhere. All life is inter-related. We are all bound in an inescapable network of mutuality, tied in a single garment of destiny. Whatever affects one directly, affects all indirectly.

**Martin Luther King**

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

**David B. Schwartz, 1992**

## Introduction

What does it mean to be a member of the community? How does community membership bring quality and meaning to our lives? How do we find community? It's important to think about the meaning of *community* in our lives before we can help support people who often haven't been participating members of communities.

# Community Participation

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This "sense of community" or "sense of place" is an essential and missing element in the lives of most people with developmental disabilities. The service system that was designed to offer people supervision, care and special services also separates them from the community and those personal relationships which offer a quality of life that no service agency can provide.

Being part of the community is a natural thing for all of us who have never been exiled. So, we often make the mistake of thinking that community membership will come naturally for people who move into regular homes in regular neighborhoods. The experience of people who have been supporting people with disabilities to live in the community is that far too often this process does not happen on its own.

Our ignorance can result in isolating people in the community, and although it is true that some people with disabilities may enjoy or prefer solitude to social interaction as much as do some people without disabilities, we may justify this isolation by saying that people are not very "sociable" or that they are making a choice to spend time alone. Since, when asked, people with disabilities will commonly say they would never choose to go "back" to a group home, service agencies may feel their work is done.

Many agencies who provide independent living services have started to recognize how common it is for people who receive their services to feel a strong sense of isolation. These agencies struggle with the tension between a philosophy of independence and autonomy and this recognition of isolation and loneliness. While support service agencies may advocate principles like "personal choice," "dignity of risk," and "natural consequences," they also struggle internally over such issues as: how much support to provide in developing relationships; whether they are stigmatizing people by their very support; and, when and how to encourage and support someone who says they don't want to go out of their home.

# Community Participation

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A significant barrier to agencies helping people find and build community and natural supports has been the reluctance and often times refusal of referral agencies to fund these efforts. Independent living programs have been seen as the final step on the continuum and most are based on a skills instruction model. So, people are provided with a limited number of service hours based on either specific measurable goals or (an arbitrary cap) and building relationships is not high on that list of services.

Supported living services offer a new opportunity to contribute resources – funding and staff time – to renew and build community connections for people with developmental disabilities. Community support services include (but are not limited to) facilitation, assistance, and support in: self-advocacy; establishing and maintaining relationships (including resolving disputes or dilemmas) between people with disabilities and other community members, neighbors, family, and friends; participation in regular community recreation; transportation to community social/recreational events; facilitation of circles of supports by networking with families and friends, encouraging their participation, and finding new members; surveying the community to find the opportunities for the membership of people with disabilities. (excerpted from California Department of Developmental Services, 1992. )

## Community Presence is Not Community Participation

While most people with developmental disabilities live in homes in regular neighborhoods and work in places located in the community they may not experience regular community life and ordinary community relationships. Most people who rely on residential or living arrangement support are surrounded by people who are paid to be with them, to organize, manage, direct and oversee their lives. These service resources exist to support them, but they can and often do take over the the life of someone they're supposed to be supporting. Typically, this acts to build a wall around someone, separating them from ordinary community life.

Communities often feel they do not have the capacity to welcome and support people

# Community Participation

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with disabilities. A community building project in Chicago, directed by Kathy Bartholomew–Lorimer, began their work in a small community called Logan Square by asking community members if they knew anyone with a disability who might like to be involved with their community building efforts. The overwhelming majority of community members didn't know anyone with a disability. Some people knew of someone they had seen around, but they didn't know a name or a way to contact them. A few people did know the name of a person, but didn't know the person directly – they usually knew the parents. But the most common response, when people were asked about people with disabilities, was to refer those who asked to a human service agency or program – not to a specific person there, but to the place itself.

This kind of consistent response is very revealing. It indicates that community people see people with disabilities as "belonging" to some kind of human service agency. Beyond that, there was also a sense of confidence that such agencies were good places, doing good things for people. The general public perception is that people with disabilities are special people, needing special places with specially trained people with them – and "special" really ends up meaning separate.

This myth offers little motivation for community members to even wonder at the absence of people with disabilities in their personal lives and in typical community life.

Mary O'Connell, 1990

## Learning from Community–Builders

As patterns of supported living services are generated from each person, community building follows that same evolving process. There are no known steps that can be recommended that will help to build community for every person. People who do the work of community building describe it as more art than science. 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,

# Community Participation

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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. In preparing this catalogue we contacted each of them for resources and ideas. They were more than willing to share ideas and their experiences. We recommend that people serious about community building refer to the section titled *Other Resources* of this catalogue and order the books that have been written by those doing community work. 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

# Community Participation

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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



# Community Participation

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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.

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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.

## 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 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

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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

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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.

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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.

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?

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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

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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 on 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

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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.



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## Albert

**Albert** is a rather heavysset 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

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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

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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 talk 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

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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

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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.

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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

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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

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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.

## Other Communities

After many of these experiences one automatically begins to ask, "Is this community a 'typical community'?" Maybe it was just some kind of fluke. Maybe I had just gotten lucky and stumbled into it by sheer chance. Or maybe not. Maybe, just maybe, it was an example of what one might find in other communities. Just walking through this tiny community you wouldn't immediately notice the climate of hospitality. It was there, but needed to be found. The finding part, tapping into the network that brought life, this was the most important thing. I went to another community to see what I could find there. One of the first persons I found was Eddie.

## Eddie

**Eddie** is an energetic and loving nine-year-old boy. He loves to run and play as other children do. Eddie also has Down Syndrome. When I first met Eddie's mother, Melanie, she was at a particularly low point. She and her husband had been embattled with our local school district over Eddie's right to go to his neighborhood school, rather than being bused out of the school district to a segregated classroom.

Melanie and her husband Ed had dreams for Eddie. They wanted him to grow up to be a contributing member of society. They wanted him to go out in the world with the support of family and friends—to be accepted—to feel loved. They had fought his entire life to realize their dreams. Melanie and Ed tried to surround Eddie with activities that involved other typical kids. However, these activities usually involved children who were peers of Eddie's younger brother. Melanie wondered if kids his own age would accept him. Could he ever be invited to a birthday party, not because of his younger brother, but in his own right? The past summer had started with plans



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for Eddie to go to a special day camp for children with disabilities. But Melanie wondered if Eddie could "make it" at a regular day camp.

Rob is an enthusiastic young minister at a local church whom I had met at a friend's house. We discussed promoting the involvement of people with disabilities in their communities. Rob told me it was easier said than done. At the church, he is involved with children's activities. One year he had tried to get several children from a nearby home for children to come to the day camp he directs, and to make whatever accommodations were necessary for them to participate fully and equally. Yet the staff at the Children's Home threw out one roadblock after another. The same thing had happened with a local rehabilitation hospital. He had extended an open invitation for any patient at the hospital to come to services at their beautifully accessible church. No one has ever come. As we were departing, Rob said if there were anything he could ever do, to let him know.

After knowing Eddie for a while, I called Rob and asked if there might be a place for him at Rob's day camp. They had one spot left. After Melanie registered Eddie she called me and said, "It's all so strange. It was too easy! No one's ever just said 'yes' to Eddie." Before camp started Melanie discussed Eddie's abilities and style with Rob. Melanie was concerned that Eddie would get too tired going the full eight hours. Maybe she should pick him up early, she thought. Rob's response was "No problem. If he gets tired he can lie down in the nurse's office for a while and then rejoin us. Don't worry."

As camp proceeded I was struck by how nervous Eddie's mom was. Would he be kicked out because he's not a good swimmer? What if he wandered off? It was as if she were expecting a call any day to say that Eddie wasn't good enough. The call never came.

Eddie's behavior was not perfect, as no child's is. He did wander off sometimes. He didn't always listen to his camp counselor. One day, while painting, his particular

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painting extended to the floor of the church building. Still no call came. On the final day of camp, parents were invited to attend an awards ceremony and final celebration. Eddie received several awards for art and nature study. He also received the "non-swimmers free-style award." It wasn't the awards that struck Eddie's mom, however; it was the feeling in being there that day. Other children hugged Eddie and said they would miss him. A parent of one of the other children in Eddie's group came up to Melanie and said that Eddie's presence was the best thing about camp this year and thanked her for sending him. I mean, imagine it—being thanked for Eddie's presence. This was a new experience! Another parent said that she too was thankful for Eddie. She said that he brought out the best in her own child. Everyone said their good-byes. They also added, "Please come to camp next summer."

After camp was over, Eddie and his family were at a community festival. During the course of the evening several children came up to Eddie to talk. They were children who had met him at camp.

My own participation in Eddie's camp experience was minimal. I knew Eddie and I knew Rob. It was only a matter of connecting them. Together Rob, the camp counselors, the children and Eddie came to their own solutions. They did it their way—as it should be done. For me it meant trusting them and resisting the impulse to interfere and give professional advice. They felt no need to call on me. My involvement took the form of supporting Eddie's mom and helping her get through her underlying fear that Eddie "wouldn't be good enough" and would be rejected.

In a postscript to Eddie's story, word has come to his family that Eddie will be finally going to his neighborhood school this fall. Although his family knows that not all children will welcome him, it is the experience at camp that renews their faith that their son will find people in his life who will accept him as he is.

## Shelly

**Shelly** is described by those who know her as a "doll." She's very friendly and very

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talkative. She lives in a residential program in a large suburb. Shelly has cerebral palsy and mental retardation. She uses a wheelchair and pretty much has to rely on other people for her physical care. Shelly wanted to be involved in something but her staff described her also as being terrified—she always backed out of everything. Knowing that Gene knew some people in Shelly's community, I decided to use this "trust network" again to find people there who would say "yes" to Shelly. After Gene had spent some time with Shelly, he found that the thing that she wanted more than anything was to find a way to help other people who had someone they loved die. About six months previously, Shelly had lost her boyfriend to cancer. She felt she knew something about what it feels like and could offer help to someone else who had those feelings.

Gene knew of several groups that met in her community which had as their focus supporting each other after this kind of experience. One met in a hospital, and one met in a church. Gene asked the leaders of both groups, and each said that Shelly would be welcome. Gene decided to take her the first time and he called to tell the staff person at her residence. The meeting happened to fall on the same night Shelly was to see her psychologist. The staff person said they'd have to see if her psychologist would change her night. A return phone call indicated that no, the psychologist would not change and furthermore she felt that it was entirely inappropriate for Shelly to go. After all, Shelly couldn't even help herself. How could she help anyone else? She herself was in a "grief denial stage" and "inappropriately displayed her grief." On the basis of the psychologist's advice, the staff said that Shelly couldn't go. When Gene went to explain it to Shelly she cried. She was also angry—angry that she hadn't had a choice. It was really important to her. Shelly's staff encouraged her to talk to her psychologist about how she felt. I didn't know if she'd be able to. But she did.

I don't hesitate to say the psychologist seemed rather furious. The report that she sent to the county expressed her opinion that we were all unethical and incompetent. We were "interfering in Shelly's behavior program." The program was that Shelly was not

# Community Participation

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allowed to talk about her grief to anyone except her psychologist. The psychologist told Shelly she could choose, it was her choice. She could keep seeing her, or she could go to the group. Shelly chose the group. The psychologist sent a report saying that this would be the last time the psychologist would see Shelly since she would be getting "treatment in a new therapeutic facility." Gene says that on Shelly's first night with the group she carried herself with such poise and class that he was knocked over. The group promptly kicked Gene out of their meeting since he had not lost anyone. When the doors opened again, he found Shelly surrounded. People were talking with her, laughing with her, being with her. Others came over to Gene and reassured him all had been well. What a delight Shelly was! How insightful Shelly was! Things couldn't have gone better. Shelly beamed and said, "I helped!"



# Check Your Understanding

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3. What does the community gain from the presence of people with disabilities?

4. What did you learn from the stories about Albert, Pete, Bonnie, Eddie and Shelly?

# Patterns of Service

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## Information Pack

*on Risks and Opportunities*

### Introduction

There are many dimensions which shape a *life of quality* for members of any community. When considering how to support people with developmental disabilities in living a life of quality we need to think about those elements which add quality to our own lives. For example, a local family doctor frequently gives lectures about how to live a balanced life. He suggests that the characteristics of the "best possible life" are: good health; reasonable wealth; family; peace; security; friends; time; and, growth. He feels so strongly about this advice that he lists these qualities on the back of his business card and hands them out to anyone who will listen. People with developmental disabilities want the *best possible life* as well and supported living services can help achieve that goal.

One quality of the best possible life that was not included on the doctor's list is having personal power over one's life. This is a characteristic of a good life that people with developmental disabilities have not often experienced. This denial of personal power combined with low status in the community creates a situation where people are at high risk for exploitation, abuse, neglect, and making risky choices. So, it's critical for supported living services to recognize and understand the vulnerability of people

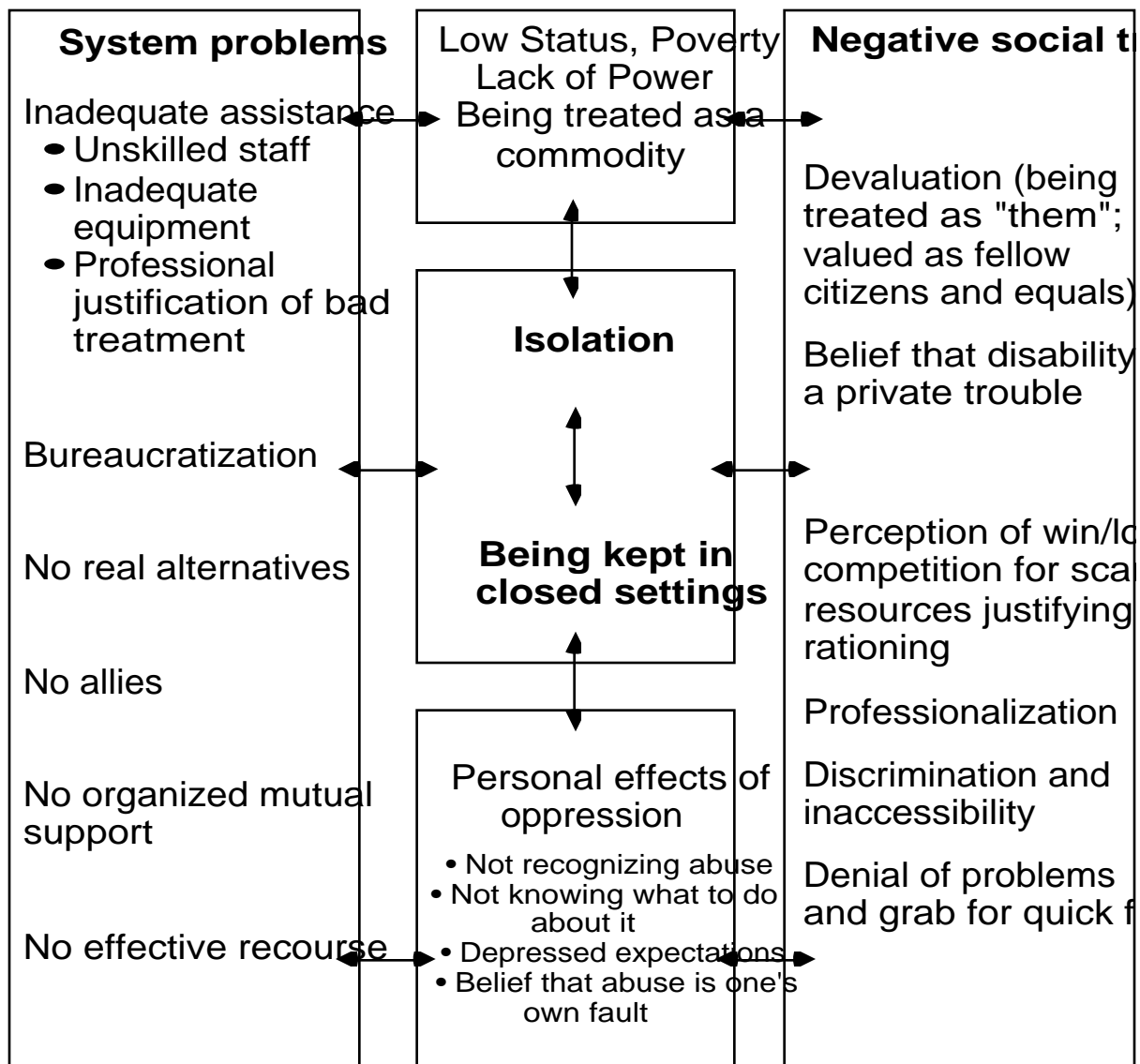
# Risks and Opportunities

and to spend time figuring out how to help people be safe in their homes and communities.

## Understanding Vulnerability

The following diagram was developed by John O'Brien (1990) to visually display the sources of people's vulnerability. The low status given people with disabilities often

### What Increases People's Vulnerability?





# Risks and Opportunities

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puts them at risk within the community and the service system designed to protect them. People often accept living in abusive conditions because they don't feel they deserve a better life.

## The Tension between Choice and Neglect

A major challenge in providing supported living services is walking the tightrope between supporting people to make their own choices and intervening to prevent choices that put people at risk. There are no answers here on where to place your next foot on the tightrope. Ultimately it must be the person with disabilities who makes the decision with support from friends, family, paid staff and community members.

Supported living is about making a serious commitment to stand by a person when life gets tough and there are hard decisions to make. It's also about power sharing and negotiation. Finally, it's as much about interdependence as it is about independence. John O'Brien advises that respecting choice can't mean avoiding a personal commitment when you're supporting someone who makes a decision that negatively affects them. At those times, you need to work on ways to form even stronger alliances with people.

Choice is not a reason for a person to live in an unsafe place.  
Choice is not a reason for a person to live in filth  
Choice is not a reason for a person to smell bad.  
Choice is not a reason for a person to inflict self-harm.

John O'Brien, 1989

When California agencies started providing independent living services, many regional centers and ILS agencies placed a very high value on *independence*. Professionals prided themselves in not influencing people's decisions, and when someone made what seemed like a bad decision, people would say *people learn best from experience* or *natural consequences are the best teacher*, or they are experiencing the *dignity of risk*. While such values are an important part of any

# Risks and Opportunities

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consideration about providing support to those who are learning how to make decisions for themselves, they are not enough. Far too often a person does not learn from natural consequences or does not feel dignified in making a bad decision.

## Regulations for Protection

Our attempts at regulating health and safety have often resulted in patterns of relationships between people with disabilities and the people who support them which promote a dual status (the protectors and those who need to be protected) and power hierarchy. We need to be aware of this phenomenon when developing policies and regulations regarding supported living. While service accountability is important, it can also inhibit natural relationships and the creativity of developing support networks.

## How One Agency Looks at Risky Decisions

*Options in Community Living*, Madison, Wisconsin, has been providing supported living services since 1974. One of the unique features about Options is their commitment to "stand by people over time." We provide you here (adapted with permission) questions that they ask themselves when considering additional support for people who are placing themselves *at risk*. Any of the Options staff can convene an At Risk Meeting whenever it is felt that someone they support is at risk in any quality of life areas (listed on the pages that follow) or there's a drastic change in lifestyle or there is feedback from community members or the person's family that indicate a concern for well-being, safety or health.

## Considerations for Increased Staff Support

# Risks and Opportunities

## 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
  - illness, injury
  - involvement with law
  - financial difficulties
  - exploitation
  - isolation, rejection by others
  - substandard living conditions
  - 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.

## A Policy on Risk and Opportunity

**Introduction.** *Options* developed this policy on risk and opportunity and it has been used by many supported living programs throughout California. The California

# Risks and Opportunities

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Department of Developmental Services even requires its use by agencies providing supportive living services through the CSLA program. This policy can be used to communicate to people with disabilities and their families, advocates and others the principles that guide supported living services. It also provides supportive living services with standards for evaluating a person's well-being and for identifying areas where more support may be needed.

The policy addresses nine major aspects of community living. Each area is divided into two sections: 1) a list of those conditions which must exist to ensure that people are not at risk in the community; and, 2) a list of further conditions that supported living programs can promote to help people achieve a valued lifestyle. Some people may need intensive and long-term support to maintain these standards.

## Risk and Opportunity Policy

### **I. Autonomy/Choice**

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
  1. The person has opportunities to make decisions and express preferences in all areas of life. The right to make these decisions shall be respected by others in the person's life (e.g. service providers, parents, roommates). The person also has the right to refuse interventions initiated by providers.
  2. The person has a method of expressing preferences and a method of acting upon these preferences in all areas of life. For example, a person who has a physical disability and is non-vocal might use a communication board to express preferences and have a personal care attendant to act on those preferences. Preferences can be expressed in non-verbal ways, such as by a change in behavior.
  3. The person has access to information and experiences that assist the person in making decisions about his/her life.
  4. The person has people in addition to service providers for support and information needed to make decisions about his/her life.

### **II. Personal Income**

- A. Conditions that must exist to ensure that a person will not be at risk in the

# Risks and Opportunities

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community:

1. The person has a stable source of income that covers basic living needs, including shelter, food, transportation, clothing.
2. There is effective management of this income to ensure that basic needs are met. (Support can be provided when needed through a double-signature bank account, representative payee, or assistance with budgeting.)

B. Conditions that will further promote a valued lifestyle:

1. There is sufficient income for items and activities that enrich one's life experience, such as vacations and other leisure activities, home decorations, and items that enhance one's personal appearance.
2. The person is able to participate as fully as possible in decision-making about the use of personal income through the development of money and budgeting concepts and values that encourage financial responsibility.
3. The person can maximize income through wise investments and purchases, and through subsidies for which the person is eligible.
4. The person has a means of earning income through employment as a supplement to or in place of government benefits.

### **III. Housing**

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has housing that meets community building codes, is secure and has adequate heat, water and electricity.
2. The person has the basic furnishings necessary for daily living, including a bed, chairs, table and lighting.
3. The person lives in a neighborhood where s/he feels safe and where there is access to needed resources.

B. Conditions that will further promote a valued lifestyle:

1. The interior and exterior of the home is maintained in a safe, clean and attractive fashion.
2. The person is able to exercise control over the home environment, including the choice of location, personalized furnishings and decor, and control of temperature and lighting.

# Risks and Opportunities

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3. The home furnishings are attractive and complete.
4. The person is able to have maximum influence over his/her housing situation through such means as participation in a tenant association, cooperative housing or home ownership.

## **IV. Physical and Mental Health**

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
  1. The person's health is maintained through adequate nutrition, exercise, safe behavior, medical monitoring, and appropriate medications when needed.
  2. The person receives prompt and up-to-date treatment for physical and mental health problems.
  3. The person employs a personal care attendant if his/her physical disability limits the person's ability to provide self-care.
- B. Conditions that will further promote a valued lifestyle:
  1. The person has established relationships with and easy access to health care providers (e.g. physicians, nurses, dentists, counselors and therapists) that know the person and monitor his/her health needs on an on-going basis.
  2. The person's lifestyle encourages wellness. For example, the person eats nutritious meals on a regular schedule and maintains an appropriate weight; does not smoke; does not drink in excess or use drugs; has coping mechanisms to relieve stress; has people to provide emotional support.

## **V. Safety**

Conditions that must exist to ensure that a person will not be at risk in the community:

1. Potential dangers in the person's environment are minimized. For example, his/her home is free of fire hazards and is locked and secure; the person does not walk alone on dark streets at night.
2. The person receives prompt and appropriate emergency services when needed, such as police, fire department, ambulance, crisis line.

## **VI. Appearance and Hygiene**

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
  1. The person minimizes health related problems through adequate personal

# Risks and Opportunities

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hygiene and clothing choices that are appropriate for weather conditions.

2. The person maintains acceptable hygiene and appearance so as not to restrict where s/he can live, work and socialize.

B. Conditions that will further promote a valued lifestyle:

1. The person has a choice of attractive clothing for different occasions.
2. The person maintains his/her hair in a manner that is becoming.
3. The person's hygiene and appearance serve to enhance self-esteem.

## **VII. Relating with Others**

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has the means to communicate on a daily basis with primary people in his/her life. (This may include speech, signing and adaptive devices.)
2. The person has support people, including Options staff, with whom s/he are able and willing to maintain contact.

B. Conditions that will further promote a valued lifestyle:

1. The person has the means of communicating in such a way that encourages interactions with other members of his/her support system and community (e.g., clarity, assertiveness, appropriate affect.)
2. The person has supportive relationships with family members that encourage independence.
3. The person has relationships with friends and peers which provide companionship, intimacy and support.
4. The person has the opportunity to responsibly engage in sexual relationships and marriage based on his/her personal beliefs and values.
5. The person's relationships include people who are non-disabled.

## **VIII. Meaningful Activities**

A. Conditions that must exist to ensure that a person will not be at risk in the

# Risks and Opportunities

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community:

1. The person has a daily routine that is designed around his/her needs and capabilities and that resembles as closely as possible a typical adult routine. Such a routine is likely to include vocational, domestic and leisure activities.
- B. Conditions that will further promote a valued lifestyle:
1. The person's activities provide opportunities for personal growth and increased life satisfaction.
  2. The person receives wages for work.
  3. The person takes part in culturally-valued leisure activities, such as parties, trips, concerts and shows.
  4. The person's activities take place in community settings that are integrated with non-disabled people.
  5. The person has the means of developing and achieving short-term and long-term goals (e.g. vocational planning, vacations, retirement).

## **IX. Mobility**

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
1. The person has the means to move about his/her home and community environments to the extent necessary to satisfy basic needs.
- B. Conditions that will further promote a valued lifestyle:
1. The person has physical access to a wide range of community resources for work, leisure, shopping, etc. Modes of transportation can include bus, car, bike, walking, vehicles equipped for wheelchairs.
  2. The person, when needed, has adaptive devices that will enhance mobility, such as canes, motorized wheelchair, three-wheel bike.



# Risks and Opportunities

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## Armistice

Written by Julie Nichols-Younes; reprinted with permission from *Options*.

For over a year now I've resisted a recurrent urge to write a story about Carol and her ongoing struggle with a mental illness and with defining Options' role in her life. I've often thought there was an important message in Carol's story, but I could never find a way to express it, probably because it was not yet complete. Looking back, it now seems as though Carol and I have come full circle, in many ways we are back to the place we started. Yet, in others, we are light years away.

The past two years of struggle and conflict could have looked to an outsider like a battle of wills to determine who would have ultimate control over Carol's life. I have to admit that in times of frustration and despair over Carol's situation, I often felt like Carol's adversary in a war of wills that I was destined to lose. But now it looks for all practical purposes like I have won. I have Carol's monthly benefit checks sent to me at the office. Options' staff are now co-signers on Carol's bank account. I accompany Carol to the grocery store every Monday, not for the purposes of training, but to be

# Risks and Opportunities

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sure she buys what I consider to be nutritious food. Every Wednesday I meet Carol at her apartment to sign spending checks, contingent on her apartment first passing "inspection", and once a month I escort her to a psychiatrist's office to obtain a prolixin shot. Yes, the battle is over, but did I win? No, I don't think so. I don't think I was ever really a combatant in the war. Carol's struggle was really an internal one. Her need for independence and autonomy was battling it out with her need for structure and support from Options. Carol was unable to see that she could only have independence and "be her own boss" in her words with certain supports and assistance from us. The more control that Options relinquished, the more out of control Carol became.

She went for months without bathing. I'm sure many of you remember the lingering olfactory evidence of Carol's visits to the office during those times. She rarely changed or washed her clothes, appearing in the same menstrual bloodstained outfit week after week. Her diet consisted primarily of Oreos, Coke, and M&Ms since she preferred to spend her grocery money on dolls and toys rather than food. She was noticeably losing weight. Carol never cleaned her apartment or took out the garbage, letting garbage and spills pile up on the living room and kitchen floors. For some reason she preferred living with the stench of her own feces rather than simply flushing the toilet. She broke every agreement and promise she made with Options' staff to change her ways, insisting she didn't need our support. Usually she managed to avoid us by running away or locking us out. She begged us to let her be her own boss and to terminate her from Options. This was not, however, the quality of life of a person in control of her own life, yet for many months I resisted making a drastic move. What about autonomy and choice, what about Carol's wishes? She seemed so tormented by our involvement in her life. Finally, in spite of my guilt, I took possession of Carol's benefit checks and backed her into a corner. She very quickly and quietly went along with the rest of my demands.

Strangely, Carol seems very at ease and comfortable with our new arrangement. She has not uttered a single word of protest or dissatisfaction with my renewed

# Risks and Opportunities

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involvement in her life. In fact, she seems more at peace with herself and her life than I've seen in several years. It's as if she is relieved that someone finally rescued her from the chaos that her life had become and that she was helpless to change. The guilt I feel now is for failing to end her misery sooner by working out a truce in Carol's private war.





# Check Your Understanding

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3. If you (or a son or daughter or friend) rely on paid support, what questions would you want to ask a supported living agency to find out if they will be on your side if you have trouble?

# Patterns of Service

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## Information Pack *on Supporting Diversity*

### *Parents with Developmental Disabilities*

#### Introduction

Anyone who is a parent will tell you that *raising children is challenging* is an understatement. When one or both parents have developmental disabilities, parenting is especially challenging. Not only do parents with developmental disabilities have to overcome or seek support for the challenges presented by their disability, they may also have grown up under environmental conditions which put them at additional *risk* for failure in successfully raising their children. Typical factors in the general society that contribute to a person's *risk* for abuse and neglect of their children include: isolation, poverty, unemployment, apathy, poor parenting models, and low self-esteem. Many of these risk factors are found in the experience of people with developmental disabilities who are parents.

We can learn a lot about the challenges of parenting and how to provide supported living services by looking outside of the development disability service system to community service agencies that support families. One such family preservation program called *Homebuilders* started in the 1970s. It's now a national movement of carefully structured services designed to keep children and parents together safely and

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to provide an alternative to the automatic removal of a child from the home. This family preservation program focuses on families within the child welfare system, and families with members who are either in the juvenile justice, mental health, or developmental disabilities system. It's interesting and not too surprising to note that the values, beliefs and service design of family preservation programs under *Homebuilders* are aligned with the values of supported living services.

## Family Preservation Program – Values and Beliefs

(Barthel, 1991)

1. Children need families
2. Safety is the first concern
3. A crisis is an opportunity for change
4. Not all problems need to be addressed
5. Most family members really care about each other
6. Everybody is doing the best they can at the time
7. Power for change resides in the family

## Family Preservation Program – Service Characteristics

1. Services in family's homes
2. Immediate response
3. Intensive: as long a session as needed; frequently, daily; and up to 20 hours a week (*differs from supported living services which have no arbitrary limit*)
4. Highly flexible scheduling
5. Accept almost all cases
6. Families set own goals
7. Small caseloads
8. Short-term, time-limited, with referral to other ongoing helping services as needed (*differs from supported living services which have no arbitrary time limit*)
9. Focus on the whole family
10. Blend of hard and soft services and availability of "flexible dollars"



# Supporting Diversity

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## Implementing Supported Living Services for Parents with Developmental Disabilities

The process for implementing supported living services to families is similar to the process used when implementing supported living with anyone. Unfortunately, many times families are not referred for services until there are critical conditions which are severely threatening to the quality of life for the family members. The parent or parents may even be at risk of losing their children or the children may have already been removed from the home. A referral for supported living services may come as part of a court ordered family reunification plan.

### Provide Concrete Help

Common sense should always prevail when providing support to families. If there are critical conditions in the home it probably won't make sense spending time getting to know the family prior to providing services and support. Family-centered planning might be done very informally and focus initially on the conditions in the home which are causing the most stress. The parents might not be able to focus on the child's needs until the immediate stressors in the home are alleviated. Concrete immediate help can take all shapes and forms and supported living agencies and their staff should be prepared to work in the home all hours of the day or night to provide whatever supports and services the family needs that they are not able to get from extended family, friends and natural supports. Supported living staff have been known to help families fix their plumbing, move after eviction, help with head lice eradication, transport to medical appointments – whatever it takes.

People who do this work say that while it can be extremely challenging and complex, it can also be most rewarding. Supported living staff have a unique opportunity to be let into the intimacy of a family. Support staff can share in the family's joy as their child takes his/her first steps, says his or her first words, enrolls in school, and learns how to become a contributing family member.

# Supporting Diversity

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We helped a group of parents plan an Easter party for their children. We were shocked to discover that many of the parents had never been on an Easter egg hunt. They thought we were quite strange when we told them it was time to hide the eggs. It was such a treat to be able to experience their first Easter egg hunt with them and to know that we had introduced them to a culturally important event for their children.

## **Training Toward Self Reliance, Sacramento**

### Multifaceted and Holistic Approach to Supports and Services

Supported living services for families must provide a full array of possible support, instruction, and facilitation. After any immediate crisis is alleviated, a family's needs and desires should be clarified through continuing to get to know the family, building trust, family-centered planning, and then plan implementation. Possible areas of support and services include but are not limited to:

- Parenting skills including nutrition, hygiene, health care, parent/child interaction (bonding, response to cues, mutually beneficial interactions around all child care tasks), discipline, and social, emotional and developmental growth
- Household safety
- Parental self-care skills
- Household management, money management, meal planning and cooking, shopping and household maintenance
- Finding and securing child care, respite and infant stimulation
- Finding and securing community resources
- Building support networks
- Decision making and problem solving

To expect a single community worker to master the whole

# Supporting Diversity

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array of available resources that relate to potential youth needs may seem overwhelming. However, to expect a youth-in-crisis or his/her often stressed parents to negotiate unassisted, the maze of agencies, programs and eligibility rules in order to get the help they need is, truly, to ask the impossible.

**Center for the Study of Social Policy, Washington, DC**

## Roles and Relationships

Providing support to families goes much deeper than simply service planning and then plan implementation. That would suggest a sterility or mechanistic relationship between the family and their supporters. The intimate relationship and commitment between the family and their supporters is extremely important. Some may question a support staff's relationship to the family and suggest that intimacy implies a lack of professional distance. When one embraces the values of supported living and makes a commitment to stand by people with disabilities they can not also keep a "professional distance." It is this very committed and caring relationship that can make a significant difference in the lives of families with challenges.

Because of the intimacy and the tension that goes along with doing this work, it is critical that supported living staff have opportunities to reflect upon their experiences with others who also do this work. Some agencies use a team approach to provide opportunities for a few staff to know a family well, so the team can problem-solve and support each other through the tension. Some agencies set aside regular staff meeting time to allow staff to reflect on their experiences. Every supported living agency should find ways to allow staff time to problem-solve, support and learn from each other, and celebrate the joy and tension of their work.

## Supporting Ethnic and Cultural Diversity

# Supporting Diversity

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Until one understands the impact of his or her own culture, language, and ethnicity on attitudes, beliefs, values, and ways of thinking and behaving, it is not possible to appreciate fully the cultures of others. . . . Thus, examining one's own roots is the place to begin any journey toward increased intercultural competence.

-- Eleanor W. Lynch and Marci J. Hanson  
*Developing Cross-Cultural Competence* (1992)

## Introduction

The demographics of California are changing dramatically:

- 41% of all people in California are members of a minority group
- By the year 2010, 55% of Californians will be Latino, Asian and Black
- 92% of Californians will live in counties where the "minority" is more than 30%

Cultural awareness and cultural sensitivity are not enough! People who provide supported living services must strive for cultural competence -- that is, for the knowledge and skill needed to respond sensitively and appropriately to differences in attitudes, values, beliefs, and behavior related to personal and family backgrounds. Much of what has been written on this subject relates to differences associated with language, religion, country of origin, ethnicity, and race.

## Avoiding Stereotypes

While acknowledging cultural differences, it is important to avoid overgeneralization, and certainly to avoid stereotypes. It may be true, for example, that 70 percent of the world's population can be said to have a collectivist perspective (i.e., making decisions and doing things as a group), which is at odds with the dominant individualistic perspective which is in the larger American society. Yet, there are Mexican-American families, quite new to life in the United States, who rather quickly adapt to a non-collectivist perspective. Then, too, some families come to the United States with an individualistic perspective to begin with. The essential point is to be

# Supporting Diversity

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aware of differences, to display good manners, to listen carefully, to observe others for comfort or discomfort, and to respond in a competent, caring way.

## Differences That May Make a Difference in Support

Supported living often calls for practices that are uncommon within the field of developmental disabilities. Some of these practices will resonate well with persons from differing cultural backgrounds; some will not. To illustrate, if one sensitively seeks an understanding of the person to be supported by using whatever ways are comfortable for the individual, his family and friends, chances are that one will be judged as culturally competent. So, where are the rubs likely to be? Here are some to think about:

- *Collectivist versus individualistic orientation.* -- For a variety of reasons (a group orientation being only one), the person with a disability may be reluctant to express her own viewpoint, expecting family members and elders to speak for her. If the individual to be supported is more group-centered than person-centered, approaching support through involvement of others (for example, a circle of friends) may be comforting. But, focusing on an individual's desired future may cause some discomfort. Certainly, in comparison with independent living services, as traditionally perceived, the ethos of supported living can foster interdependence, which may be viewed warmly by persons with a collectivist world view.
- *Dreams for the future.* - - It is not common in any culture to ask people with developmental disabilities to dream, and one often encounters a blank stare -- at first, until the idea catches on. If the individual/family is accustomed to a deterministic perspective on life, focusing on practical, immediate concerns may be a better way to proceed. On the other hand, if it is comfortable to practice collective problem-solving and consensus decision-making, the objection may be mitigated.

# Supporting Diversity

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- *Privacy, shame, stigma and approved roles.* -- In many cultures and sub-cultures, privacy can be an issue. The emphasis on privacy may (or may not) reflect beliefs and attitudes about mental retardation or related conditions (for example, shame). Certain kinds of support (for example, group counseling) may be viewed negatively, because the support is not as private or discreet as the person, family, and friends would like. Privacy concerns may also condition the size and composition of any circle-of-support. Cultures vary in expectations for adults with developmental disabilities. A family may want a young woman with mental retardation to work at home rather than be in supported employment, and this preference may not reflect shame, risk factors, or anything else other than culturally approved roles.
- *Safety and risk.* -- Cultures assess needs differently, and view the care-giving responsibility differently. Often, views about the proper role of the person and caregivers may be at odds with ideas of the dignity of risk. This may circumscribe certain lifestyles and ways of supporting the person.
- *Formality, informality, and the role of the professional.* -- Many cultures accord professionals great deference. This may stem, in some cultures, from the practice of handing over care-giving responsibility to physicians and other professionals. Or, it may simply reflect the status accorded people who have many years of education and advanced degrees. If the prevalent view is the professional knows best, it may be difficult to get the person and the family to contribute ideas. If the family is very business-oriented, to strive for lightness and fun at a planning meeting may not be the correct approach. If boasting is frowned upon, it may be wise to avoid asking the person a question such as "What are some great things about you?"

## A Value Base of Cultural Competency\*

To move services towards cultural competency requires a set of underlying values

# Supporting Diversity

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which provide a foundation for policy and practice. A culturally competent service:

- Respects the unique, culturally-defined needs of all persons served;
- Acknowledges culture as a major force in shaping behaviors, values, and service systems;
- Views natural systems (family, community, church, healers, etc.) as primary sources of support for ethnic populations;
- Starts with the "family", as defined by each culture, as the primary *customer* of service;
- Recognizes that the concepts of "family", "community", etc. are different from various cultures;
- Believes that diversity within cultures is as important as diversity between cultures;
- Operates with the awareness that the dignity of the person is not guaranteed unless the dignity of his/her people are preserved;
- Understands that people are usually best served by others who are part of or in tune with their culture;
- Acknowledges and accepts that cultural differences exist and have an impact on service delivery;
- Advocates for effective services on the basis that the absence of cultural competence anywhere is a threat to competent services everywhere;

\* This section was adapted from *Towards a Culturally Competent System of Care* which is an excellent resource (please see Reference section for a complete listing of this document).

# Supporting Diversity

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- Recognizes that the thought pattern of non-western European peoples though different, are equally valid and influence how people view problems and solutions;
- Respects cultural preferences which value process rather than product and harmony or balance within one's life rather than achievement.
- Acknowledges that when working with people from cultures other than our own, process is as important as productivity;
- Recognizes that taking the best of both worlds enhances the capacity of all.

## Supporting People with Physical Challenges



# Supporting Diversity

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*Steven:*

## On Supporting Someone With a Physical Challenge

Steven was referred to our agency for supported living services because he needed more physical assistance than he was getting through In-Home Supportive Services. He also needed help figuring out how to schedule and supervise his personal assistance workers. When I met Steven, he was working all day and then he had a two hour bus ride home. He would arrive home around 5:00p.m. and prepare his own dinner. This took him two to three hours because of his physical challenges. By the time he finished dinner he went to bed because he was so exhausted. He was getting by, but the point is to live a life not just survive. People with disabilities can be so anxious to get out of nursing homes (as was Steven's case) that they think it is fine just to survive. They may not expect more than survival. His personal assistants came over whenever they wanted and more than one of his assistants had financially exploited him. The first thing I did was help him assess his assistance needs. The prior assessment, which had been done by a county worker had way under estimated his needs. They may have done this in part because Steven did not want to admit to them that he needed a lot of help. For example, he told them he could transfer himself – well he could if he had to – but to do so put him at great risk for falling, possible injury and he could have been on the ground quite a while before anyone would find him. When I am helping someone prepare for their IHSS evaluation I talk to them about expecting more from their lives than just survival. I encourage them to get as much assistance as they really need so they can live a better life.

**Jerry Tamburino**

Community Support Facilitator  
Training Toward Self-Reliance, Inc.

## Introduction

Supportive living services offer people with physical disabilities the opportunity to receive the individualized supports, services, and technology to live in their own home. The methods or process for figuring out with the person what they needs and how a supported living program can help, are the same methods used to figure out a pattern of support for anyone else. Only the answers through support and service patterns will differ.

## How One Agency Provides Support

Training Toward Self-Reliance, Inc. (TTSR, Sacramento, CA) has been providing supported living services to people with physical assistance needs for many years.

# Supporting Diversity

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Their services have evolved over time as they learned what supports and services people need. When they first started, personal assistance issues were addressed on an individual basis between the community support facilitator (direct service staff) and the person requesting services. TTSR was fortunate to have Jerry Tamburino on staff, who had provided personal assistance himself and had many friends who relied on assistance. Jerry became the *in-house* resource on IHSS and the needs of people who are physically challenged. Jerry started to recognize that a few of the people he knew who had repeated problems getting good personal care represented the problems of many people who were living in their own homes and relying on personal assistance. Jerry heard repeated stories of abuse, exploitation, and neglect.

Jerry and a few of his friends who relied on physical assistance decided to start a peer support group. They saw the group as having two purposes: 1) to give people an opportunity to problem solve with each other and to provide mutual support; and, 2) to provide an avenue of information (for example, how to find and employ a personal assistant, and how to get the hours you need from IHSS).

A few of the group members were very resourceful and experienced at employing personal assistants. These group members were a resource to the others who were struggling. People who had been vulnerable to exploitation started to feel more powerful and started to take control of their lives and the supports they needed. They started to believe there was more to life than just surviving. The group members became resources for each other.

TTSR continually evaluates its services and how well they are meeting people's needs. They recognized that the group was not helpful enough to people who needed step-by-step information on how to determine the range of personal assistance services they require from an attendant and how to perform as effective employers. TTSR was able to get the local community college to sponsor and house an Attendant Management Course. Students who enroll in the course have the added benefit of becoming a participant in college life.

# Supporting Diversity

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The TTSR Attendant Management Course was designed to help each person identify and meet his or her personal needs. Though the information is presented in a class format, during the class facilitators spend time with each individual helping them benefit from the class. TTSR also uses the class materials outside of the class as part of their regular daily work with people. For information on the course, you can contact: Training Toward Self-Reliance, 2755 Cottage Way #15, Sacramento, CA 95825. You can also refer to the Information Pack on In-Home Supportive Services for examples of ways people with physical challenges clarify their individual support needs, develop job descriptions, and hire and manage their personal assistance staff.

This discussion of how one agency is supporting people with physical challenges is only an example. Each agency must develop their services from the needs of their community and the people who rely on their support. People with developmental disabilities will need varying amounts and kinds of support from a supported living agency as they recruit, hire and manage their personal assistants. Supervising staff is difficult for most people. This difficulty becomes even more complicated for people with physical challenges because they may be physically vulnerable and dependent on the person they are supervising.

## Supporting People with Challenging Behaviors

People with severe reputations tell us more about what is wrong with our system than what is "wrong" with the individual; and many people with severe reputations have

# Supporting Diversity

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modest but essential lifestyle choices that are not being met.

**Smull, Harrison (1991)**

*Supporting People with Severe Reputations*

## Introduction

People with challenging behaviors have usually been denied opportunities to live in their own homes. They have been seen as needing "special services" and as "not ready" for the community. The values of supported living *challenge* these concepts. Supported living services do not exclude people on the basis of their disability, rather they develop a pattern of individually designed supports and services to meet the person where they stand. Supported living services are not about changing people or modifying their behavior, they are about figuring out what behaviors work and what don't work.

The process of figuring out what someone needs and wants may be challenging and take time. A person may verbally say one thing while their behavior may indicate something else. The challenge to the supported living agency is to make a commitment to stand by the person and to be flexible and creative in responding to changing needs.

## Discovering what matters to the person

Some people with histories of behavioral challenges appear to be telling us that they are unable to tolerate some aspect of their life. Our challenge is to discover what they find tolerable and what they find intolerable. Some people need privacy, others need people or someone with them all the time. Some people need a consistent schedule of daily activities, others would find this intolerable. Michael Smull and Susan Burke Harrison, Department of Pediatrics, University of Maryland, Baltimore, Maryland, refer to intolerance as "non-negotiables". This is a helpful way to refer to people's intolerance, so we are consistently reminded when planning with the person that there

# Supporting Diversity

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are some aspects of their lives that are non-negotiable.

## Eric

Eric is a very shy but very funny guy who had a run of bad luck. He was placed in a residential school when his grandmother was no longer able to provide the care he needed. He had an immediate need for a place to live at a time when there were no vacancies in the programs in his home community. His luck did not improve as the system attended to the next crisis and did not consider his return. His reputation was his placement. Anyone in a residential school must be challenging. When we met Eric he had "graduated" from school but was still living there with 24 hour supervision. He always wanted to be a cashier so his "training program" was to operate a play cash register with play money.

When we asked Eric where he would like to live he named five different towns. He was willing to live anywhere, so long as he was able to leave the school. When we spent time with him it became clear that he wanted to be close to his family. He wanted to be able to visit them when he wanted to and not just when transportation could be arranged. Eric now lives near a bus line that is no more than one transfer from his important family members (including his grandmother). He lives by himself with staff who come by each evening and spend time with him on weekends. He is thinking about having a roommate because it is "pretty lonely" living by himself. As for work, he has a job at Rite-Aid. He started with a full time job coach but he only needed him for the first day. Being a cashier is still a goal but it is now only one of a number of goals for his career in retail sales.

by Michael Smull and Susan Harrison  
Supporting People with Severe Reputations (1992)  
Reprinted with permission from the authors.

Smull and Harrison (1992) use a person-centered planning process they refer to as "essential lifestyle planning." Discussion during the planning meeting centers around the following questions:

- ⊕ What is non-negotiable?
- ⊕ What is strongly preferred?

# Supporting Diversity

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- ⊕ What is highly desirable?
- ⊕ People who really know and care about \_\_\_\_\_ say \_\_\_\_\_
- ⊕ To be successful in supporting \_\_\_\_\_ –
- ⊕ \_\_\_\_\_'s reputation says –
- ⊕ If this is going to happen we must –

These questions may be helpful when getting to know anyone who is requesting supported living services. The process for implementing supported living services for people with behavioral challenges is the same process used with any other person requesting support and services.







# Patterns of Service

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## Reflections

If you provide support to people:

### Develop a Support Plan for Yourself and Your Agency

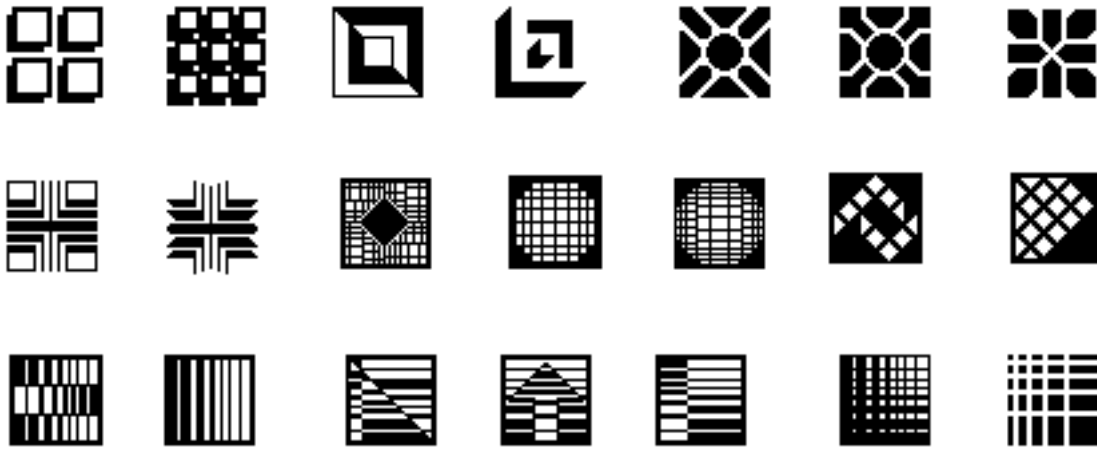
Go back through this chapter and look at your answers for *Check Your Understanding* (you'll find them on pages 9, 19, 33, 45, 63, 91, 107, and 125). Take the space below to summarize what are the biggest challenges in providing supported living services. Also, take a few minutes to write down a list of the ways that your agency can support you in meeting these challenges. When you complete this activity, you'll have support plan for yourself and one for your agency as well.

If you (or a son or daughter or friend) rely on the support of a supported living agency:

### What Do You Want from a Supportive Living Service Provider

Go back through this chapter and look at your answers for *Check Your Understanding* (you'll find them on pages 9, 19, 33, 45, 63, 91, 107, and 125). Your answers will help you think about what you want from a supported living agency and what kind of relationship you would like to have with them.





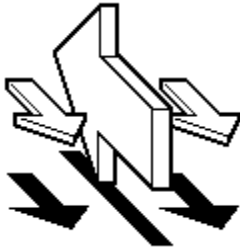
*Patterns of Supported Living*

# Community Resources



# Community Resources

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## Directory

### Introduction

Building community connections for and with people with disabilities goes well beyond the scope of teaching the skills associated with utilizing resources and services. This chapter details a wealth of information about available services and useful resources common to communities across the State of California.

Some will help people to access assistive technology and still others will focus on needed services, information or referral. While these are all important, the most significant listings are those which support people in developing relationships with others or in making a meaningful contribution to their communities. Each of us seeks a valued social role where we can build relationships with people who share our interests and goals.

Whether it is in a small setting which we consider community such as a church committee, a self-help group or a neighborhood club, or a larger group with the greater responsibilities of civic events, local government, a business organization or ethnic association, membership is an important part of our lives. Please remember that the following lists of services, resources, or organizations is no substitute for real belonging or membership. All of these resources combined cannot equal or replace meaningful relationships between the individuals who look to us for support and other community members who share their interests and enjoy their company.

*Community Resources* includes:

		<b>Page</b>
<i>Snapshots</i>	Bernard	CR 5
	Sherri	CR 6
<i>Quick Start</i>	Housing	CR 7
	Medical-Social Services	CR 11
	General-Social Services	CR 15

The *Directory for Community Resources* is continued on the next page.

<i>Quick Start</i>	Transportation	CR 19
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This chapter was developed by Connie Saverino, Executive Director of *Toward Maximum Independence*, San Diego, California.

# Directory On Community Resources

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	Career/Educational Services	CR 21
	Legal/Advocacy Services	CR 23
	Specialized, Non-Generic Services	
	Disabilities and Ethnicity	CR 27
<i>Check Your Understanding Information Pack</i>	A Review Just for You	CR 29
	Housing Subsidies	CR 31
	In-Home Support Services	CR 37
<i>Reflections</i>	Employer/Employee Woes!!!	CR 57
	Putting Together a Shared Household	CR 58

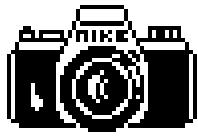
In your area are a number of generic housing services to consider when developing a pattern of support.

## 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

# Community Resources

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## Snapshots

### Bernard

Bernard shares a four bedroom house with a long-time friend and two housemates who answered room-to-rent ads. Bernard has a chronic medical condition, which is set off by eating the wrong kinds of food. Although he knows what to avoid eating on his own, he needs extra support and encouragement planning, shopping and cooking the right foods. So, In-Home Supportive Services were sought and eighty hours per month were approved. IHSS funds make it possible to pay one of the housemates for this support. There is also support from an Independent Living Service which helps with banking, and planning social activities. Members of his *circle-of-support* (family members and friends) have also helped in a variety of ways with his job (helping him buy a uniform at the hotel where he works), maintaining the house, following-up on medical appointments, and his social life (occasional help in setting up a date).

Bernard's pattern of life includes support from:

- His housemates
- In-Home Support
- Independent Living Agency
- Regional Center
- Circle of Support
- Supported Employment Agency

# Snapshots

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## Sherri

Sherri left her mother's home and lived in a group home for several years before deciding that she wanted to live by herself. Her mother helped her find an apartment and assisted her in obtaining an emergency Section 8 voucher. Sherri had some problems in her apartment (playing loud music) and was asked to leave. Again, with the help of her mother, she found a studio apartment, where she could use her Section 8 voucher. This place is much more comfortable, and issues like being up at night, loud talking, and having the stereo or television on 'too loud' aren't a problem since her neighbor's habits are much like her own. Sherri's *circle-of-friends* has supported her in going to a weight-control group, helping her to report changes in earnings to the local housing authority, and assisting with minor repairs and adaptations to her apartment. Sherri fired her ILS instructor some time ago (they just didn't get along) and now has services from a supportive living agency to provide her with some additional support in cooking safely and getting more connected to her community.

Sherri's pattern of life includes support from:

- Her new neighbors
- Housing Authority
- Regional Center
- Circle of Support
- Supportive Living Program
- Supported Employment Agency



# Community Resources

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## QUICK START

### On Housing

Housing Codes. For example, they're interested in sub-standard 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.

#### 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.

#### 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.

#### Section 8

The Public Housing Program of the U.S. Department of Housing and Urban Development (HUD) is administered by local County Housing Commissions. Section 8 Certificates are available throughout the State of California and provide a housing subsidy for people with low income. Individuals who use this support service are screened for eligibility by the local Housing Commission. Patience is a key since most communities have long waiting lists. For more information, see the Information Pack on Section 8 Housing Subsidies later in this chapter.

#### 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

# Quick Start On Housing

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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*. The State Bar of California publishes a pamphlet "What Should I Know Before I Rent." A free copy will be mailed to anyone who sends a stamped, self-addressed envelope to Communications Division, 555 Franklin Street, San Francisco, CA 94102. In the Information Pack on Section 8, you'll find the Perfect Apartment Checklist which can be used when looking for a place to live.

## In-Home Support Services

This program is provided through your local Department of Social Services and offers assistance to people with disabilities who are unable to remain safely in their own homes without help. Individuals are generally eligible for services if they are living in their own home and currently receiving SSI/SSA, or they meet all SSI/SSA eligibility criteria (except for income) but they do not receive it. To apply, contact your local office, which is usually found in the County Government Offices section of your phone book. See the Information Pack on In-Home Support Services later in this chapter which includes IHSS Packet: Guidelines For Accessing & Utilizing Attendant Services.

## 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.

## Other Housing Resources

### 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

# Quick Start On Housing

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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.

Medical services aren't always easy to find, but there are lots of places to look in every community.

## Adaptations and Rehabilitation Engineering Services

Local home health agencies, rehabilitation hospitals or centers,

## California Department of Housing and Community Development (HCD)

HCD produces a variety of publications that provide useful information. To obtain a list of HCD and related publications, on a wide variety of topics, contact:

Department of Housing and  
Community Development  
Business Services Office  
1800 3rd Street  
P.O. Box 952-050  
Sacramento, CA 94252-2050  
(916) 322-0303

HCD has a number of programs, several important ones making available grants and low-interest loans from funds generated through the sale of bonds, authorized by the citizens of California.

## U.S. Department of Housing and Urban Development (HUD)

HUD administers a number of programs, many of which involve mortgage insurance, and may make it easier than otherwise to qualify for a loan. Other programs, especially the ones noted below, are of special interest. Some are administered through HCD, the State Housing Authority; some through local, public housing authorities (cities, counties, etc.); and some by both. The very important Community Development Block Grant (CDBG) program, for example, is administered through larger cities (generally 50,000 or more) and counties (typically, 200,000 or more). HCD administers this program for smaller towns and smaller counties.

# Quick Start On Housing

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For general information about federal HUD programs, in our area, write:

Public Affairs Officer  
U.S. Department of Housing and  
Urban Development  
San Francisco Regional Office,  
Region IX  
450 Golden Gate Avenue  
San Francisco, CA 94102-3448  
(415) 556-4752, OR for general  
information about HUD programs,  
(415) 556-5900

Or, contact:

Director, Housing for the Elderly and  
Handicapped People Division  
Office of Elderly and Assisted  
Housing  
U.S. Department of Housing and  
Urban Development  
Washington, D.C. 20410  
(202) 708-2730 (elderly)  
(202) 708-3287 (handicapped)

D.C.: GPO, June 1990, with updates  
on changes. The price: less than \$40.  
Ask your reference librarian to see if it  
is carried in your public library.

## *Other Federal Assistance*

As at the State level, many agencies of the federal government are involved in housing. There are several financial intermediaries. The Resolution Trust Corporation has been selling properties at bargain basement prices in some areas, but mostly in Texas and the Southwest. The Department of Agriculture has several relevant programs for farmers, and rural areas, and so forth.

A good source of information, and available from the U.S. Government Printing Office, which has an office in San Francisco, at the Federal Building, is: U.S. Office of Management and Budget, 1990 Catalog of Federal Domestic Assistance. Washington,

# Community Resources

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## QUICK START

### On Medical Social Services

university departments for Rehab-Engineering or medical equipment vendors are good sources of information regarding research and development, as well as care and maintenance of adaptive or assistive devices and medical equipment. Your regional center occupational or physical therapist may also have valuable information regarding free-lance engineers, Medi-Cal eligibility, etc. Check your local phone directory yellow pages under "Community Service Centers for the Disabled" for referrals to organizations providing Rehabilitation/Engineering Services.

#### American Cancer Society

A non-profit organization which operates through physician referral. They typically provide a variety of rehabilitation services, adaptive equipment, counseling and support groups. See your local phone directory for county chapter listing.

#### American Red Cross

This organization provides emergency and disaster relief, community education, and referral services statewide. Some chapters also operate a seniors volunteer program.

#### Alcohol/Drug Abuse Services

Self-help groups such as Narcotics or Alcoholics Anonymous are generally listed in local phone directories. The National Council on Alcoholism provides education services, as well as statewide referral to local community services.

#### County Departments of Health Service

County health services typically provide eligibility information on Medi-Cal and Medicare programs and services, listings of community clinics and participating pharmacies. They will also make referrals to other counties when an eligible participant is moving. The following services with a ✓ before the name of the service can

# Quick Start On Medical Social Services

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usually be found in the County Government Offices section of your local phone book under Health Department or Health Services.

## ✓ California (Child Health & Disability Prevention Program) CHDP

Provides health check-ups, information and referral on health care for children and young adults using Medi-Cal reimbursed services.

## ✓ County Community Clinics

Most counties provide low cost medical services on a sliding scale basis, as well as for Medi-Cal recipients through a system of local community clinics. They also offer periodic free immunizations and health screenings to eligible children. You can usually find this service in the County Government Offices section of your local phone book under Health Department.

## ✓ County Drug & Alcohol Services

Most county health services offer referral services to drug and alcohol rehabilitation and support services available within the community.

## ✓ Office of AIDS Coordination

Many county health departments now

provide AIDS information, referral services and directories to all providers of HIV-related health and social services as well as hospitals and participating in-home nursing agencies.

## ✓ WIC - Women, Infants and Children

Typically a division of the local Department of Health Services and available to low income families as a supplemental food program separate from food stamps. Screenings for eligibility are completed in local offices.

## County Mental Health Services

Most counties provide Medi-Cal eligibility information and referral for mental health services. Many counties operate mental health clinics where eligible persons may receive out-patient counseling on a sliding scale or Medi-Cal basis. Some counties also operate in-patient hospitals where short term, emergency mental health services are available to persons presenting themselves to be a danger to self or others in the community.

## Direct Link For The Disabled

Offers information on disability-related needs along with referrals to local, state and national resources. Their phone number is (805) 688-1603.

## Dial-A-Dentist

This is one of many national or state referral systems for dentists and it's a particularly useful one since it lists only

# Quick Start On Medical Social Services

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dentists who accept Medi-Cal. If it's not available in your area, you can also call your local Medi-Cal office for a listing of participating dentists.

## Easter Seals Society

A non-profit organization providing referrals to rehabilitation services, support groups and funding for people with disabilities. See your phone directory for listing of local society.

## Lions Club

A non-profit service organization which offers a variety of health-related services at low cost or free. Intake is through an agency referral. Check your phone directory for local chapter.

## Local-Ask-A-Nurse

A service of TEL MED (not available in all counties) which provides health information, referral, physician listings, and special community services such as drug and alcohol treatment referrals.

## Local Family Planning Clinics and Planned Parenthood

These are good resources for counseling and family health care services.

## Local Hospital Rehabilitation Centers

Local hospitals often provide evaluation, rehabilitation treatment, adaptive equipment and referrals.

## Local United Way Information Line

This local, non-profit organization will typically help you find information on

rehabilitation services. It's usually a cooperative service provided by United Way, City and County governments.

## National Low Cost Eye Care Referral

This is an 800 number (1-800-222-3937) referral for reasonable eye care providers in local neighborhoods/communities.

## National Medical Association of Comprehensive Health Centers

This association (with local affiliates in larger, urban areas of the state) provides and operates local centers offering outpatient health care and prenatal services.

## National Rehabilitation Information Center

Provides information on numerous nationwide rehabilitation services. You can reach them at (800) 346-2742.

## State Department of Rehabilitation

State funded and administered locally through county offices. Offers case management, coordinates services available such as vocational/medical services. Contact your local office.

## TEL MED

This is a local phone information service available in many areas and

# Quick Start On Medical Social Services

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offered through the county's health services which provides taped messages on a variety of health problems. It is usually listed in the community access pages of the local telephone directory or under the county listings.

A variety of public and private social services available to everyone throughout the state.

## California Self-Help Center

You can reach them at 1-800-222-Link and they offer statewide referral services for self help resources. Locally based mental health associations can also provide this information and referral to available services. In addition, many hospital community education programs offer support groups around specific needs and interests.



# Community Resources

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## QUICK START

### On General Social Services

#### Chambers of Commerce

Each city has a Chamber of Commerce. It's a great resource for activities, community issues and events, and learning about the area. Refer to your local phone directory.

#### Childcare Resource Services

The local phone directory has specific listing of services in local areas. County child care licensing can give free child care referrals. Churches, YMCA, local school districts can offer information. In many communities, the Childcare Resource Service is a program of the YMCA and provides referrals on day care options ranging from licensed preschool/day care centers to licensed family day care homes. Information regarding available HeadStart services should be accessible through this resource service.

#### County Departments of Social Services

Local County Departments of Social Services typically maintain or monitor several programs such as:

- 1) Public Inquiries/Complaints
- 2) Community Relations for the Deaf (TDD)
- 3) Child Abuse and Neglect
- 4) Adult Abuse and Neglect
- 5) Community Action Partnership

Bureau

- 6) Welfare Fraud
- 7) Adoptions
- 8) Foster Care

The following services with a ✓ before the name of the service can usually be found in the County Government Offices section of your local phone book under Social Services.

#### ✓ Adult Protective Services

This service provides crisis intervention and/or case management services to adults 18 years and over who are unable to protect their own interests. APS is responsible for investigating allegations of dependent adult and elder abuse and for intervening when necessary. No cost.

#### ✓ Child Protective Services

Provides services to children and families when their parents or guardians are unable to provide adequate care because of abuse, molestation, neglect, exploitation, abandonment, drug abuse or alcoholism. Contact local office for other services available. No cost.

#### ✓ Aid To Families With

# Quick Start On General Social Services

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## Dependent Children (AFDC)

Provides financial support to children who are deprived of support from one or both parents as a result of absence, incapacity, unemployment or death. Recipients are also provided with eligibility determination for Medi-Cal and food stamps. Intake is done on a walk-in basis - subsequent interviews are usually by appointment.

## Counseling Services Infoline - United Way

At 1-800-351-0797, they offer information about counseling and referral to all ages. It's free.

## Disaster Preparedness and Safety

Local police departments, community affairs offices are a good resource for gathering important information on safety concerns. Local community centers often offer educational and referral services for disaster preparedness, as does the American Red Cross and the Salvation Army. The yellow pages of the local phone directory has an entire section devoted to practical aspects of preparing for a disaster.

## Food Bank Programs

Food Banks are typically non-profit, community-based program. Food banks usually offer emergency food boxes and commodities like cheese and butter. Emergency food supplies can also be obtained from various community organizations (e.g., Salvation Army, Catholic Community Services, Crisis Houses, Episcopal Community Services, Jewish Family Services).

## HeadStart

This is a federally funded program administered by Parent Board of Directors. Targeted ages are 3, 4 and 5 year olds. Students taken on an as needed basis, priority given to low income, functional limitations, and single parenthood. Check your local phone book for a program in your area.

## Hospital Community Education

These programs are a good source of information via classes, newsletters, etc. on available services in the community both in and out-patient.

## Local Psychological Associations

A referral system of local, licensed clinical psychologists, LCSW's and MFCC's accepting most California health insurance plans and some psychologists accepting Medi-Cal coverage. You can usually find them in the yellow pages of your phone book under *Psychologist's Information and Referral Services*.

## Local Women's Shelters

Many communities have women's centers or shelters where services are available to women, infants and children in crises.

## National Mental Health Hotline

Available at 1-800-969-6642, they provide referral services for local community services and self-help

# Quick Start On General Social Services

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groups such as Alcoholics Anonymous, Drug Abuse Treatment Programs, Eating Disorder Clinics, etc.

## Other Social Service Agencies

Many services are available in most communities and they can provide a variety of opportunities for people to participate in social activities, establish connections, or contribute to the life of the community. Local recreation, community centers, or Y's offer classes, support groups, fitness programs, lunch programs, etc. Local churches and religious organizations provide access to community building opportunities, social services, and volunteerism. Environmental groups such as the Sierra Club are another means of drawing people together with similar passions. Gay and Lesbian Centers, Mens' and Womens' Support Groups, as well as self-help groups all serve to offer opportunities for people to come together over common issues, concerns and interests.

## Religious Community Service Organizations

You can contact your local religious group by referring to the phone directory. Organizations such as Catholic Community Services, Episcopal Community Services, Jewish Family Services, and Methodist Services are offered in most communities. They provide social, medical, housing and counseling services.

## Salvation Army

This non-profit organization has a wide variety of community services. Refer to local phone book for specific services in your area.

## Senior Programs

There are a multitude of ways to access information on senior services in local communities. One way is to use the community access pages in the local phone directory; another is to consult the local newspaper or other local publications which usually devote a column or section to activities and services specifically geared to seniors' interests. Most communities now have an Area Agency on Aging. Statewide referral is available for local senior services, education, and information. Many hospitals, through their community education programs, provide senior resources, newsletters regarding various senior health issues, as well as education and support groups. Many neighborhood clubs and community centers sponsor "seniors only" events and activities, as well as provide information and referral for local outside community services. Check your local phone directory in the City Government pages under Senior Citizen's Services.

## United Way - Self-Help Directory

United Way Resource Centers are typically available in most metropolitan areas. These centers usually have a directory which provides printed information on health and human care services within the area. Directories are generally printed every two years and cost of \$35-50.

# Quick Start On General Social Services

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## Volunteer Agencies

Again the community access pages at the front of the local phone directory is a good resource for information on available resources regarding volunteer opportunities in the local community. Most communities put out at least one pamphlet or flyer on volunteerism in the community. These are often free and available at local libraries or even grocery stores, convenience stores, etc. The United Way in most communities, provides referral for local volunteer organizations and opportunities.

## Volunteers of America Alcoholism Service Center

In some areas, they offer a residential program, as well as out-patient counseling, and a one-to-five day detoxification program available to persons 18 years or older on a sliding scale basis.

## YMCA/YWCA

The YMCA in most communities operates a counseling center on a sliding scale basis. In some areas, they also operate Family Stress Centers. This is primarily focused on assistance to families experiencing problems of abuse. Services are provided on a free or sliding scale.

## Youth and Community Services

See Youth and Teen Services in the community access pages at the front of local phone directory. Services typically include recreation options and employment opportunities.

While urban and rural areas differ significantly in the availability of transportation, there are resources you

should pursue no matter where you are located.

## Air and Rail Transportation

The Air Carrier Access Act of 1986 (ACAA) prohibits discrimination against qualified people with disabilities. Air carriers are mandated to establish procedures for resolving complaints including complaints resolution officials (CROS). These officials are available at public airports and must be available via TDD's if they are accessible via regular telephones. More information is available regarding ACAA from: Office of General Counsel U.S. Department of Transportation, 400 7th Street, S.W. - Room 10424 Washington, D.C. 20590, or phone (202) 366-9306 (voice) or (202) 755-7687 (TDD).

For a booklet entitled "New Horizons for the Air Traveler With A Disability" write to the U.S. Department of Transportation, Office of the Secretary of Transportation 400 7th Street, S.W., Room 10424, Washington, D.C. 20590. This booklet is a very practical guide to air travel, discussing everything from getting advance information about the aircraft to boarding and deplaning.

## The Americans with Disabilities Act (ADA)

**Airline Travel.** Title II affects public airport accessibility and Title III covers accessibility of private airports. Information is available in a pamphlet entitled, "A Guide To Accessibility of Terminals" published by Airport Operators Council International, Inc. and single free copies are available from: Consumer Information Center, Pueblo, CO 81009

**Train Travel.** Information regarding

# Community Resources

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## QUICK START

### On Transportation

accessibility of rail travel can be obtained by contacting local Amtrak office. Though currently not specifically addressed under the ADA, most major carriers are attempting to make reasonable accommodation. Local rail terminals or stations would be the best resource for information on accessible trains and routes.

**Bus Travel.** The ADA provides for complementary service if buses or trolleys are not accessible or if a person's disability or condition prevents them from using public transportation. This means people are entitled to alternative transportation which operates at the same time and to the same locations as the public transit system. Most communities have developed an application and certification system for identifying persons eligible for these services. Coordinated Transportation Service Agencies (CTSAs) are handling this in many communities. Contact your local CTSA-ADA Eligibility Coordinator or your Regional Center about who is coordinating these services locally.

#### Public Transportation

The Americans With Disabilities Act requires that the U.S. Department of Transportation issue regulations mandating accessible public transit vehicles and facilities. The regulations must include a requirement that all new

fixed-route public transit buses be accessible and that supplementary paratransit services be provided for those individuals with disabilities who cannot use fixed route services. For more information, contact U.S. Department of Transportation - 400 Seventh Street S.W., Washington, D.C. 20590, or by phone, (202) 366-9305 (voice), or (202) 755-7687 (TDD).

Public transportation services in most communities are administered by a local metropolitan transportation commission or board. These organizations generally work with committees which represent and include persons with disabilities. This is a way to become involved in advocating for improvements in the local public transportation system. They often work with local community college districts in developing programs to teach students with disabilities how to access user-friendly buses, trolleys, etc. Contact local public transit authority for listing of accessible lift-equipped buses and routes, as well as a transit guide to all regional transit operators. The transit authority is also often able to provide a listing or directory of specialized transportation providers available locally.

#### Specialized Transportation

# Quick Start On Transportation

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## Services

If a listing is not available through local public transit authority, most local phone directories now generally publish listings in the community services and access pages. Listings generally include vendors serving smaller communities within a metropolitan area. Most counties administer a rural transportation service. Up-to-date lists should provide vendor phone numbers, areas served, stipulations (i.e., eligibility, whether it is a door-to-door service, lift-equipped, times of operation, etc.) and the cost. Most listings also include ride-share information for persons interested in car-pooling. This is a great option for getting to know people and using a truly generic resource. Non-emergency medical transportation is also often available and stipulations vary from one provider to another. Many hospitals and clinics provide shuttle services for their own patients.

Local career and educational services are often important considerations in developing patterns of support.

## Community Colleges, State Universities - Disabled Student Services

Most community colleges and state colleges and universities have an information office for students with disabilities most commonly called *Disabled Student Services*. This can be a good resource for gathering information about other available generic services, transportation, etc. A word of caution is warranted however, since this can also lead to a "tracking" of sorts which can limit potential for

full inclusion in campus life. When supporting a student in the campus community, it's advisable to utilize generic student services, clubs, and the general course catalog. Declining occupancy has made campus housing on state college campuses much more available, often even to non-students if enrolled in a local community college or adult education program. The *social* life of a college campus can provide numerous opportunities for social and recreational inclusion.

## Employment Development Department

Aside from the unemployment services for which the department is most known, jobs service provides job leads even to persons not currently drawing unemployment benefits. Individuals themselves or their support agencies often overlook this useful resource.

## Occupational Rehabilitation Services

Neighborhood Outreach programs or local occupational training services can provide job search and skills training for youth ages 18-21. These are often provided free or on a sliding scale. Local community college districts often have a skills center where job training and referral is provided free to adults.

## Parenting Training Services

Training in parenting skills is offered

# Community Resources

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## QUICK START

### On Career/Educational Services

through a multitude of organizations in most communities. Almost all hospitals provide follow-up, infant care and lactation counseling services. They also publish a newsletter which announce class offerings in community education program services. Aside from the parenting support available through such non-generic resources as regional center vendored parenting and ILS agencies, there are agencies vendored with the county's social services, child protection division. These services are available only to people who have active cases with CPS. Other non-profit corporations, such as Homestart, provide child abuse prevention and intervention services which target low-income populations, come into the home, and are available to persons regardless of whether or not they have an open case with the county's Child Protective Services (CPS). The Planned Parenthood Federation of America, Inc. has local Planned Parenthood affiliates in most metropolitan communities. Other than their health, counseling, and referral services, most offer classes in specific parenting topics which are often available for screening via taped messages. The community college system and adult education programs are also valuable resources for parenting training and services. They can often make referrals to parent support groups which are a means of

connecting persons served to others with like needs, interests and children of similar age.

### Regional Occupational Services

ROP or the Regional Occupational Program is part of the public school system. It is an accredited service maintained generally by the County Board of Education and administered by the county superintendent of schools and County Office of Education. Generally ROP courses are operated by high school and community college districts throughout the county. The program offers practical job training, career counseling and job search instruction for high school students, out-of-school youths, and adults without regard to race, religion, sex, disability or income. Course offerings range from accounting to veterinary assistant. There is no tuition and participants are followed through placement upon completion.

Introduction -  
Understanding the  
Americans with Disabilities

# Quick Start On Occupational/Educational Services

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## Act (ADA)

The ADA gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, sex, national origin, age, and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, state and local government services, and telecommunications. For more information, contact the office on:

The Americans  
With Disabilities Act  
Civil Rights Division  
U.S. Department of Justice  
P.O. Box 66118  
Washington, D.C. 20035-6118.  
(202) 514-0301 (voice)  
(202) 514-0381 (TDD)

## Area Boards/Regional Center Advocate/PAI

Though they are not generic resources, the Area Boards and Regional Center Clients Rights Advocate both serve as advocates for the rights of individuals served, or who have applied for services through the Regional Center. Both agencies will investigate and facilitate resolution of complaints and/or issues and refer individuals to another agency or organization which can provide representation. For further information contact the local Regional



# Community Resources

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## QUICK START

### On Legal/Advocacy Services

Center or Area Board. Protection and Advocacy, Inc. is a statewide legal advocacy firm specializing in the legal needs of students and adults with disabilities. Either a staff attorney or an attorney in private practice under contract with PAI can handle appeals both of individual cases and systems or class action cases. PAI maintains an active role in public affairs and provides legislative watch over issues pertinent to persons with developmental and other disabilities, as well as mental illness. Persons interested in more information or in subscribing to PAI's newsletter can contact:

Editor, PAI Newsletter  
100 Howe Avenue, South 185-N  
Sacramento, CA 95825

#### California Public Interest Research Group (CAL-PIRG)

CAL-PIRG conducts research and advocacy on consumer and environmental issues. They also publish price surveys and guides on various consumer products. CAL-PIRG is an advocate for "renters rights" and will offer assistance in resolution of conflicts regarding landlord/tenant relations. Most metropolitan communities in California have a

CAL-PIRG chapter.

#### Landlord/Tenant Relations Associations

There are Human Relations Associations in most communities which provide tenant and landlord counseling, mediation and fair housing services. They will investigate discrimination complaints and provide community seminars regarding housing issues. Contact the Human Relations Association in your area for further information or the local chapter of the United Way for a listing of available social services organizations.

#### Legal Aide Services

There is a Legal Aide Society located in most counties. It provides legal services to low-income people in such areas as criminal justice, health, consumer and family law, landlord and tenant issues, welfare, civil rights, discrimination and juvenile law. They provide legal services which include legal counseling, advice and representation. They serve persons who are homeless, low-income, or unemployed.

#### Local Legislative Offices (Federal, State, County)

For the names, addresses and phone numbers of your local legislators, look in the *Government Pages* of the white

# Quick Start On Legal/Advocacy Services

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(or blue) pages in the front of your phone book.

## Peace Resource Center

Peace Resource Centers are being developed in many communities. They are proving to be a vital source of information on such topics as family violence, violence in the media, nuclear power, nuclear weapons proliferation, etc. Many have provided valuable libraries and screening material on children's toys and literature. They have often combined efforts with other groups such as Amnesty International or local interfaith peace organizations. They often provide up-to-date legislative listings, as well as current phone (voice and fax) and address lists for not only government (local, state and federal) offices and officials, but also local and national television, radio and print media organizations. Persons compelled toward letter writing campaigns would do well to hook-up to their local peace resource centers. They sponsor many opportunities for peaceful protest and vigils through which people can come together over a common cause.

## People First

Though not a generic resource, People First is a strong advocacy group created by and for individuals with disabilities. This advocacy organization continues to develop chapters in all states across the nation. People First advocates for the rights of individuals in the areas of choice, transportation, specialized services, and issues surrounding

accessibility. People First chapters generally hold State conferences on an annual basis and officers and members will often present at other conferences within the state. For information about People First Chapters, contact your local Area Board office.

## Volunteer Tax Assistance Program

This volunteer bureau, V.I.T.A., offers volunteer income tax assistance, which operates in conjunction with the IRS each January 1st through April 15th. Volunteers are utilized to staff sites county-wide to assist people with disabilities, those who are elderly, and low income persons with income tax forms and filing. Some community recreation centers also provide this service. For further information in your area, contact your local volunteer bureau or the Internal Revenue Service.

# Quick Start On Legal/Advocacy Services

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## Disabilities

The Regional Centers offer information and referral services - especially to other non-generic agencies and services within their catchment areas. These agencies such as the local "Service Centers for the Blind," "Deaf Community Services," "Community Service Centers for the Disabled" offer useful information —germaine to the specific interests of a particular group of individuals and their family members. They often are able to provide classes, community education,



# Community Resources

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## QUICK START

### On Specialized, Non-Generic Services

assistive devices or more generic referrals. Most larger communities also have local chapters of such specialized statewide or national groups as Easter Seals, Epilepsy Foundation, Downs Syndrome League, or Autism Society for examples. These groups can provide information and often sponsor support groups, though some people feel too much emphasis on a particular type of disability dilutes the effectiveness of diverse groups working together to promote full inclusion for all persons regardless of the type or severity of their disability. Again, these groups may well come together for the noble purpose of sharing information, supporting one another and gaining strength by advocating together for a specific group of individuals. However, their methods, though perhaps not intentionally divisive, may in fact be counter-productive to the overall goals of the disabilities rights movement. The lack of unity and consensus within this movement on how best to accomplish our goals or even on exactly what those goals ought to be, continues to be a cause for concern. It is a source of frustration for many that common ground cannot be reached on even such basic areas as the use of "people first language."

#### Ethnicity

Many programs are available which are specifically targeted to certain ethnic

groups. They often provide a social outlet for people, a way to connect people to their ethnic culture, history, and neighborhood community. We have list a few of those organizations below:

American Indian/Native American Association offers wide variety of resources and recreational groups (i.e., Boys and Girls Club, California Indian Legal Services)

Black/Afro American Urban Leagues

Hispanic-Chicano Federation

Also YWCA, YMCA offer variety of social and recreational activities specific to ethnic backgrounds. Community Colleges and Universities have many cultural groups that offer social and educational gatherings.

Other groups may exist in your area such as; Barrio Club, Girls and Boys Clubs, Youth and Community Services, Neighborhood Outreach Programs, church organizations. Some people encourage starting groups in areas which do not have anything available. Contact local groups for information or local Chamber of Commerce for specific ethnic groups, clubs, etc.

# Quick Start On Specialized Services

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1. What are some of the community resources that you could put together in your area to support someone who wants to live in a house or apartment and whose income is too low to afford it without some financial assistance?







# Community Resources

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## Information Pack on Housing Subsidies

successful plan for living independently or with support from others.

### Section 8

The Section 8 Rental Assistance Program, funded through the U.S. Department of Housing and Urban Development, provides housing subsidies to eligible low-income households. A Section 8 *certificate* requires of a landlord an agreement with the public housing authority, and charging only approved fair-market rents (for units of given size). A Section 8 *voucher* also requires an agreement between the landlord and the public housing agency, but the landlord can charge a rent higher than the approved rate for the area. With a certificate, the low-income family pays 30% of its income toward the approved rent, and the housing authority makes up the difference. With a voucher, the household receives the same subsidy, but can pay as much as it wishes. To illustrate, a low-income household consisting of one person, who has SSI/SSP and other income totaling \$700 per month, would likely be approved for a 1-bedroom apartment. Let's say, the approved rent is \$400. With a certificate, the tenant would pay \$210 per month (or, 30% of \$700), and the housing authority would chip in with \$190 per month (or, \$400 minus \$210). With a voucher, this person might seek a unit (say, in a nicer neighborhood) renting for \$500. The subsidy (\$190 per month) would remain the same, with the tenant paying \$210 plus the difference between actual rent and the approved rental amount for the area, or an extra \$100 per month, for a total of \$310 per month. The housing authority, once again, pays \$190 per month.

# Information Pack On Subsidized Housing

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and ask when and where you can sign up. Also ask if they offer certificates and vouchers. Some large, older cities have their own public housing, and may offer limited options with different waiting times. Check out the possibilities.

With long waiting lists (often 3 years or so), some housing authorities accept new applications only once in awhile, with little advance notice. Ask if they will take your name and address and notify you. Ask where opportunities to apply will be announced (e.g., in a section of your local newspaper). Tell the housing authority representative that you have a disability and ask whether there is a way to access after-care certificates or vouchers.

## Might you or someone you support be able to get a subsidy quicker?

After-Care certificates or vouchers are ones set-aside for persons with disabilities. Some housing authorities have After-Care coordinators. Ask for the name, address, and telephone number of the nearest one in your area. Sometimes, use of After-Care subsidies is a “fast-track” to getting rental assistance quicker.

Another way you may get assistance quicker is meeting a federal preference. There are three: (1) paying more than half your income for rent and utilities; (2) having been involuntarily displaced from where you are living now (e.g., eviction); or (3) living in substandard housing.

If the housing authority helps you (or your landlord) to rehabilitate the place you live, ask whether -- upon completion of the work -- a certificate will be attached to your unit. In one instance, in Contra Costa County, a young woman who uses a wheelchair is working on a plan, wherein a ‘friendly investor’ (or group of investors) will acquire a place that needs accessibility and other modifications. The young woman will move in, and with advance planning work will begin immediately to modify her home.

While inconvenient for a month or two, once the work is completed (under a low-interest, moderate rehabilitation loan), a certificate will come with the unit, and

# Information Pack On Subsidized Housing

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she will have her rental assistance.

## What if you or someone you support needs an attendant at night?

If you need a night-time attendant, the housing authority will typically authorize a 2-bedroom unit for you. In this case, if the fair-market rent for a two-bedroom apartment is \$650 per month, and the income of the disabled person is \$700 per month, the renter will pay \$210 (30% of \$700) and the housing authority will pay the difference of \$440 (or, \$650 minus \$210).

It is optional for housing authorities to support shared living arrangements, meaning situations where two or more unrelated, low-income adults -- each with their own bedroom -- share a common unit. In the absence of an explicit policy, a housing authority may permit two people (one with a Section 8 subsidy, one without) to share a one-bedroom place. But if, say, two or three unrelated adults share a two- or three-bedroom place, the housing authority will typically consider the group a 'family of 2' or 'family of 3,' add their incomes together, and this typically results in not being eligible under family income guidelines.

If your housing authority supports shared housing, each person is considered a 'family of 1' and has a right to 1 bedroom within a larger unit. If the approved fair market rent for a three-bedroom place is \$1,100 per month (including utilities), and each person is expected to pay one-third or \$367 per month, a person with SSI and other income of \$700 per month would pay \$210 (30% of \$700), and the housing authority would pay the difference of \$157 (\$367 minus \$210) for that individual.

Not all housing authorities support shared living arrangements. There are many reasons for this. One is the administrative cost of overseeing such arrangements. It may be difficult to determine responsibility for any damage to property. What happens if one roommate moves out and a vacancy occurs? Will housemates be recruited and selected in a non-discriminatory manner?

# Information Pack On Subsidized Housing

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Shared housing is a way to make shelter more affordable. Certainly, if you find that sharing is in line with personal preferences and needs, and that even with sharing rent and utilities will be close to 50% of a person's income, it makes a lot of sense to work with your housing authority to get them to support shared living arrangements.

## Introduction

Often, when people with disabilities or their parents or both are ready for greater independence, issues of support are on everyone's mind. In this Information Pack, you'll find an overview of a government-based program which can often be worked

# Information Pack On Subsidized Housing

## TMI Supported Living Perfect Apartment Checklist\*

Apartment Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Manager: \_\_\_\_\_ Date: \_\_\_\_\_

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 accomodate your wheelchair)
  
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

\* Whether you have Section 8 or not, this is a good way to look at a place you're thinking about renting.

10. Do you have a wheelchair accessible apartment?                       Yes                       No

**IF YES, PLEASE CONTINUE. IF NO, YOU MAY STOP HERE.**

# Information Pack On Subsidized Housing

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10. Do you have a wheelchair accessible apartment?  Yes  No

**IF YES, PLEASE CONTINUE. IF NO, YOU MAY STOP HERE.**

11. Are there disabled parking spaces near the apartment  Yes  No

12. Are there grab bars around the toilet?  Yes  No

13. Has the kitchen sink been lowered?  Yes  No

Has the kitchen counter space been lowered?  Yes  No

Has the stove top been lowered?  Yes  No

14. Are the hanging rods in the clothes closet lowered?  Yes  No

15. Is there an emergency call system in the bedroom?  Yes  No

16. Is there space enough under the kitchen sink for a sitting person to comfortably put his legs?  Yes  No

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?  Yes  No

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# Community Resources

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## Information Pack on In-Home Support Services

into a successful plan for living more independently, in your own place or a home of your choosing.

### In-Home Supportive Services (IHSS)

IHSS is administered, for the most part, by the county welfare office, often known as the Department of Social Services. This program provides assistance to eligible aged, blind, and disabled persons who are unable to remain safely in their homes without assistance.

### Eligibility

An individual is eligible for IHSS, if he or she receives SSI/SSP, or similar types of assistance, and if IHSS is needed to live safely in his or her home. Occasionally, a person who is not an SSI recipient is eligible for IHSS. To illustrate, if a person is no longer eligible for SSI because of earnings, that individual may still be eligible for IHSS if still disabled, needs the service, and has resources that do not exceed the SSI resource limitation. A 'home of one's choosing' may be the parents' home, but the person cannot be receiving SSI at the board-and-care rate and be eligible for IHSS. If living with a relative and receiving the higher SSI rate, the person may elect to waive the board-and-care rate and receive SSI at the individual rate, so as to also be eligible for IHSS. In calculating need for IHSS, county workers must determine that (1) the services needed are not available through alternative resources, and (2) the individual is unable to remain safely at home without the services.

### Services

The primary services are: (1) domestic and related (e.g., cooking, cleaning, laundry,

# Information Pack On In-Home Supportive Services

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shopping); (2) personal care services (e.g., bathing, dressing, helping the person eat); (3) essential transportation (e.g., to doctor's appointments); (4) protective supervision (e.g., watching and intervening if the person would walk out of the house and into traffic, or would cook unsafely, etc.); and (5) paramedical services, including giving injections, under the supervision of a licensed professional. Limited yard hazard clean-up and, under the condition that the person will become more self-sufficient, some teaching and demonstration can be included.

## Assessment of need

The county worker will do an initial assessment of need, and annually reevaluate that need. In some service areas, the county worker will write down 'standard norms' unless you indicate (and can support) a need for more services. If there are special circumstances -- such as frequent incontinence requiring more frequent change in sheets, more laundry, more bathing than twice a week, slowness in chewing, allergy to dust so that housecleaning must be more frequent, special diet, etc. -- be sure to bring these to the county worker's attention. The person is entitled to services on weekends and in the evening if needed. Be sure to ask for a paramedical form if you need help with injections, tracheotomy suctioning, range-of-motion, or other assistance.

The county worker will fill out forms known as "SOC 293" and "SOC 293a," which will set out how much time per week you have been allowed for service. Your county worker must give you a copy of these forms if you ask for them. They provide more information than notices sent by the County.

If you need more than 20 hours per week in personal care services, meal preparation and cooking (and clean-up, if helped eating), and paramedical services, you will be classified as severely impaired, even if some of the help comes from a family member or friend who is not paid through IHSS. If you need less time, you will be categorized as non-severely impaired. If you are evaluated as severely impaired, you are eligible for up to 283 hours of service per month, assuming you have hired your own IHSS worker(s). If you are non-severely impaired, the monthly maximum is 195 hours.



# Information Pack On In-Home Supportive Services

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Time-for-task guidelines are for entire households, and when you share a dwelling with others the number of hours authorized for some activities may be less. Domestic services, typically set at 6 hours per month, is an example. If three people occupy the dwelling, your allowance may be 2 hours per month. The six-hour guideline was based on someone providing domestic services twice a month. You may be able to show that the person needs to come more often -- say, because sheets need to be changed more frequently, or trash taken out more than twice a month. Individual differences in need, and health and safety issues, typically guide. Incidentally, time-for-task standards may not be used in determining personal care needs, meal preparation and meal clean-up, or paramedical services.

## Protective Supervision

Under IHSS regulations, protective supervision is only available to “non self-directing, confused, mentally impaired, or mentally ill persons” to “safeguard the recipient against injury, hazard or accident.” Regulations further stipulate that the need (1) may not be a medical condition and the form of supervision is medical; or (2) be in anticipation of a medical emergency; or (3) be to prevent or to control anti-social or aggressive behavior.

## How are IHSS organized, delivered, and paid for?

Generally speaking, it is thought good practice for the person with the disability to hire his or her own IHSS worker(s). Persons with severe impairments have a right to do this, even if the county uses a contract agency as the employer and this approach is the only option for persons who are non-severely impaired. If you are in one category, but think you should be in the other, you may ask for a reevaluation. If there is a disagreement with the county worker that you cannot resolve, you may ask for a fair hearing.

The County will typically pay \$4.25 per hour (sometime slightly more in unusual circumstances), when the IHSS person is hired by the person with a disability. IHSS workers paid by contract agencies typically earn more. IHSS workers are covered by workers' compensation if hurt on the job, and have state disability and unemployment

# Information Pack On In-Home Supportive Services

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insurance coverage. In most cases, the worker(s) turn in a time sheet twice a month, and get paid on the 10th and 25th of the month. Sometimes, the person with a disability will supplement the worker's pay, or pay for additional services. This is permissible. Likewise, a family member or friend may supplement the hourly rate or pay for extra services. And, so long as the money goes directly to the IHSS worker, and does not go through the SSI recipient's hands, it will not be counted as income to the person with a disability, and therefore will not affect the person's entitlement to IHSS or SSI.

If the person receiving IHSS services is not in a position to be a good employer, there may be several options to consider. If the person is receiving supportive living services, a community support services facilitator may be able to assist the person to be (or learn to be) a better employer. In some cases, a personal advocate, parent, or close family member or friend may be able to help.

If a person lives in his or her own place (either buys or rents), a combination of IHSS, supportive living service funds (if accessible and used imaginatively), is likely to be the 'paid support service arrangement of choice' for many adults with developmental disabilities. Coordination of services -- especially in complex cases where the individual needs lots of help -- can come from an interested agency, a family, a conservator, or in some cases a circle-of-friends.

For an excellent overview, see *In-Home Supportive Services*, which can be ordered from Protection and Advocacy, 100 Howe Avenue, Suite 185 North, Sacramento, CA 95825. Call (800) 776-5746. Suggested donation \$14.00.

# Information Pack On In-Home Supportive Services

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## IHSS PACKET

### Guidelines For Accessing & Utilizing Attendant Services

Reprinted with permission from *Toward Maximum Independence*, San Diego, CA

#### 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.

# Information Pack On In-Home Supportive Services

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## 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, \$4.25 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.

## INTERVIEWING A PROSPECTIVE ATTENDANT\*

1. Try to make your prospective attendant feel comfortable. (Invite them to sit down, offer them a drink, etc.)

# Information Pack On In-Home Supportive Services

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2. Ask the prospective attendant about past jobs they have had. (Look at application)
3. Ask them if he/she has worked for a person with a disability before.
4. Explain your disability if you feel comfortable.
5. Give job description or IHSS contract for him/her to read.
6. If this is a job the person is interested in, you might want them to fill out an application.
7. After the person is finished, you may want to ask these questions. Do you feel uncomfortable about performing any of these duties and responsibilities? Do you have any questions? Let them know you will train if necessary.
8. Ask any other questions that may be specific to this position.
9. Ask when she/he is available to start.
  - Let the person know you will be checking his/hers references and will call them after you have made a decision.
  - Thank the person for coming by and escort to the door.
  - At this point, while it is still fresh in your mind, it is wise to list what you liked and disliked about the prospective attendant.

\* Be sure and have someone you trust at this interview.

## Attendant Application

### Part A -

Name: \_\_\_\_\_

Phone No#.: Home \_\_\_\_\_/Work \_\_\_\_\_

# Information Pack On In-Home Supportive Services

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Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Contact incase 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.)

# Information Pack On In-Home Supportive Services

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## 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?

### Part F -

List two other references (other than family):

1. Name	Address	Phone	Relationship
_____	_____	_____	_____
_____	_____	_____	_____

TELEPHONE REFERENCE CHECK\*  
(Sample)

# Information Pack On In-Home Supportive Services

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\_\_\_\_\_ has recently applied to be my attendant. \_\_\_\_\_ has put you down as a reference. Would you mind telling me about \_\_\_\_\_? All this information will be kept completely confidential. The job is not a high paying one but there is a lot of responsibility that comes with the position. \_\_\_\_\_ will be assisting me with personal and domestic tasks.

How long have you known \_\_\_\_\_?

Are you related to \_\_\_\_\_?

How long did \_\_\_\_\_ work for you?

Why did \_\_\_\_\_ leave?

Would you rehire \_\_\_\_\_?

Why? \_\_\_\_\_.

Is \_\_\_\_\_ punctual?

Is \_\_\_\_\_ reliable?

Is \_\_\_\_\_ trustworthy?

Does \_\_\_\_\_ tell you when commitments can't be met?

Would you recommend \_\_\_\_\_ for this job?

Thank you for your time, Good-Bye.

\* Be prepared that some of this information may not be legally shared.

## Applicant Profile

You can use this form to review the qualifications of an attendant or roommate.

Name: \_\_\_\_\_

Male  Female

**Experience:**

**References: (Professional)**



# Information Pack On In-Home Supportive Services

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1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

**Characteristics:**

**Comments:**

- |   |       |
|---|-------|
| <input type="checkbox"/> Friendly                                     | _____ |
| <input type="checkbox"/> Open   | _____ |
| <input type="checkbox"/> Asked good questions                         | _____ |
| <input type="checkbox"/> Confident                                    | _____ |
| <input type="checkbox"/> Used respectful language                     | _____ |
| <input type="checkbox"/> Gave impression that commitment was critical | _____ |
| <input type="checkbox"/> Nicely dressed                               | _____ |
| <input type="checkbox"/> Interested in focus person                   | _____ |
| <input type="checkbox"/> Comfortable with philosophy                  | _____ |

**Personal References:**

Name	Relationship	Phone #
1.		
2.		
3.		

**Applicant Profile - Continued**

**Skills:**

- CPR
- First Aid

# Information Pack On In-Home Supportive Services

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OT/PT Training

Comments:

## **Personal:**

Pet(s)

Children

Smokes

Willing to assist with personal care/IHSS

Comments:

## **Reason For Desiring Roommate/Neighbor Position:**

## **On File:**

Fingerprints

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

# Information Pack On In-Home Supportive Services

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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.)

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B. Complex/Medical Needs (Think about specific assistance you will require with such things as medication, equipment, lifting, transferring, etc.)

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C. Interests, Hobbies, Preferences (What do you like to do? Where do you like to go? Favorite foods. Pet Peeves. Allergies, etc.)

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# Information Pack On In-Home Supportive Services

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B. Other (Consider any other important things someone might need to know about you.)

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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. It is kept in the apartment book.

## What Services You Need and When You Need Them

**SERVICES  
INFORMATION**

**WHEN**

**OTHER**

**Domestic Services:**

# Information Pack On In-Home Supportive Services

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<b>Related Services:</b> <ul style="list-style-type: none"> <li>• Prepare meals</li> </ul>		
<ul style="list-style-type: none"> <li>• Meal clean-up</li> <li>• Laundry</li> <li>• Shopping for food</li> <li>• Other shopping errands</li> </ul>		
<b>Non-Medical Personal Services:</b> <ul style="list-style-type: none"> <li>• Respiration Assistance</li> <li>• Bowel, bladder care</li> <li>• Eating</li> <li>• Routine bed baths</li> <li>• Dressing</li> <li>• Menstrual Care</li> <li>• Ambulation</li> <li>• Move in/out of bed</li> <li>• Bathe, oral hygiene/grooming</li> <li>• Rub skin, repositioning, help on/off seats, in/out vehicle</li> <li>• Care/assistance with prosthesis</li> </ul>		
<b>Transportation Services:</b> <ul style="list-style-type: none"> <li>• Medical Appointment</li> <li>• To alternate resources</li> </ul>		
<b>Protective Supervision:</b>		
<b>Teaching Demonstration:</b>		
<b>Paramedical Services:</b>		
<b>Total Monthly Hours:</b>		
<b>Basic Schedule:</b>		
<p style="text-align: center;">HIRING</p> <p>Now it is time to make a decision.</p> <ol style="list-style-type: none"> <li>1. Call the person you have chosen to tell her/him the good news. Also, be</li> </ol>		

# Information Pack On In-Home Supportive Services

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prepared to give a start date.

2. Call 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.

# Information Pack On In-Home Supportive Services

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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

# Information Pack On In-Home Supportive Services

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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.



# Information Pack On In-Home Supportive Services

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## 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.



# Community Resources

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## Reflections

### Employer/Employee Woes!!!

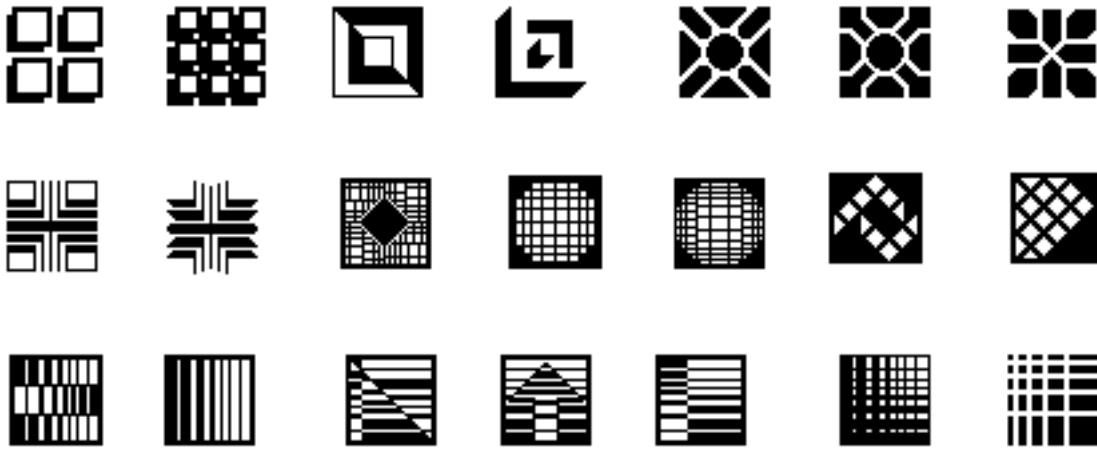
Ben has some special medical needs and uses the services of an attendant paid for through the In-Home Support Service program in your county. He tells you that he's not getting the service he wants from this person. You suggest that he needs to be assertive and speak up for himself. He does and the attendant quits at the beginning of his next shift. How will you assist him in finding someone to fill in right away? How will you support Ben in finding the right person next time?

# Reflections on Community Resources

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## Putting Together a Shared Household

Jenny is moving from a group home to her own place in the next few months. She has stated to you that she would prefer to live with 1 or 2 other persons who are not disabled. Your local housing authority supports shared housing and she will be using a Section 8 certificate for her share of the rent. How will you go about assisting her in putting together a shared household? Who will hold the lease? How will utilities be paid? How will Jenny find a place and select her housemates?



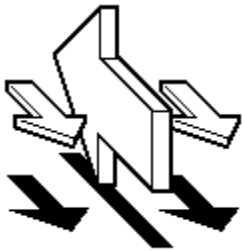
*Patterns of Supported Living*

# Community Employment



# Community Employment

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## Directory

### Introduction

For most of us, having a valued role means having a job. While employment services are not usually provided by a supported living agency, the connection between work and support at home is well known, e.g., getting to and from work, getting there on time, having the right work clothes. In addition, since there may be some confusion over roles and responsibilities between supported living and supported employment services, a basic knowledge of the supported employment services system is critical.

*Community Employment* focuses on supported employment because people who want and need support in their living arrangement often use some support in their employment as well. *Supported employment* is paid employment for people with developmental disabilities who need some sort of ongoing support to progress in their careers. It's different from *sheltered employment* because it's work in an integrated setting in the community. It's also different than *competitive employment* where a person does not need any sort of ongoing support on or related to the job.

### A Word About Supported Employment and Supportive Living Service Providers

Human services typically specialize by discipline or slice of a person's life. Physicians specialize in illness and disease. Teachers focus on instruction and learning. Job coaches and other supported employment specialists concentrate on jobs and careers.

When a person has someone (for example, a job coach) to assist with work, and needs support in other areas of life, this support typically comes from other sources: a parent, a friend, or a supported living service of some kind. A few agencies provide both supported employment and supported living services, but this appears to be the exception rather than the rule. Even in these instances, it is not uncommon to have different people in the same agency specializing by providing work or non-work support. To be sure, there can be advantages in this approach -- early problem identification; enhanced communication; and better collaboration. We all know of instances where 'life apart from work' impacted on work, or work impacted on other aspects of life. The chief disadvantage is probably the potential loss of freedom, if a single important person is providing support in all (or nearly all) areas of a person's

# Introduction

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life.

Some supported employment providers may be trapped in the culturally-determined pecking order just discussed, and expect (automatically) that a person providing support apart from work will make sure that the supported person will have a bus pass, be properly groomed, and get to work on time. This may not be the best (or even a 'good') approach. Similarly, a job coach may not trust the person with a disability, and want a call from another professional when the person is unable (or unwilling) to go to work. Again, learning to work thoughtfully together -- in a way that respects the individuality of the person -- is often the key to success. Through a three-way conversation -- involving the person served, the supported employment agency, and the supported living provider -- certain ground rules may be established, reviewed occasionally, and adjusted by mutual agreement.

In this section, you'll also find information on *Social Security* and *The Americans with Disabilities Act* which can both affect employment and living situations for people with developmental disabilities. ***Community Employment*** includes:

		<b>Page</b>
<i>Snapshots</i>	Jean	CE 5
	Jose	CE 6
<i>Quick Start</i>	Supported Employment	CE 7
	Social Security	CE 11
	Americans with Disabilities Act	CE 15
	Reauthorization of the Rehabilitation Act	CE 19
<i>Check Your Understanding</i>	A Review Just For You	CE 21
<i>Information Pack</i>	Supported Employment	CE 23
	Social Security	CE 29
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# Community Employment

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## Snapshots

### Jean

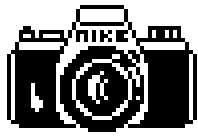
For many years, Jean has lived in a group home and has needed a lot of mental health support. Until recently, she attended a day treatment program at the local mental health center. About a year ago, she started her first job in the community, as a housekeeper at a motel near her home. She loves to stay busy, doesn't mind being around people as long as they don't talk much, and she particularly likes cleaning up, so the job match was ideal. For awhile, she was part of a supervised crew of workers, but her employer hired her to work on her own. Jean walks to work. In her spare time, she reads the bible and watches the sports channel. The community mental health center provides funding for someone who comes to visit her twice a week to offer support and counseling if she needs it. About a month ago, she told her social worker at the regional center that she would like to live in an apartment with a friend, so she was referred to a supportive living service in her community.

Jean's pattern of life includes support from:

- Her Residential Service Provider
- Department of Rehabilitation
- Regional Center
- Community Mental Health
- Supported Employment Agency
- Supportive Living Program

# Snapshots

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## Jose '

José is deaf and uses some *signs* to communicate. He lived with his parents until he graduated from high school and he now lives in a nearby house with his brother who shares the household chores, helps him with budgeting and cooking. This living arrangement was developed by his family and is supported by a regional center funded supported living agency. Jose worked for 'several months in a small restaurant, a job which he found through neighborhood friends. After graduation, he transitioned to a supported employment service and was supported in finding a job in an auto parts store, where he unpacks shipments, stocks shelves and cleans up. Jose really likes this job because it's near his home, he knows a lot of the customers and everyone speaks Spanish. Also, his boss is ideal because he has a daughter who also signs and he understands signs himself.

José's pattern of life includes support from:

- His Family
- His Employer
- Department of Rehabilitation
- Regional Center
- Supported Living Service
- Supported Employment Agency

For more information about families and the support they can offer, turn back to *Patterns of Support*.

# Community Employment

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## QUICK START

### On Supported Employment

#### **Introduction**

In this *Quick Start*, you'll find the answers to some of the questions that people ask about Supported Employment. What you'll see is a strong similarity with the process of providing supportive living services.

#### **How Would You Know If Someone Might Need Employment Support?**

In general, people with developmental disabilities who need assistance in getting or keeping a job, like assistance and support in:

- Interviewing for a job;
- Learning a job;
- Getting to/from a job;
- Developing adaptations that make the job easier to learn or complete;
- Understanding benefits & how work affects them; or,
- Other aspects of their lives that affect work, or are affected by work.

#### **Who can use Supported Employment services?**

People with developmental disabilities who need ongoing support in order to get and keep a job and for whom the resources to provide follow-along services have been identified.

#### **What about people with significant disabilities?**

Many people with significant disabilities are now working in California. The development of technological and natural support systems has opened a variety of work environments to individuals with significant physical and developmental disabilities. In fact, many employers have stated that the *tools* used for training and supporting people with disabilities have helped all of their employees in performing their jobs in a more efficient way.

#### **Are there barriers to employment for people with developmental disabilities?**

There are barriers to employment for everyone. For example: not enough work experience, changes in the local labor market, lack of work skills, you name it. However, in spite of those barriers and the additional barriers that people with severe

This brief was adapted from *The Work Book: A Guide to Supported Employment for People with Disabilities and their Families* (developed by Allen, Shea & Associates for the California Department of Rehabilitation, 1990).

# Quick Start On Supported Employment

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developmental disabilities face, thousands of people with all kinds of disabilities in California have found jobs in supported employment with the assistance of the Department of Rehabilitation.

## **What do people have to do to get a job through a Supported Employment service?**

Persons are typically referred to a local Department of Rehabilitation office by their regional center program coordinator (also known as social worker or case manager). There are many ways that persons can be referred such as through the school, mental health center, regional center.

**What kinds of work placements are available through Supported Employment?** While there are several types of work placements available through Supported Employment in California, they are typically either *individual* or *group* placements. In both of these options, the Supported Employment service assists persons in gaining employment by comparing their work preferences and needs with those of a potential employer. Typically, the job is observed and learned by someone who can assist as a co-worker or on-the-job trainer. As work performance improves, the on-the-job trainer provides assistance only as needed. This assistance might occur when: there is a change in job duties; a new supervisor is hired; there are problems with co-workers; Social Security paperwork needs to be completed, etc.

## **What kinds of jobs are available?**

The same types of jobs available to all of us! Job availability depends on a number of community variables, e.g. the business growth potential, employment trends, the efforts of job developers.

## **How soon after referral do people typically get a job?**

It varies! However, regardless of the time it takes, a good job match will help determine the long-term success of a job. There is required paperwork for both the local Department of Rehabilitation and the Supported Employment service to complete. For example, the Department of Rehabilitation may need to have current medical and psychological information to be sure that the job is appropriate for the individual. Once the job development phase begins, identifying job strengths, job preferences and local job availability are additional factors which take time.

## **What do people do in the meantime?**

If people are working right now, they have probably applied for Supported Employment services because they need additional support in keeping their job. If at all possible, try to provide them with the support that they need to hold on to their job for a while longer. If not working, you might suggest the following: ask friends or family about job leads; check out the local JTPA (Joint Training and Partnership Act) or PIC (Private Industry Council) employment programs; go to the local volunteer center and find out about temporary volunteer work; attend a community college or adult education class; or, join a recreation program, like an exercise class.

## **How much do people earn?**

It depends whether it's an entry level job, advanced level job or a job based on productivity. Many persons with developmental disabilities are earning above the

# Quick Start On Supported Employment

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minimum wage.

## **What support services are available?**

A plan for support is developed based on what people need to get and keep a job. This can include, for example: identifying job preferences; helping people get ready for job interviews; discussing job responsibilities before someone starts a job; on-the-job training until someone learns a job to the employer's standards; assistance with things related to work (like transportation and handling finances); developing support from co-workers; and, talking to the employer and others about how things are going at work and providing follow-along support as needed.

## **What happens if there are problems on the job?**

No job is perfect! For example, sometimes the pay isn't what we hoped for, other times it's our co-workers and then again, sometimes we just want a change. It's important to find out as much about job problems before someone quits or is fired. In situations where someone has just started a job, it's possible that communication between the employer and employee can resolve the problem. One of the tasks of a Supported Employment service is to identify and resolve problems early so that job loss can be prevented.

## **What happens if there is a job loss or a need to change jobs?**

The Department of Rehabilitation and/or Supported Employment service may be able to help in locating a different job.

## **What about benefits, like medical, sick time and vacation?**

As all of us know, some jobs offer benefits and some do not. This is something that must be explored when someone is seeking a job. It's important to coordinate employer benefits with the current benefits of an employee to provide a comprehensive package of health care coverage.

## **What if someone can't complete all of a job?**


A job may be adapted to meet the skills of an individual. This could mean changing the order in which the job is done, job sharing, adapting or bringing in an extra piece of equipment to help make the job easier. The Department of Rehabilitation and/or Supported Employment service may be able to assist.


## **What about transportation to and from work?**

The most typical ways are the best! That is, sharing a ride with a co-worker or taking a public bus. If these means of transportation are not available, then transportation requires some cooperative problem-solving by everyone involved before someone starts a job.

# Quick Start On Supported Employment

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	<h2>California Department of Rehabilitation</h2>
<p>If you don't already have the number, you can find it in the phone book (usually in the front of the <i>White Pages</i>) under —</p>	
<p><b>State Government Offices California State Of Rehabilitation Department</b></p>	
<p><b>Address:</b> _____</p>	
<p><b>Phone number:</b> _____</p>	
<p><b>Person I spoke with:</b> _____</p>	
<h3>Regional Center</h3>	
<p>If you don't already have the number, you can find it in the phone book (usually in the front of the <i>White Pages</i>) under —</p>	
<p><b>Developmental Disabilities Regional Center</b></p>	
<p><b>Address:</b> _____</p>	
<p><b>Phone number:</b> _____</p>	
<p><b>Person I spoke with:</b> _____</p>	



# Community Employment

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## QUICK START

### On Social Security

#### **Introduction**

The Social Security Administration administers two programs of importance to many adults with disabilities: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). The first is a social insurance program, wherein an individual with a disability receives a cash payment based, typically, on the covered earnings of a parent who has retired or died (or sometimes it's based on his or her own earnings). The latter (SSI) is an income maintenance program for aged, blind, individuals or couples with disabilities who have low income and few resources. Cash payments are not predicated on prior contributions to the Social Security Fund.

Both programs use the same definition of disability -- namely, that the person is unable to engage in substantial gainful activity (SGA) because of a medically determinable physical or mental disability which is expected to last 12 months or more. Activity is substantial if it is productive mental or physical work. It is gainful if done for pay or profit. If self-employed, SGA now means 40 or more hours of work per month. If an employee, \$500 per month (after certain work-related costs) is the SGA criterion.

#### **Social Security Disability Insurance (SSDI)**

SSDI benefits, typically based on the earnings record of a retired or deceased parent, are available to 'disabled children.' There is no resource (or asset) test for receipt of SSDI, unlike SSI, which has such a test. 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.

#### **Supplemental Security Income (SSI)**

This federal cash benefit program, with a California State Supplemental Payment (SSP), provides for individuals who are aged, blind, or disabled and who have little (or no) other income and few resources. This program is needs based. There are both income and asset tests (or requirements) for receipt of SSI benefits, and it is not based on anyone's prior contributions to Social Security.

The Maximum Cash Benefit depends on age, disability, whether an individual or a couple, and living arrangement. Minors receive somewhat less; individuals who are blind receive a little more. Couples receive more than individuals, but not twice as much. The monthly cash maximums, on the following page, are for individual adults with disabilities. (Check with Social Security for other rates.)

# Quick Start On Social Security

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Monthly Cash Maximums (June, 1993):

- \$630.00 independent living arrangement, with cooking facilities
- \$501.34 living in household of another; reduced needs
- \$698.00 independent living arrangement without cooking facilities (Note: The \$68 extra is for eating out.)
- \$709.00 non-medical board and care (Note: \$626 is share of cost for board and care; \$83 is for personal incidental expenses.)

In California, under work incentive provisions signed into law in 1987, an SSI recipient can earn in excess of \$1,000 per month and still maintain eligibility for SSI. Countable assets cannot exceed \$2,000 (\$3,000 for a couple). If countable assets exceed this figure, SSI benefits may be terminated until those assets are spent down -- that is, until any excess above the asset limit has been eliminated. Countable assets include cash, bank accounts or other resources which can readily be converted to cash (e.g., securities), except for 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).

An SSI recipient may receive \$20 per month from any source without experiencing a reduction in SSI benefits. Most income, other than earnings, above this amount, results in a dollar-for-dollar reduction in SSI. The first \$65 per month in earnings does not affect the benefit amount. If there are no sources of income other than earnings, an SSI recipient may earn \$85 per month (i.e., \$65 plus \$20) without prejudice. For every two dollars above that figure, SSI is reduced by one dollar. To illustrate, a person earning \$185 per month, with no other income except SSI, will have the first \$85 of earnings ignored. \$100 remains, and reduces the SSI benefit by \$50. Net of the SSI reduction, the individual is better off from working by \$135 per month (i.e., \$185 less \$50, the reduction in SSI).

## **1619(a)&(b)**



Section 1619(a) of Social Security Act, as amended, makes it possible to earn more than the substantial gainful activity level, without being removed from the SSI rolls. The disability status remains, unless the person medically improves or is terminated for a non-disability reason. Section 1619(b) provides that should a disabled person's earnings reduce SSI benefits to zero, one may, for some time, continue to receive Medi-Cal benefits.

Medi-Cal coverage is categorically attached to SSI, and is also available to some individuals not receiving SSI under medically needy or medically indigent criteria. For example, some low-income individuals with disabilities who reside in health service facilities do not receive SSI, but remain eligible for Medi-Cal. By health care financing rules, if a disabled person receives SSDI (typically on a retired parent's account), he or she will be taken off the SSI rolls while living in certain health service facilities (e.g., ICF/DD-H). To cover the cost of medical services, this person remains



# Quick Start On Social Security

eligible for Medi-Cal through the local welfare department (Social Services).

	<h2>Social Security Administration</h2>
<p>If you don't already have the number, you can find it in the phone book (usually in the front <b>White Pages</b> under —</p>	
<p><b>United States Government Offices</b> <b>U.S. Government</b> <b>Health and Human Services</b> <b>Department Of Social Security Administration</b></p>	
<p><b>Address:</b> _____</p>	
<p><b>Phone number:</b> _____</p>	
<p><b>Person I spoke with:</b> _____</p>	



# Community Employment

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## QUICK START

### On The Americans with Disabilities Act

#### **Introduction**

On July 26, 1990, then President George Bush signed The *Americans with Disabilities Act* (ADA) into law. This landmark legislation guarantees equal opportunity for individuals with disabilities in employment, public accommodations, transportation, state and local government services and telecommunications. A basic knowledge of the ADA can help service providers and consumers advocate for equal employment and transportation opportunities.

#### ADA Fact Sheet

Source: U.S. Department of Justice

#### **Employment**

- Employers may not discriminate against an individual with a disability in hiring or promotion if the person 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.
- Employers will need to provide "reasonable accommodation" to individuals with disabilities. This includes steps such as job restructuring and modification of equipment.
- Employers do not need to provide accommodations that impose an "undue hardship" on business operations.

#### *Who needs to comply:*

- All employers with 25 or more employees must comply, effective July 26, 1992.
- All employers with 15-24 employees must comply, effective July 26, 1994.

#### **Transportation**

- New public transit buses ordered after August 26, 1990, must be accessible to

# Quick Start On The Americans with Disabilities Act

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individuals with disabilities.

- 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.
- Existing rail systems must have one accessible car per train by July 26, 1995.
- New rail cars ordered after August 26, 1990, must be accessible.
- 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.

## **Public Accommodations**

- Private entities such as restaurants, hotels, and retail stores may not discriminate against individuals with disabilities, effective January 26, 1992
- 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.
- All new construction and facilities must be accessible.

## **State and Local Government**

- State and local governments may not discriminate against qualified individuals with disabilities.
- All government facilities, services, and communications must be accessible consistent with section 504 of the Rehabilitation Act of 1974.

## **Telecommunications**

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

# Quick Start On The Americans with Disabilities Act

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## Area Board on Developmental Disabilities

For more information about the ADA, you can contact your local Area Board. If you don't already have the number, you can find it in the phone book (usually in the front of the *White Pages*) under —

**California State of  
Developmental Disabilities  
Area Board**

**Address:** \_\_\_\_\_

**Phone number:** \_\_\_\_\_

**Person I spoke with:** \_\_\_\_\_

You can also contact:

**U.S. Department of Justice**

**U.S. Department of Justice  
Civil Rights Division  
Coordination and Review Section  
P.O. Box 66118  
Washington DC 20035-6118  
(202) 514-0301 (Voice)  
(202) 514-0381 (TDD)  
(202) 514-0383 (TDD)**

**Person I spoke with:** \_\_\_\_\_







# QUICK START

## On the Reauthorization of the Rehabilitation Act

### **Introduction**

In October, 1992, the Rehabilitation Act of 1973 was amended, reauthorized and signed into law by then President Bush. The law is now consistent with the Americans with Disabilities Act of 1990 in that it highlights participation by people with disabilities in rehabilitation planning and services. It also makes it easier for people to obtain the services they need. Some of the revisions include:

- |  |  |
|--|--|
| <i>Rehabilitation Technology</i>               | Defined to include rehabilitation engineering, assistive technology devices, and services. There is a strong emphasis on using technology to support people in where they live and work.   |
| <i>Eligibility</i>                             | All people with disabilities are presumed to have employment potential. This shifts the responsibility from individuals proving they can be employed to state agencies providing <i>clear and convincing</i> evidence otherwise. |
| <i>Individual Written Rehabilitation Plans</i> | Plans must include a statement by the person with a disability about how they were included in the process and how they were informed about choices among services.  |
| <i>Appeals</i>                                 | State directors of rehabilitation agencies cannot overturn the decision of a hearing officer unless there is clear and convincing evidence that the decision is not a legal one.   |
| <i>Consumer Power</i>                          | Fifty-one percent of members of State Rehabilitation Advisory Councils, the National Council on Disability, and State Independent Living Councils must be people with disabilities.  |

A special January/February, 1993 issue of the *Disability Rag* on employment was used as a reference in writing this brief summary.









# Community Employment

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## Information Pack on Supported Employment\*

### What is Supported Employment?

It's the ongoing support service that a person with a disability might need to find and keep a job in the community working alongside persons who are not disabled. The support in Supported Employment starts whenever people need it. It typically starts with finding out what types of jobs people like or might be good at. For example, does someone like to work indoors or outdoors, or what about lifting and carrying, using a machine? How much money is needed to pay the bills? Is working on weekends or at night okay?

It could also mean support in looking for a job that meets someone's needs. This is where the *Supported Employment* service really goes to work. Once a possible job is located, someone from the Supported Employment service agency will look at it to figure out what it takes to complete the job. If the match between a person with a disability and the employer looks good, the support needed to go to a job interview is provided.

Supported Employment services will also assist with the training needed to start a job which could mean working at the job alongside someone until they get used to it.

\*Excerpted from *Making It Work: A Guide to Supported Employment for Human Service Professionals* by Allen, Shea & Associates for the California Department of Rehabilitation, 1990.

# Information Pack on Supported Employment

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Once someone knows the job, the Supported Employment service will stand back. However, if other support is needed (like understanding changes in Social Security benefits) or if the job changes or there is a problem at work, then the support needed to keep the job will be provided. In other words, Supported Employment services provide support when it is needed!

## How Do People Get Access to Supported Employment services?

People who use regional center support services are typically referred to the Department of Rehabilitation by their regional center program coordinator, social worker or case manager. Counselors from local offices of the Department of Rehabilitation can provide or purchase Supported Employment services from Supported Employment service providers. How is it different from other Rehabilitation services? For the first time ever, Vocational Rehabilitation counselors have access to a variety of services in developing a package of support to assist persons with severe disabilities in finding and keeping a job.

## How Does it Work?

**Referral.** While the referral process for people with developmental disabilities (regional center to Department of Rehabilitation) is basically the same throughout the state, it's important to find out how the system works within a particular community. Staff from Supported Employment services are typically good resources for information on local referral systems.

**Assessment.** Once a referral to a Supported Employment service by the Department of Rehabilitation is made, an assessment process is initiated for determining individual support needs. Methods of assessment used in Supported Employment services include looking at an individual's work preferences, work history, and

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non-work issues and interests. Those issues and interests may be related to financial resources, transportation and mobility, social skills, community access, physical endurance, stamina, etc. Methods for obtaining this information are similar to supported living service assessments and might include:

- Interviewing the individual and/or significant others in the individual's life, i.e., parents, teachers, housemates, current work supervisors, siblings;
- Situational assessments completed in a real work setting; and
- Informal behavioral observations.

This assessment information provides an overall picture of the individual, including critical lifestyle variables.

**Job Development.** This part of the process depends on reliable information about the types of jobs that are needed by both employers and potential employees. That is, the assessment of job preferences and work strengths must happen concurrently with job development. This allows the job developer to target specific area of the local labor market. Typical job development activities include: reviewing local employment opportunities; developing potential employer/customers through cold calls, referrals and personal contacts, newspaper, family, friends; completing personal presentations to employers; and, negotiation of a hiring agreement.

**Job Analysis.** The best way to complete a thorough analysis of a job is to observe it, do it and talk to others who do it. A job site analysis typically includes an analysis of: the application and interview process; hiring and firing procedures; personnel paperwork required; the layout of the business; safety requirements and procedures; an understanding of benefits and work schedules; channels of communication; identifying the sequence of job duties; learning how to perform the job; and, a review of the job description. The extent to which each of these steps is broken down depends on the job requirements and the training needs of the person with a disability.

**Job Match.** Matching employers with prospective employees is considered to be

# Information Pack on Supported Employment

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more art than science. Basically, it's taking the information gathered about the worker during assessment and the employer during the work site analysis and making a best 'fit'.

***Job Training.*** A plan for job training will vary according to the needs of the new employee and the complexity of the job. Training is typically more intensive when the job first starts and then tapers down as the new employee feels more comfortable and has learned the job to the employer's satisfaction. Some individuals may not require training to complete a job, but may have other support needs like how to ask for help or getting along with co-workers. Support can include talking to the new employee before work and debriefing about the job after work.

Advocacy with the employer and co-workers takes place from the time the job developer begins the discussion of Supported Employment with the employer through the follow-along period. At the workplace, employers, supervisors and co-workers need to understand training methods and any accommodation needed by the worker. Co-workers and supervisors are made a part of the training program. This encourages communication and *natural support* enabling the worker to become a valued part of the company. The job trainer often facilitates co-worker socialization during breaks and lunch, as well as during those momentary social interactions. The job trainer's contact with the employee's family and/or other interested persons is equally critical to the success of the job placement.

***Follow-Along.*** After someone has learned the job and is performing at the employer's standards, routine follow-up with the employer, the employee, family, friends and other interested persons is crucial to continued job success. This follow-along may well be the most critical element in the long-term effectiveness of a Supported Employment service. Typical problems that may occur during follow-along are: employees may lose assignment or supervisor; and, changes in nonwork environments, e.g. home, social life.

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Follow-along activities are those which are employment-related and needed to promote job adjustment and retention. These may include: social skills training at the job site; training in certain independent living skills, e.g. mobility, money management; counseling with family and other service providers; employer training; and, advocacy. Funding for follow-along services in California have come from a number of sources or combinations of sources, such as: Habilitation funds for persons who are regional center eligible; Short-Doyle funds from community mental health centers; an approved Social Security work incentive, e.g. PASS or IRWE; a religious or community organization; a client's trust fund dedicated in full, or in part; a family set aside; a private non-profit agency; or, an agreement by the employer to provide the service with assistance from a case management agency.

## Questions and Answers About Supported Employment

**What kinds of work placements are available through Supported Employment?** There are several types of work placements available through Supported Employment in California. Here are the two major ones:

**INDIVIDUAL PLACEMENTS** In this work option, persons with disabilities are employed by the company just like other employees. While an on-the-job trainer might assist in helping someone learn a new job, this assistance is typically faded to a supervisor or co-worker. Wages and benefits are the same for persons with and without disabilities, depending on their job classification.

**GROUP PLACEMENTS** In this work option, a small group of persons with disabilities work together at a community business site alongside workers who are not disabled, with opportunities for interaction. Training and support is either provided by an on-the-job trainer from the Supported Employment service or by another worker from the company. Typically, persons are either paid a regular hourly wage or according to how much they produce.

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In both of the options above, the Supported Employment service assists persons in gaining employment by comparing their work preferences and needs with those of a potential employer. Typically, the job is observed and learned by someone who can assist as a co-worker or on-the-job trainer. As work performance improves, the on-the-job trainer provides assistance only as needed. This assistance might occur when: there is a change in job duties; a new supervisor is hired; there are problems with co-workers; Social Security paperwork needs to be completed, etc.

## **What kinds of things should people ask when they're thinking about using the Supported Employment services from a particular agency?**

- Do people like their jobs?
- Are people satisfied with how much money they earn?
- Are they satisfied with how many hours they work?
- Do they get support from someone when they need it?
- Are employers satisfied with the ability of the Supported Employment service to train employees?
- Are employers satisfied with the appearance, dependability, absence rate and job performance of employees who have been placed in their business?
- How long does it take to find someone a job?
- What kinds of jobs have been found?
- How long do people stay at their jobs?
- Are family, friends and advocates included in service planning?
- Are job adaptations available for persons with physical disabilities?
- Is there documentation of gross pay, hours worked, use of sick time, etc?
- Are SSI/SSDI wage reports completed when requested?
- Are there opportunities for interaction with co-workers on the job?
- Is the transportation used to get to work typical for all workers?
- Are jobs located in a reasonable proximity to where people live?



# Community Employment

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## Information Pack on Social Security

### Basic Facts About Supplemental Security Income (SSI)\*

**What is SSI?** SSI is short for Supplemental Security Income. It pays monthly checks to people who are aged, disabled, or blind and who don't own much or have a lot of income. SSI isn't just for adults. Monthly checks can go to disabled and blind children, too. In California, people who get SSI usually get Medicaid, too. Medicaid helps pay doctor and hospital bills.

**How much do people get?** California is a State that adds money to the Federal check. Your first month's SSI check may be for less than a full month. That's because you will be paid only for the days since you applied for SSI. Starting with the second month, you will get your full check.

**Other help you can get.** If you get SSI, you also may be able to get other help from your State or county. For example, you may be able to get Medicaid, food stamps, or some social services. For information about all the services available in your community, call your local social services department or public welfare office.

\* Adapted from *SSA Publication No. 05-11000*, U.S. Department of Health and Human Services Social Security Administration Baltimore, Maryland 21235 July 1990 ICN 480200

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**Medicaid.** Usually, when you get SSI you can also get Medicaid. Medicaid helps pay your doctor and hospital bills. You can get more information about Medicaid at your local medical assistance office.

**Who can receive SSI?** To get SSI, you must be aged or blind or disabled.

- Aged means you are 65 or older.
- Blind means you are either totally blind or have very poor eyesight. Children as well as adults can get benefits because of blindness.
- Disabled means you have a physical or mental condition that keeps you from working very much and is expected to last at least a year or to result in death.

Children as well as adults can get benefits because of disability. Sometimes, a person whose sight is not poor enough to be considered blind may be able to get checks as a disabled person.

**Your Income and Resources.** Whether you can get SSI also depends on what resources you own and how much income you have. Resources are the things you own. Income is the money you have coming in such as wages, Social Security checks, and pensions. Income also includes non-cash items you receive such as food, clothing, or shelter. If you're married, we also look at the resources and income of your spouse. If you're under 18, we may look at the resources and income of your parents. And, if you're a sponsored alien, we may also look at the resources and income of your sponsor.

**Income.** The amount of income you can have each month and still get SSI depends partly on where you live. In all States, you can usually get SSI if your income is less than \$406 for one person and \$599 for a couple. But many States allow much more income. And Social Security doesn't count all of your income in deciding if you can get SSI. For example, we don't count:

- the first \$65 a month you earn from working and half of the amount over \$65;
- food stamps;
- Section 8 rental assistance payments;

# Information Pack on Social Security

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- food, clothing, or shelter you get from private nonprofit organizations; or
- most home energy assistance.

If you are a student, some of your wages or scholarships you receive may not count.

If you are disabled but work, Social Security does not count any wages you use to pay for items or services you need to work because of your disability (this is called an *Impairment Related Work Expense* and has to be approved by the local Social Security Office). For example, if you need a wheelchair, the wages you use to pay for the wheelchair don't count as income.

Also, Social Security does not count any wages a blind person uses to pay expenses that are caused by working. For example, if a blind person uses wages to pay for transportation to and from work, the transportation cost isn't counted as income. If you're disabled or blind, some of the income you use (or save) for training or to buy things you need to work or earn more money may not count.

**Resources.** Resources are things you own, such as real estate, personal belongings, bank accounts, cash, or stocks and bonds. A person may be able to get SSI with resources of up to \$2,000. A couple may be able to get SSI with resources of up to \$3,000. Social Security doesn't count everything you own in figuring the amount of your resources. The following do not count as resources:

- The home you live in and the land it's on do not count.
- Your personal and household goods and life insurance policies may not count, depending on their value.
- Your car usually does not count.
- Burial plots for you and members of your immediate family do not count.
- Up to \$1,500 in burial funds for you and up to \$1,500 in burial funds for your spouse may not count.
- If you are disabled or blind, some resources may not count if you plan to use them to work or earn extra income.

**A Special Note for Blind and Disabled People.** If you work, there are special rules to help you. You may be able to keep getting some money from SSI while you work. As you earn more money, your SSI checks may go down or stop. Even if your

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SSI checks stop, you may be able to keep your Medicaid coverage.

You also may be able to go to school. The people at Social Security can tell you how to do this. The money you set aside isn't counted under the SSI income or resource limits. Therefore, it won't reduce the amount of your SSI check. If you're already working, setting aside some of your money might help you be able to get SSI. Blind or disabled people who apply for SSI may get special services from their State. These services include counseling, job training, and help in finding work.

**Other Rules You Must Meet.** Before you can get SSI, you also must meet other rules.

- You must live in the U.S. or Northern Mariana Islands.
- You must be a U.S. citizen or be in the U.S. legally.
- If you're eligible for Social Security or other money benefits, you must apply for them. (You can get SSI and Social Security checks if you're eligible for both.)
- If you're disabled, you must accept vocational rehabilitation services if they are offered.

**If You Live in a Public or Private Institution.** People who live in city or county rest homes, halfway houses, or other public institutions usually cannot get SSI checks. But there are some exceptions.

If you live in a publicly operated community residence which serves no more than 16 people, you may get SSI.

If you live in a public institution mainly to attend approved educational or job training that will help you get a job, you may get SSI.

If you're living in a public emergency shelter for the homeless, you may be able to get SSI checks.

If you're in a public or private institution and Medicaid is paying more than half the

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cost of your care, you may get SSI. But your monthly SSI check will usually be no more than \$30. (In some States, it will be more than \$30.)

**How to Sign Up For SSI.** It's easy. Just visit your local Social Security office. Or call us at 1-800-2345-SSA (1-800-234-5772) for an appointment with a Social Security representative who will help you sign up. You should apply for SSI right away. This is because SSI cannot start before the day you apply. Parents or guardians can apply for blind or disabled children under 18.

It can help if you have the following things before you apply. However, even if you don't have all of the things listed, apply anyway. The people in the Social Security office can help you get whatever is needed.

- Your Social Security card or a record of your Social Security number;
- Your birth certificate or other proof of your age;
- Information about the home where you live, such as your mortgage or your lease and landlord's name;
- Payroll slips, bank books, insurance policies, car registration, burial fund records, and other information about your income and resources;
- The names and addresses of doctors, hospitals, and clinics that have seen you and the names and addresses of social workers or institution superintendents.

If you want your SSI checks to go directly into your bank account, you should bring your checkbook or any other papers you have that show your name and account number. Many people choose to have their checks sent to the bank. They find it safer and easier than getting their checks by mail. But the choice is yours. If you want to get your checks through the mail, that's fine.

**What About Social Security Disability Insurance (SSDI).** SSDI benefits, typically based on the earnings record of a retired or deceased parent, are available to 'disabled children.' There is no resource (or asset) test for receipt of SSDI, unlike SSI, which has such a test. 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.

# Information Pack on Social Security

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For more information, visit or write any Social Security office. Or phone our toll-free number, 1-800-234-SSA (1-800-234-5772). ~~If you think you might be able to get SSI, don't delay. Call today. SSA's toll-free telephone service is available from 7 a.m. to 7 p.m. on weekdays. The best times to call are early in the morning and early in the evening. And if you can, it's best to call later in the week and later in the month.~~

The Social Security Administration treats each call confidentially. But we also want to ensure that you receive accurate and courteous service. That is why we have a second Social Security representative listen to some telephone calls.

## Basic Facts About Social Security Income and Work\*

**Introduction.** Often times, people with disabilities are fearful about the effects of money earned from a job on Social Security and other benefits. On the following pages, you will find the answers to many of the questions that people ask about Social Security.

**What Happens to Social Security Benefits When Someone Works?** The Social Security Administration has two programs which are important to many people with disabilities: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). SSDI provides an income to people who need it based on a person's earnings or of a parent who has retired or died. SSI provides an income to people with disabilities who have low income and few resources. So, it depends on whether someone gets SSI, SSDI or both. In general, as income goes up, Social Security benefits may go down.

**What Happens to SSDI When Someone Works?** After someone has worked for awhile, the local Social Security office will look at earnings to see if they're still

\* Adapted from *The Work Book: A Guide to Supported Employment for People with Disabilities and their Families*. Developed by Allen, Shea & Associates for the California Department of Rehabilitation, 1990.

# Information Pack on Social Security

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eligible.

**What Happens to SSI When Someone Works?** Social Security checks may decrease as earnings increase, but overall the wage earner will come out ahead.

**What Happens to Medi-Care or Medi-Cal When Someone Works?** Even if someone earns too much for a Social Security check, they may still be eligible for Medi-Care or Medi-Cal.

**When Someone Starts Working What Do They Need to Do?** It's the responsibility of the individual worker to report his/her earnings from a job to Social Security. If someone needs assistance, they can ask for help from the Work Incentive liaison from the local Social Security office. Often family members or someone from the Supported Employment service can help as well.

**What If Someone Gets Overpaid From Social Security While Working?** It's important to let Social Security know about changes in earnings, so that SSDI and SSI checks are the right amount. If someone thinks they have been overpaid, it's important to talk to someone at the local Social Security office or the Supported Employment service and to hold on to that extra money. Eventually, Social Security will send something called a Notice of Overpayment. If it's correct, then that amount must be repaid. However, if the notice looks like it's wrong, then a form called a Reconsideration of Overpayment must be filed. Again, this is something that the local Social Security office, a family member or someone from the Supported Employment service can help people fill out.

**What's An Impairment-Related Work Expense? (IRWE)** People who receive SSI or SSDI can claim certain impairment-related work expenses, if they result from a disability. These expenses can be deducted from earnings which will, in return, reduce the amount that the benefit decreases each month. If approved by Social Security, *IRWEs* may include: follow-along support services; job training;

# Information Pack on Social Security

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medical devices; certain attendant care services (to get ready, and to get to or from work); out of the ordinary transportation costs; work-related equipment; drugs and medical services; some home modifications; and, other expenses (e.g., cost of keeping a guide dog, expendable medical supplies). An *IRWE* helps reimburse someone 50% of the cost of these services.

**What's A Plan for Achieving Self-Support? (PASS)** A person with a disability can have additional income and resources (from any source) that can be set aside if needed to return to work or to meet an occupational goal. A plan for achieving self-support (PASS) is something which can be developed and approved by a local Social Security representative (anyone can help write one). *PASS* 'protected' income and resources are set aside and are not counted against SSI benefits for some period of time -- typically 18 months, but as long as 48 months. A *PASS* may be developed for: follow-along support services; ongoing support; education and training; obtaining tools; a van, a car; getting enough money together for self-employment; relocating; and so forth.

It's really important to develop a relationship with the local Social Security office. For more information, you can request a copy of the Social Security publication commonly called "The Red Book." The full title of the publication is **A Summary Guide to Social Security and Supplemental Security Income Work Incentives for the Disabled and Blind**. (Be sure the publication was printed in July 1987 or later.) There are many other publications which may be helpful as well.



# Community Employment

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## Reflections

### Between a Rock and a . . .

Remember Jean from our *Snapshot* section, she was the great employee who was hired from a work crew that provides hotel housekeeping services. She had been living in a group home until about six months ago when she told her social worker at the regional center that she would like to live in an apartment with a friend. At that time, she was referred to your supported living agency and with your support is living with her friend in a nice, two-bedroom apartment close enough so that she can still walk to work. However, there have been problems with her employer in the past month. Jean is not showing up on time, is not wearing clean clothes and does not appear to take a shower every day. Jean's employer really wants to get things cleared up. Her case manager says that Jean is communicating that she doesn't like the job any more. The supported employment agency blames you because you're not providing the support needed to help her and they say that this wouldn't have happened if she hadn't moved. To make it more interesting, you and the supported employment provider both work for the same *umbrella* agency. Whose problem is it? What do you do? How can you support Jean? Where do you start?

### What's Your Plan?

# Reflections on Community Employment

## Assisting Someone Write a *Plan for Achieving Self-Support*

On this page, you'll find a Sample PASS (covering job development and job coaching) which was written by a rehabilitation counselor for a person with developmental disabilities who was not receiving regional center services and needed additional job coaching. Turn to the next page, to try your hand.

### SAMPLE LETTER WRITTEN TO SSA

May 13, 1988

Social Security Administration  
ATTN:  
P.O. Box 7980  
San Dimas, CA

Dear \_\_\_\_\_,

Jack Smith is requesting a PASS to purchase job development and job coaching services totalling \$4,000.00 over one year. Our office initially purchased these services for him through June, 1987, when his case was closed. At that time he was working 20 hours per weeks at \$2.89 per hour. SD Personnel has subsequently been able to upgrade his employment to a replacement job, working 20 hours per week at \$4.50 per hour. Because our services are exhausted and his file is closed, he would like to purchase these vocational services on his own. This will result in a significant improvement in his earnings and employment position and I support this change. By setting aside PASS funds averaging \$333.00 per month over 12 months (or a total of \$4,000), all development and coaching fees will be covered.

I believe that Jack will continue to require some job coaching and support services after the expiration of the PASS. These costs can be partially paid by him, which he intends to do, and partially paid through IRWE writeoffs. Since he has SSDI (\$351.00 per month) and as of 4/1/88 has wages of about \$364.00 per month, he has sufficient earned income to accomplish a PASS averaging costs of \$333.00 per month.

Please contact me if you have any questions. We would like the effective date of the PASS to go back to 3/1/88 if possible.

Sincerely,

### EXCERPTED SECTIONS FROM THE SAMPLE PASS APPLICATION

#### *Section I.- Applicant/Beneficiary Identification*

3. Description of Disability/Limitations: Requires individual job development, training and job retention services.

#### *Section II.- Self Support Plan*

1. Occupational Objective: Food Service Worker
2. Describe the Plan to Achieve the Occupational Objective: Purchase job development and job coaching over one year period. Past performance suggests training needs described in plan are realistic.
4. Monthly Expenditures Necessary to Fulfill the Plan:
  1. Job Development and Placement Fee \$400.00
  2. 180 hours Job Coaching @ \$20.00 per hour \$3,600.00
  - TOTAL \$4,000.00

# Reflections on Community Employment

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## Writing a Request for a PASS

You could be asked for support from someone who uses regional center and supported living services and wants to buy a car to drive to and from work. Try your hand at helping someone write a letter to the Social Security Administration requesting a PASS to save up enough money for a down payment on a used car and 6 months of insurance. Saving this much will place this (single) person's savings over the \$2,000 resource limit. In fact, it will take about \$2,500 to make these purchases. You don't have to write up a second page as in the previous example. However, remember to include why it's needed, how much will need to be saved, and how long it will take to save it. Once the request is made by the person you're supporting, a local SSA representative can take it from there.

## The Letter You Helped Write to SSA

May 13, 1988

Social Security Administration  
ATTN:  
P.O. Box 7980  
San Dimas, CA

Dear \_\_\_\_\_,

Sincerely,

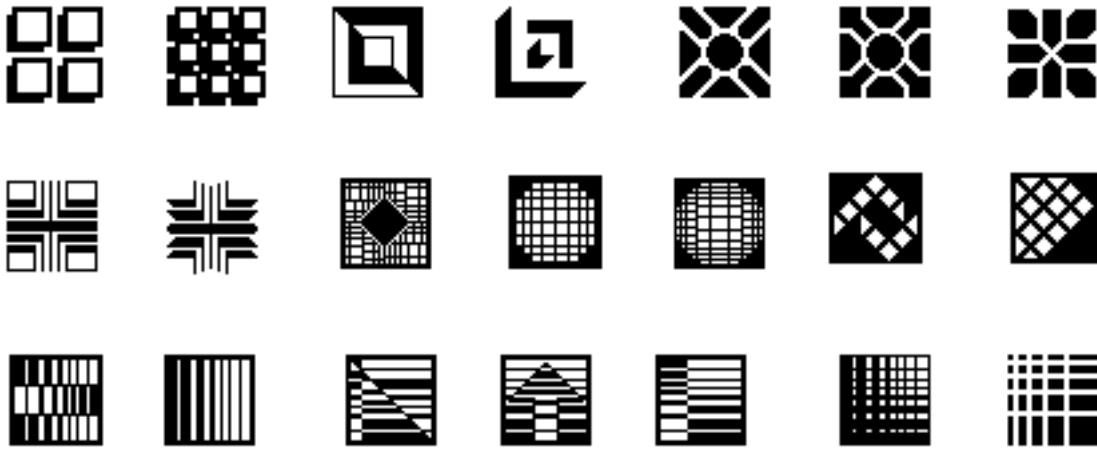
# Reflections on Community Employment

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## Accessible Transportation

Your local paratransit company doesn't have any wheelchair accessible vans and some of the people you support need that transportation to get around town and to work. Using *The Americans with Disabilities Act* as a reference, what kinds of strategies could you and the people you support think of that might help make a change in your local transportation system. Remember, you all have to live there when you're finished working on this critical issue.

## A Strategic Plan

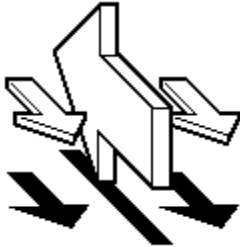


*Patterns of Supported Living*

Stories of  
People's Lives



# Stories of People's Lives



## Directory

### Introduction

Listening to people's stories and celebrating their lives has become an important part of supported living services. In the listening, we hear about people's strengths and struggles and see opportunities for ways we can work together. In the telling, people with developmental disabilities have a chance to pass on the rich experiences of their lives. In this section of the catalogue, you'll find stories told in different ways. One is in journal fashion by someone who is getting to know a person that they will be supporting. Another was written by a person who has moved into his own home for the first time. You'll find many stories throughout this catalogue titled *Snapshots*, these are brief stories with some focus like attendant services or employment. In this section, however, we present stories only as celebrations of people's life journeys.

*Stories of People's Lives* includes:

	<b>Page</b>
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<i>My Struggle for Independence</i>	S 6
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# Stories of People's Lives

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## Celebration

Celebration is delighting in that which tells us who we are.  
Celebration is taking the time to cherish each other.

*--Reba House*

Celebration is something present that needs to be made  
visible so we can all say yes to it.

*--Father Joseph C. Gengras*

Celebration is a communal experience of joy, a song of  
thanksgiving. We celebrate the fact of being together, we  
give thanks for the gifts we have been given. Celebration  
nourishes us, restores hope, and brings us the strength to  
live the . . . difficulties of everyday life.

*--Jean Vanier*

Perhaps all human beings need to celebrate -- to renew the spirit by coming together  
to dance, sing, play games, and eat. Individuals who *work with* persons with severe  
disabilities -- whether family, friends, or paid service providers -- may need  
celebration more, especially if the work is difficult and the gains slow.

As with story-telling, celebration is balm for the human spirit. Celebration can be  
*circles-of-friends* meeting in regular community places like bars or restaurants to have  
a good time, to share, and to feel that wonderful sense of community that can come

# Stories of People's Lives

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from friendship and caring for one another. Many parents show great delight in the accomplishments of their children even as they become adults. It is this spirit of acceptance and joy -- in the company of others -- that is celebration.

Celebration is a wonderful resource, and differs from the way we honor success and power with applause and prizes. Rather, as Vanier has said: *Celebration is a shout of love, and of openness, not a feeling of power and superiority.* Now, for some stories of celebration.

## My Struggle for Independence

by Richard Trawick, San Diego, California

My name is Richard and my life began on July 4, 1959 - Independence Day. Like most babies, I spent the first years of my life learning to sit up, crawl, walk and explore the world around me. I began using a few words, started nursery school, and at three years old I moved with my family from Dallas, Texas to California. When I was five I attended the Language Development Center in Minorca, California. My teacher's name was Gladys. The following year I started kindergarten. During the next couple of years while other children were concentrating on the basics of reading, writing and arithmetic, I was being taught to weave pot holders.

In 1967 I left the Mariner School to go to Seeman School in El Monte, California. I was seven years old and I remember being carried inside. It was a "special boarding school". It was the start- the beginning - the first of many institutions. Soon after, my family moved to Illinois and my mom came to visit me only now and then. Gradually she, my dad and my two brothers, John and Dave, saw me less and less. Since I had so few visitors, Mrs. Butler, one of the people who worked in my dormitory, would take me home with her once in awhile.

# Stories of People's Lives

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I didn't have a great appetite and when I wouldn't eat Miss Monique would force feed me. She made me sit in the dining room all day once. When I didn't finish my meal she would take away my things.

When I was 10 years old Mr. Hitz, another dormitory worker, would spend time with me. Sometimes we watched scary movies. We did a lot of "monster talking" about devils and demons, vampires and witches, and werewolves and Frankenstein movies. I had trouble sleeping.

At eleven, I was put on dilantin. This made my gums red and swollen. They almost covered my teeth. I learned that the scientific name for this was "gingival hyperplasia". I was upset with the doctor. I was dizzy. Sometimes I would fall down or see things that weren't there. I hated the side - effects from seizure medication.

In 1972 when I was 13 my brother John and a friend of my mother's, Helen, came to see me. They were shocked to see the condition I was in. My gums were very swollen and I was so drowsy all the time. They tried to take me places, but there were always problems. Once they took me to a restaurant where I became very sick and threw up all over. I can't remember if they took me anywhere else after that.

A couple of years later my mom came to visit me and Helen came with her. I didn't see my father much because he had multiple sclerosis and it was hard for him to travel such a long way. Mom came back for Easter. Illinois was so far away and I missed my family. The following year (1975) my mother came out again. This time she went to Special Olympics with me for two days. Afterwards she took me home to Illinois. I was so happy to see my dad for the first time in eight years.

For the first three months, I was home with my mom, dad, John and Dave. I was happy and excited to be a part of the family. But soon I was enrolled at the Joseph P. Kennedy school for boys. It was a boarding school where I stayed during the week. I got to go home on weekends. There was a boy named Tim who made fun of me.

# Stories of People's Lives

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Once he tried to kill me with a knife. There were other kids who liked to tease me too. They made me very angry. I went from being very happy to having full-blown temper tantrums.

On August 1, 1976 I was transferred to the BJC school. That stood for Brother James Court. At first it wasn't bad and I was involved in a lot of activities. The following year my Dad died and I wasn't allowed to take the bus home for his funeral. After that things began to change. There were rules that punished everyone when one person did something. I couldn't have second helpings because a guy named Ken cheated on his diet. Activities were restricted for everyone when one of us did something against the rules. I wore a suit and tie all the time. Once Brother John Francis was mad at me for a whole week. He always criticized the way I dressed. I felt that the brothers were trying to control and dominate me. Once Brother Christian blamed me for eating too many donuts. Several people had more than two but I was the one who got in trouble even though I only had two donuts. I really got angry about that.

A year later my mother took me out of BJC, but there weren't many choices available. At first I went to Kishwaukee hospital's psychiatric ward. Later I was transferred to Singer mental hospital where I stayed for almost three months. From there I went to Sheltered Village/Genesis House in 1981. Here I was told I would learn independence. I lived and worked there and took some classes. I passed "Health Care" and "Nail Care." The better I did, the more freedom I earned.

The next year was tough. I argued with my family about little things. When I would visit there would be arguments about things like what to watch on television. Inside I was very hurt and angry about big things. I didn't understand why I had to always live somewhere else and why my family had left me at Seeman School in California while they moved to Illinois.

# Stories of People's Lives

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I took other classes at Sheltered Village and I passed. Just when I began to learn about me and all the things I could do for myself, my mother became angry with me. I argued about a lot of things. She didn't speak to me for three months.

I wanted to learn to cook. I kept trying to get Greg, one of the staff, to hold cooking classes. I guess they were too busy to help me to cook independently. During the day I worked at a workshop. I did this for two years. I looked forward to classes in the evenings, but they didn't always teach me the important things that I needed to learn. Little by little I earned more freedom. I attended OJT at Northern Illinois University. In 1984 my mother and I took a trip to California.

In 1985 I began to work in the community, first at WICO where I was laid-off three months later and then at Phyto-Farms. At WICO I helped make computer components. At Phyto-Farms I was planting, harvesting and cleaning. I liked the job. I tried to convince Tom, one of the counselors at Sheltered Village that I could move out and be independent, but he didn't think I was ready. Seven months later Ben, another staff member, told me I couldn't stay because it seemed a mistake had been made, and I was actually "normal." Different staff said different things. Cheryl tried to help me to be more independent. Maria however slowed everything down and even changed my room without asking me. Barry told me I would always need to live somewhere like Genesis House, that I would never be independent. Another staff member, Rob, told me to "be patient."

In 1986 new owners took over and there were changes. In December I went home for a visit and when I returned many strange things had happened. There were many rule changes. First I was no longer allowed to do my own laundry, then I was forced to clean my room and throw away many things I wanted to keep. There were threats of revoking my banking privileges. Later it was decided that I could have two checks per month. I was forced to attend Core Group against my will. All we did was talk about the same old stuff over and over. My room and board was raised and my downtown privileges were limited to two hours except in winter when I wasn't

# Stories of People's Lives

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allowed to go at all. The time I spent at the N.I. Library was severely limited. At one point a staff person named Jeff told me I would be spending the rest of my life at Genesis House. I was so upset that he threatened to physically restrain me. I was angry and began to lose my temper. I ran across the hall, upset and screaming. Finally I was terminated from Genesis House. This might have been the best thing that ever happened to me. I was at Sheltered Village/Genesis House for 6 years, 6 months and one day. I ended up back on the *psych* ward at Kishwaukee hospital but this time I was actually relieved. I spent another three months at Singer Mental Hospital in Rockford, Illinois. While I was there my hopes were raised about a hi-rise apartment program. It didn't happen.

In May of 1988 at 29 years old I moved back to California after almost thirteen years in Illinois. I lived with my mom for three months. From there I moved to an apartment program where I learned a few more "steps" toward independence. Again people were telling me to be patient. Programs and classes would start soon. My mother began to understand what I wanted and needed, and it wasn't living in an apartment program with lots of people with disabilities. I wanted to choose my own place and I wanted to live alone. I wanted to have a garden. After a month in the apartment program a lady named Kathryn came to see me. She said I could live where I wanted to; I didn't have to live with anyone. We looked for apartments for me and I found the right one. In December of 1988 I moved into my own place with a yard where I could have a garden. I spent a little over 21 years in institutions, but finally I was free. People who kill and steal should go to institutions - prisons. There should be a law against taking the community away from people who haven't committed a crime. I attend a self-advocacy meeting twice a month. It is important to let others know how to fight for their freedom. We all have rights and no one should give up their rights. We have the right to be treated with dignity and respect. I have my dignity back and no one can take it away again. I have my independence and I am exceedingly joyful! I listen to music, watch T.V., and eat what I want, whenever I want to. I go to the park, zoo, Sea World or the library whenever I can. I read about places I'd like to visit someday. These seem like simple things, but if you have never

# Stories of People's Lives

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had someone dominate you or control you, then you can't know how good it feels to have control over your own life. My struggle has been worth it. I work at Taco Bell and someday I would like to own a house of my own.

Six months after moving into my own apartment, on July 4, 1989 my 30th birthday I celebrated my very first real Independence Day.

# Stories of People's Lives

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The ancient redwood trees of Northern California, huge as they are, have a very shallow root system, yet they cannot be blown over by the strongest wind. The secret of their stability is the interweaving of each tree's roots with those that stand by it. Thus a vast network of support is formed just beneath the surface. In the wildest of storms, these trees hold each other up.

*Dawna Markova*  
The Art of the Possible (1991)

## Story-telling

Story-telling has become an important practice in some supported living services. John O'Brien and Connie Lyle O'Brien, for example, recently edited stories by staff of Options in Community Living, Madison, Wisconsin. This collection was then published by *Options* last year under the title *Remembering the Soul of Our Work* (you can find out where to get this by referring to page OR 7 in *Other Resources*).

Story-writing, as practiced by *Options*, fulfills several needs:

- a way to talk about one's day-to-day life, with its joys, frustrations, victories and dilemmas;
- honors the dignity and intrinsic importance of each person;
- provides a *renewal* for staff, which helps when the going gets tough; and,
- offers a description of the kinds of support, successes and failures that the agency has experienced.

At *Options*, time is set aside for staff to write and read their stories -- not to get advice and to problem-solve, but simply to express one's feelings and thoughts. For people who want to experiment with story-telling, Gail Jacob, the Director of Options, offers several suggestions.



# Stories of People's Lives

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## Suggestions for Story-tellers

- ✓ Share stories as part of a group.
- ✓ Commit to a schedule of one or more stories each time the group meets.
- ✓ Read stories enough times as a group (say, 4 or more times each person) to decide whether you want to continue.
- ✓ Listen and share; do not use this time to offer advice or problem-solve.
- ✓ Write about concrete experiences.
- ✓ Include things that challenge or confuse, mistakes that evoke strong emotion.
- ✓ Use your own voice; don't worry about grammar; be honest.

## First Vacation

by Leslie Wilmot; reprinted with permission from *Remembering the Soul of Our Work*, Stories by the staff of Options in Community Living, Madison, Wisconsin.

Sometimes I have to really struggle to let go of my own protective nature, especially when it comes to supporting people in taking their own risks. As difficult as it is - I acknowledge the importance of this practice. It's been easier to do this when I've had the opportunity to witness very positive changes in individuals, when protective shields of our own creation are relaxed and a person unfolds into the individual they can be.

Recently, Lorraine and Vivian traveled to Florida on their first vacation together.

# Stories of People's Lives

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Lorraine has traveled some with her family. For Vivian, this trip was a first; one of historic importance in the development of her own personal history.

The genesis of this vacation idea came early in the spring during a car ride home from a group Lorraine and Vivian participated in together. At first, both Lorraine and Vivian were nervously reluctant to give a traveling vacation serious thought. But, soon they animatedly brainstormed all sorts of possibilities.

"California."

"Yeah, yeah...well, it may be too hot."

"New York?"

"That's a ripoff place."

"Where do you want to go?"

"Florida? That's pretty far away though."

"How about Nashville? I like country music. What about you, Vick.?"

"Disneyworld. Yeah, let's go to Florida."

"OK, Florida it is."

That's about like the rest of the process went for planning their first vacation together. Brainstorming, feedback, agreement. As the trip drew closer all of our anxiety increased. (I tried not to show it though.) To relieve some of that, Lorraine and Vivian remained actively involved in all travel preparations. They met weekly to keep in touch about arrangements and to role play many of the new and various tasks that they would face. Though I doubt they would admit it now, their hearts held a little terror the day of their departure. So did mine.

Four days later, Lorraine and Vivian returned from a fun packed holiday in Orlando. Epcot Center, Disneyworld, Radisson Inn, swimming, shopping, dining out, music, lots of sun, spending money, souvenirs, photographs, and memories. Lorraine and Vivian returned seasoned travelers, each of them filled with stories of the places they went, other vacationers they met and socialized with, traveling glitches they

# Stories of People's Lives

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overcame, and a partnership with each other that felt complementary. They also recognized the tasks or things that made them uncomfortable. Vivian wasn't thrilled with flying, it makes her queasy - next time Dramamine first. Lorraine would like to go when it's not quite so hot. These things aside, Lorraine and Vivian had a great vacation! One of the last things I heard each of them mention was organizing another vacation in the winter.

"Nashville, California, Disneyworld again? This time we need to go for longer, four days was too short."

Their next trip I probably won't need to drink quite so much Maalox.

## *Herb Revisited*

Adapted material from a journal (with names changes) by Mary Ellen Sousa, *Creative Support Alternatives*, San Diego , CA.

**September, 92.** Exhausting! We're trying to hang in there with Mari - - it's so frustrating when she says one thing and does another. We're talking about how relationships work - or don't work- one part has to be open and honest communication.

When she took off with Herb this weekend and blew off work, I was so angry with her. Why do I feel so betrayed? The rational part of me says she's learning so much and so are we. I know it will take time for her to drop some of her old baggage and trust us. The irrational part of me says *How can you screw up what we're all working so hard for?*

Still, I can't blame her. She only wants what we all want- to have someone who really

# Stories of People's Lives

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cares, a partner, boyfriend, significant other, whatever. But does it have to be Herb?

**October, 92.** Betty and I picked up Mari at school with her belongings - she's higher than a kite. Then, we helped Teresa move her stuff. It's obvious at Teresa's current dorm room that she's well connected and liked. We helped Mari finish her dorm paperwork, get a meal card and so on.

We left the two to unpack that evening. They'll have their first dinner together. Now I know how the parents of freshmen feel - I resolve not to call them tonight to see if Mari is OK.

**November, 92.** Mari showed up for a meeting with her boss, teacher and me and I recognized the cute green dress she was wearing from some where. I know, I saw Teresa wearing the same dress the week before. I had to smile because Mari and her roommate were sharing clothes. Such an ordinary, insignificant thing and I'll bet a first for her.

**February, 93.** I met with Kellie, Mari's friend. She said she really felt honored to be invited to her futures planning meeting. She said *Thanks for inviting me to Mari's party... I'm just her friend... everyone was there just for Mari... it was really neat! I thought how great it was that she thought of it as a party.* How many IPP meetings have I been to that I would call a party?

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## Moving

by Kim Turner; reprinted with permission from *Remembering the Soul of Our Work*, Stories by the staff of Options in Community Living, Madison, Wisconsin.

I have to admit that I hate helping people move. I hate doing it myself, but even more I hate moving other people. It's hard work - packing, carrying, unpacking... I usually hurt myself, bang up my car and feel exhausted by the time a move is over.

I am trying to adjust my attitude about moves for people we support. People move for a lot of reasons - not all of which are positive. But frequently people move as a part of reaching a goal to have more of what they want: a bigger apartment, a more compatible roommate, no roommate, a better location.

Sally and Frannie moved in together a couple of years back. They became good friends. Everyone thought they would stay together forever. They had found their home. But, alas, things change. Sally's mental illness has made her last year very rough for her and for Frannie. Frannie, perhaps feeling a sense of "deja vu" firmly decided that she was done having roommates; the time had come to try living on her own.

It is a positive step for Frannie. She has always struggled with stating her opinion and feeling strong enough to assertively ask for what she really wants. But what about Sally, and rent subsidies, and finding the right apartment, and packing and moving, and learning a new neighborhood?

Oh, yea. . . that's my job to take care of those little details. The important part is that Frannie has chosen to take a new step toward her feeling independent and having a home she feels safe in.

This story isn't finished - Frannie is still in the apartment hunting phase, and no box gathering or packing has begun. Soon. .. though. It will have to. And when she is all settled in her new digs, I hope she has one of those wonderful celebrations to warm her new home and remind me that moving is a celebration of dreams realized, not a plot to wreck my back!

# Stories of People's Lives

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## Thanksgiving

by Kathryn Mazack; reprinted with permission from *Remembering the Soul of Our Work, Stories* by the staff of Options in Community Living, Madison, Wisconsin.

I pick up Wanda to take her to her friend Ed's house for Thanksgiving. She is packed and ready to go except for a few miscellaneous items in the frig: homemade cranberry sauce, brownies, Tommy's cat food. As I gather her packages, Wanda stops me and says, "Here Kathy, this is for you, take it." I take a card with my name on it. Written inside I read: "Here is a dollar for your treat from me and Tommy too. Thank you for taking us (to Ed's). Love you, have a good day, from Wanda, Tommy and Eddie too." As I read the card she shoves \$.75 into my hand and says, "I owe you a quarter for your treat. I always give a dollar." Wanda's thoughtfulness and generosity always surprises me. I, like the others in Wanda's life, am endlessly receiving some token of appreciation: books, trinkets, bags of food. I thank Wanda for the card and we head off to Sentry to shop for her Thanksgiving meal.

After shopping, we stop for coffee. It's Wanda's turn to buy. She orders two cinnamon rolls and coffee for herself and asks me what I want. I order coffee, explaining I just had breakfast. Wanda yells at the cashier's back, "and a sweet roll for her too." Looking my way, she admonishes me, "Don't talk crazy, don't talk crazy, Kathryn. You can eat it." She gave her the change and hands me the quarter she owes me for my treat. I accept. We take our seats.

Wanda loves to talk over coffee or a meal. As she begins talking, I listen, and watch her endearing movements: the way she holds her head to the side, brushes her face with the back of her hand, curls her upper lip when making a point or waiting for a response. The eagerness with which she speaks about events of the past day or week commands my attention. Wanda says, "Say, honey, I got a card from my real cousin Jean, in Warren, Illinois." She hands me the card and has me read it. We then begin our ritual of her dictating, I writing, a second Thanksgiving letter to Jean. We finish the letter and our coffee and get ready to leave. Wanda thanks the cashier, bids him a Merry Christmas, and off we go to Ed's.

# Stories of People's Lives

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## Sometime Anne and I Just Cry

Excerpted from a story written by a staff member at CHOICCESS, Arcadia, California

Anne is a gift to me. Since she has come in to my life she has opened my eyes to many new experiences and new ways of looking at old experiences. She is also one of the most complex people I have ever begun a relationship with. I met her 1 1/2 years ago at a State Hospital. She has lived most of her 35 years in places she was "placed" in and did not have any control over. She has lived in foster homes, group homes, hospitals, state hospitals, mental institutions.

Anne has known a great deal of pain in her life. She has been physically, sexually and emotionally abused by many people who should have loved and nourished her. One particular night she was trying to explain to me why she had such a difficult time trusting people. She began to speak very clearly and concisely of a remembrance of a particular evening of her childhood. She spoke of it as if it were yesterday and as if she was sitting and watching the scene as an outsider. "My mom told me to go on in to the bathroom and get ready for a bath because we were going to be going to a birthday party. I was really excited because we did not often get to do things like parties. I went in to the bathroom and took off my clothes. The door opened and she walked in with a nylon rope wrapped around her hand and she began to whip me with it. I knew I was not going to a birthday party."

This story was followed by many other stories of being beaten while her twin sister was made to watch and looking at her sister's concerned and crying face over her's asking if she was OK. Two seven year old little girls who loved each other and clung together to survive the woman who had given birth to both of them and then continuously betrayed their love. "I love my mother-- I know she did bad things to me but I still love my mother--I wish I knew why she did those things to me."

Then when Anne and her sister were finally removed from this "home" and "placed" in a group home for girls another lie betrayed her. One morning the social worker came to see Anne at the home and said she needed to go to court but would return that

# Stories of People's Lives

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afternoon. Anne said good-bye to her sister and promised to return later that day-- she never was returned. She was 13 or 14 and has had almost no contact with her twin sister since that date.

I listened because there seemed no other response. But Anne just talked and she never cried. She says she cries when she is alone and she gets angry when she is alone. And sometimes she gets angry at other people and things because they remind her of something that happened in those many, many years of darkness and pain. It became glaringly clear to me and to her that her life was changing very quickly and that there were times when she needed to pull back and take some time to adjust to the reality of having the opportunity to have love and commitment as a part of her life. Sometimes she imagines that all of the support that she feels now will disappear in the next moment or she feels like she would rather throw us out of her life than have the opposite happen. We have talked and talked and cried together about these happenings. Every time it comes up we learn something about each other and about ourselves and then we go on. It is often easy to forget how dramatically her life is changing and how little experience she has had with relationships that are positive, nurturing and accepting.



# Stories of People's Lives

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## The Teacher

by Connie Saverino, *Toward Maximum Independence*, San Diego, CA

John had one of those impressive histories, you know the kind - a three inch thick social summary, a stack of psychologicals dating back to the early ice age and a Franklin Factor soaring off the scale. His mother had left a trail of broken and beaten casemanagers and amassed a wealth of information on surviving the system and winning appeals. Together their reputations were larger than life and sent fear down the spines of even the most self-respecting professionals. So it was with little hope of success that the regional center issued a request for proposal in the spring of 1989. It was their mandated response to another appeal won by mom. It called for the development of an individualized living arrangement which would accommodate John's intensive needs for "behavioral" intervention. The litany of behaviors John needed to have "intervened" could have earned him some sort of recognition - perhaps a place in the Guinness book or an 8 x 10 glossy on the post office wall. Heaven knows that most of us don't find property destruction, self injury, head-banging, biting, scratching, spitting, smearing feces, running away, or non-compliance to be the most common descriptions of our best friends.

A naive group of "do-gooder" social service types responded to the request and were awarded an opportunity to work with John and his mother in putting together an array of supports which met the family's approval. Mom, having been thrashed by a long line of well-intentioned professionals, approached the process with visible distrust and skepticism. The early months were tough, nothing seemed to go right. John broke windows, slammed doors, punched holes in walls, while neighbors complained, mom shook her head in disillusionment and the team of increasingly less naive professionals went back to the drawing board. They took Marc Gold literally when he said *try another way*. "What is John telling us?" they asked. They tried to encourage John to use his limited language skills to give them some sort of glimmer into what he wanted, what triggered his outbursts. During the countless "circle" meetings, John hid behind a book or magazine which he couldn't read, or sat quietly with his head-set planted firmly in place, refusing to participate, answer questions, or even give eye

# Stories of People's Lives

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contact to the others present. He and his "roommate" Ron experienced intermittent periods of calm between episodes of destruction and aggression. Often John refused to go to work, or to groom appropriately for work. Once he took the trolley to Tijuana from his home in the East County area of San Diego instead of going to work. Needless to say mom, roommate, agency staff, all were panicked. The trolley station, nearby mall and surrounding area were combed and re-combed. The police were contacted. Mom showed a security guard at the mall John's picture so when John showed up late that night, the guard was able to call mom just in time to have the story pulled from the late night news as it was about to go to air.

At the end of the first year, Ron announced that he was returning to graduate school on a full-time basis and would be leaving. The hunt began for another roommate. Someone from inside the agency couldn't resist a challenge and soon he, his wife and young son were living with John. After all, John never indicated that he didn't like him during the interview process.

Regardless, it wasn't long before John began to communicate his distaste for this group living arrangement. He locked his new roommate's cat in the broom closet, removed his personal effects from walls, tables and counters, and smeared feces all over the kitchen one day while the cable man was there to repair the cable T.V. Things grew so tense that the roommate's wife, baby son and cat moved out leaving him there to sleep behind a locked door and listen to John's incessant banging on walls all night. Of course this was ill-tolerated by the neighbors and eventually John was asked to move and politely given notice. The transition presented an opportunity to explore new options. John's mom waited, fully expecting the "infamous discharge notice." None came. She was perhaps justified in her lack of faith given John's history of non-acceptance and short term quick fix attempts, but she was a little shocked and much relieved when the next "circle" meeting - one that looked a lot more like "who's who on the Regional Center SWAT Team" - netted a very different result. The support agency director started the meeting by turning to John and saying, "Well John, we're not doing so well are we? Are you willing to give us another chance?"

# Stories of People's Lives

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John looked puzzled, mom looked puzzled; several people from regional center looked puzzled. "What shall we do next? Is there Someone you would like to live with?"

John, a man of very few words, looked sheepishly around the table, no doubt a little intimidated by the multitudes amassed to discuss him, analyze him and decide what to do with him or for him. "Alone." he said simply. "Alone? You want to live alone?" Several people began to speak at once. It became an impossibility before any of the strategies could be considered. Regional Center, agency staff, even mom brushed the "whim" away, proceeding to discuss the practical aspects of finding yet another roommate for John. No one really remembers who, but someone there that day headed off a retreat by John who was close to putting his headset on and bailing out of the meeting. "John wants to live alone. Can we just spend some time thinking about that? Let's imagine how that might work, what it might look like."

By the end of that very long meeting, a plan had been negotiated to try something a little different - to see if an arrangement could be made to find a support person who would be as readily available to John as his roommates had been, but would not actually live with John. Thus a "neighbor" was sought. Again, an existing staff member within the agency applied for the position and was chosen, not only by the director but by, of course, John. Inspired as the idea was to actually listen to John and heed his preferences, it did not immediately result in "blissful community living." In his new apartment, John had no one to share his expenses so his budget was very tight. Every available resource for supplementing his monthly food allotment or utilities bill was tapped. It became more important than ever to help John be successful at work, but John was not quick to see the connection between going to work every day and the size of his weekly paycheck. The connection between that paycheck and the quality of his life was an even more abstract concept for him to grasp.

He only became angry or frustrated that he couldn't go to the movies or do other

# Stories of People's Lives

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things that clearly were not in the budget. Mom's cooperation in allowing John to endure the natural financial consequences of choosing a daily dip in the pool with his neighbors who worked the night shift over his own day job was critical.

This once "Mother of all mothers" became a partner in John's life and an ally to those who had won or earned her trust. Alas, all was not peachy and this was not to be as long-lived as every one hoped. Eventually, John's employer - one in a long line of employers demonstrated his belief in natural consequences too. At home, repeated complaints of disturbances such as door slamming, loud music, threats or even "indecent behavior" lead to yet another eviction. The second "neighbor" and the next complex - a very small intimate one, appear to have held some answers or solutions. For over two years, John has lived upstairs above Kathy, her husband and two small children. Though he was a little jealous of Travis, the baby, at first, John has never threatened the children. His "regular" neighbors know him and when necessary, are direct with their requests for John to "turn down the music, or close doors softly." He is working and seems to like his job, averages fewer than one to two monthly absences and likes his job coach. Two years ago, visitors to John's place noted that every appliance, gadget or electronics device was broken - the result of anger or just curiosity. Today John's personal belongings are working - a reflection of his pride of ownership. Kathy shares the responsibility of supporting John with others and seeks ways for him to participate in his community and neighborhood. They are friends and friends don't always get along perfectly. John hasn't abandoned his entire repertoire of odd behaviors, but he has added some new responses. He has learned that friends are there for one another and so when he and Kathy sat together on a panel at a recent conference and he listened to Kathy tell an emotional story which caused her voice to crack and waver just a bit, he reached over, not for his headset, but for her hand and, like any friend, he patted it reassuringly. At that moment everyone present who had shared in the roller coaster of John's life over the previous three years felt an utter sense of awe. Though many of them had often felt that their work was about stopping leaks in the dam or putting out persistent little brush fires, they came to witness the fruits of their listening and their acceptance. John was growing and changing and

# Stories of People's Lives

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caring. He had something to give a friend - it was called support.

It has been over four years since John's trip to the developmental center was averted by his mom and some naive do-gooders. None of them would ever deny that John has presented them with enough challenges to fill a book or that he has a gift for teaching difficult lessons. He has taught us that real change happens slowly and happens from the inside out. He taught us what it means to be real; sometimes that lesson first learned as children through the eyes of a sawdust-stuffed rabbit fades with our maturity and sophistication. Most assuredly John taught us about perseverance. He persevered for 25 years to get people to hear what he wanted and needed. He continues to persevere when we fail to listen actively. He has taught us what it means to stand with people - to persevere - over time.

# Stories of People's Lives

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## Thelma's Story

by Sharon Fallis, *Training Toward Self-Reliance*, Sacramento, CA

I met Thelma almost four years ago. She started receiving services from TTSR about one year before that to help her to find an apartment and live independently in the community. Thelma is 29 years old and grew up in a foster home after being relinquished by her mother at the age of four. Thelma has a seizure disorder and has been on dilantin or phenobarbital for most of her life. She has tried living with several different people as roommates but she usually ends up being exploited financially or physically and has lived alone in her apartment for about one year. Thelma is for the most part a very independent young woman. She likes to handle everything herself and requests help from us when she runs into problems. Thelma has limited reading and writing skills and uses our agency for support with her mail, handling her finances, and any paperwork which comes her way. Thelma lives on \$620 each month from SSI and receives a housing subsidy through Section 8. Thelma uses food 'closets' occasionally to get her through the month.

Thelma has many acquaintances in the community and she'll talk your ear off if you let her. But not many "friends" with whom she has lasting relationships and that do not lead to exploitation or unhappiness. She has a boyfriend, Thomas, who she has known for the last two years. They have tried living together, but it didn't work due to Thomas's drinking and going through money as if it were water. Thelma decided it would be best if they continued seeing one another, but not in the same apartment. Thelma continues to speak of her foster family as her own, but they have proven to be less supportive over the years. Her foster family has had many children live with them and Thelma has often referred to them as only taking in kids for the money.

Thelma has a supported employment agency she is currently working with and they have found her a new job downtown. She washes dishes for a cafeteria in a state building and seems to be thrilled that she is able to go back to work. The employer and other employees think Thelma is great. She does her job well and enjoys the people she is now working with.

# Stories of People's Lives

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Over the last six months, Thelma has been dealing with a life threatening situation which has caused her to be admitted for two back to back brain surgeries and many days of tests such as MRIs and blood work ups. She was originally told that she had brain cancer.

After the surgeries, she was being set up for radiation therapy since they were unable to remove the whole tumor. Two days before radiation of her brain was to begin, the Mayo Clinic called to disqualify the original diagnosis of cancer and instead gave her results which concluded that she has an untreatable brain tumor. Thelma has recently started getting her "symptoms" again. They include blurred vision, massive headaches to the point of vomiting and seizures. To date, these problems have been manageable and TTSR helps Thelma to keep a log of her symptoms for the doctor. Thomas tried to be there for her during this time, and was, but it was difficult for him to "keep it together." Her foster family showed up the day of her first surgery and held her hand. From then on the family was unavailable and ambivalent, in fact, they had made other plans during her second surgery. This period of time reinforced for me the importance of everyone having someone they can call friend when they truly are in need. Thelma and I spoke a lot of her dreams and nightmares. She wants someone to love her and stay with her forever and she's afraid of dying. We wrote out her will and she talked about what she felt the world would be like without her. Her past and current regional center casemanagers were the only other people who gave her encouragement and support through phone calls and visits afterwards.

Thelma came to TTSR in need of support and instruction on how to live independently in the community. It goes far beyond that. There are people who truly have no natural supports yet may know lots of people. Our agency tries to assist people in finding out who their "natural supports" are. We are not a counseling agency and do not claim to be "paid" friends. However, we often find ourselves overstepping the professional boundaries of our work. It is one of those human service grey areas that often times leads to burn-out and unreal expectations, but for me and

# Stories of People's Lives

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Thelma its friendship and regardless if I continue my work with TTSR or not, it will always be.



# Stories of People's Lives

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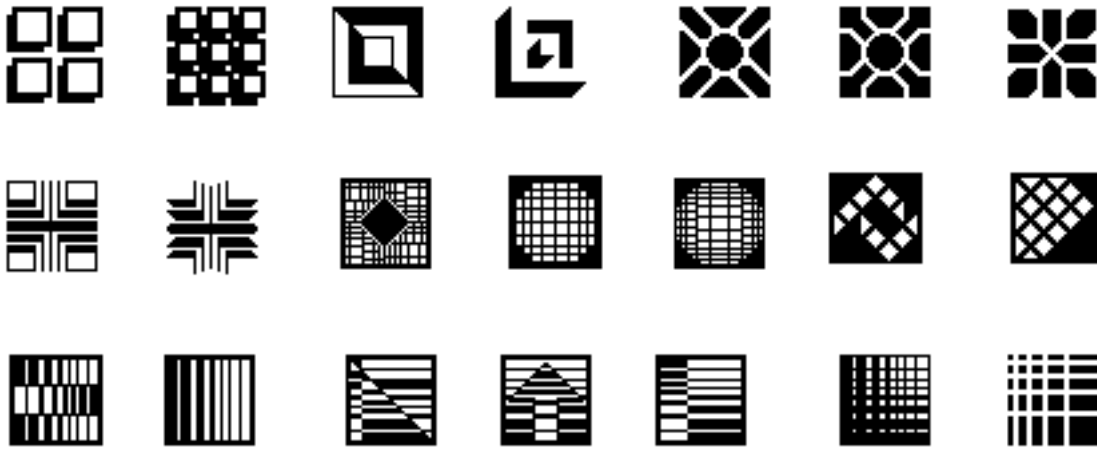


## Reflections

### Write Your Own Story

Here's a chance to write a story about someone that you support. If you're not working with anyone right now, write a story about your own life the past several months. Write about what has gone well and what could be better; about something that has created confusion or has challenged your usual way of doing things; about the support you get from friends and family; or, about how you've been involved in your community.





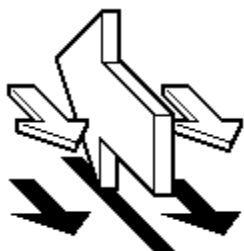
*Patterns of Supported Living*

# Other Resources



# Other Resources

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## Directory

### Introduction

In this section, we've tried to list some printed material and video tapes that helped us develop this guide and that we think will interest you as well. Each listing includes a brief explanation, how to get it and the price if we know it. You will find many other resources as well in the Reference section. So that we don't duplicate our efforts, materials you find in this section are not in the *Reference* section and vice versa. ***Other Resources*** includes:

	<b>Page</b>
<i>Americans with Disabilities Act</i>	OR 5
<i>Community Building, Relationships, Natural Supports, and Supported Living</i>	OR 5
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<i>Supported Parenting</i>	OR 12
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# Other Resources

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## Americans with Disabilities Act

People with Disabilities Explain It All For You: Your Guide to the Public Accommodations Requirements of the Americans with Disabilities Act

Developed by advocates for people with disabilities, this guide was edited by Mary Johnson & the Editors of The Disability Rag, The Avocado Press, P.O. Box 145, Louisville, Kentucky, 40201.

## Community Building, Relationships, Natural Supports, and Supported Living

Regenerating Community  
Why Servanthood is Bad  
Do No Harm  
Professionalized Service and  
Disabling Help  
On Good Works and Good  
Work

Beyond Community Services  
All of the above are by John McKnight who has written several publications which help us understand regular community life and the role professionals have had in separating people with disabilities from the community. To order his articles contact: Audrey Chambers, Publications Department, Center for Urban Affairs and Policy Research, Northwestern University, 2040 Sheridan Road, Evanston, IL 60208-4100, (708) 491-3395.

## Community Building in Logan Square

This report describes how one Chicago neighborhood, its people and their neighborhood organization, grew more powerful. They called the empowerment process "community building" because it mobilized the underdeveloped capacities and gifts of local people. This unique community effort identified local residents who were isolated and uninvolved. Based upon the special talents and gifts of these residents, they were introduced to local community groups. They shared their talents, became active in the community, and added new strength to the community's life. By Mary O'Connell (1988) Northwestern University, Community Life Project, 2040 Sheridan Road, Evanston, IL 60208-4100, (708) 491-3395. \$4.00

## Getting Connected: How to Find Out About Groups and Organizations in Your Neighborhoods

"This book is a guide to finding out about the organizations and groups people belong to in a city neighborhood. It was produced as part of the Community Life Project, which attempts to bring disabled people – often isolated in a world of social services and institutions – into the everyday life of their communities." Written by Mary O'Connell (1988) at the above address. \$3.00

## Gift of Hospitality

"This book suggests how we can break down some of the barriers to community, barriers created by fear or misunderstanding or those who are different. From the experiences of

# Other Resources

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committed people who have broken down social walls come the success stories of people with disabilities: a woman who started a national community life movement; a man who captivated a nightclub audience with his spontaneous singing; a young woman whose affinity for children gives her a special role in a daycare center; a tiny nonverbal woman who found community in a local diner where friends discovered that she loves washing dishes..." by Mary O'Connell (1988) at the address for Northwestern University on the previous page. \$4.00

*The following 8 publications are available from Communitas, P.O. Box 374, Manchester, CT 06040 (203) 645-6976:*

## What We are Learning About Bridge-Building

A summary of a dialogue between people seeking to build community for people with disabilities. By Beth Mount, Pat Beeman, and George Ducharme (1988).

## 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).

## Person-Centered Development A Journey in Learning to Listen To People With Disabilities

by Beth Mount, Pat Beeman, George Ducharme (1991).

## One Candle Power

### Building Bridges into Community Life for People with Disabilities

by Pat Beeman, George Ducharme, and Beth Mount (1989)

## Dare to Dream

### An Analysis of the Conditions Leading to Personal Change for People with Disabilities

by Beth Mount (1991)

## Imperfect Change

### Embracing the Tensions of Person-Centered Work

by Beth Mount (1990)

## The Whole Community Catalogue

Welcoming people with disabilities into the heart of community life. Shares new visions of people with disabilities, of the community, of ourselves, and of our collective responsibilities toward one another. It is a sourcebook of tools and ideas from the pioneers in the movement towards full community participation. Edited by David Wetherow. \$15.00

## The Communitas Communicator

Published four times a year, a collection of stories and thoughts about people with disabilities being included in community life.

## Remembering the Soul of Our Work

This book presents 150 stories written by staff who support people with disabilities living in their own homes. These stories have to do with the human side of supporting people in the community: the joys and frustration, the victories and the dilemmas. Edited by John O'Brien and Connie Lyle O'Brien, published by Options in



# Other Resources

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Community Living, 22 North Second Street, Madison, WI 53704, (608) 249-1585. \$15.00

## Unequal Justice? What Can Happen When Persons with Retardation or Other Developmental Disabilities Encounter the Criminal Justice System

"A man with an I.Q. of 49, who had confessed to a murder in Georgia, sat on the witness stand. "Jerome, did you assassinate President Lincoln?" "Yes," Jerome said. "Did you assassinate President Kennedy?" "Yes," Jerome said. Incidents like this demonstrate that people with retardation or similar disabilities – whether they are guilty or innocent of the crimes they are accused of committing – often can be shockingly defenseless when caught in America's criminal justice system. *Unequal Justice?* helps readers address the critical question: Did the system treat this person with disabilities as other citizens are treated when charged with a crime? By Robert Perske (1991). Abingdon Press, 201 8th Ave., Nashville, TN 37202

## TMI Supported Living Resource Book

Developed and printed by Toward Maximum Independence, this book has all kinds of ideas, forms, and materials that TMI uses as they help people achieve their dreams about where they want to live, work and socialize. It is written as a manual for TMI staff. The TMI resource book was given to me with reluctance. The staff "... at TMI are concerned that replication of "supported living" will lead to the development of "models" or "programs" which are contrary to the

essence of providing supports and services on a personalized basis...." We hope the resource book will be just that, one really great resource. Toward Maximum Independence, 9370 Sky Park Ct., Ste. 250, San Diego, CA 92123 (619) 467-0600. \$25.00

## Training Toward Self-Reliance: Attendant Management Course

A twenty two session course to help people with developmental disabilities determine the range of personal assistance services they require from an attendant and how to perform as effective employers. The course is taught by Training Toward Self-Reliance, Sacramento, CA, through a local community college. The course manual is an excellent resource when working individually with people or in a class room environment. Training Toward Self-Reliance, Inc., 2755 Cottage Way, #15, Sacramento, CA 95825.

## Personal Community Support Association of Alberta: Building Community through Personal Inclusion, Participation and Membership

This association's purpose is "to facilitate and encourage community involvement and support by creating opportunities for individual adults who live with a disability to participate in community life as full citizens". A Personal community worker facilitates the connection of an excluded person with community life. The Personal Community Support Association of Alberta publishes a newsletter, NEWS, which includes stories, ideas, and questions about people with disabilities

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being included in community life. To receive the newsletter and find out what they are learning contact: Cathie Duchesne, Executive Director, Personal Community Support Association of Alberta, 11728 Kingsway Avenue, Edmonton, Alberta T5G 0X5, (403) 453-5210.

### Crossing the River: Creating A Conceptual Revolution in Community and Disability

The author points out the promise, potential, and limits of what he refers to as the conceptual revolution. The conceptual revolution has to do with rediscovering the importance for all people of being and feeling embedded in a web of personal relationships. By David B. Schwartz (1992), published by Brookline Press, order from: Citizen Advocacy Forum, P.O. Box 86, Beaver, PA 15009

### Life in the Community, Volume I Housing, Support and Community, Choices and Strategies for Adults with Disabilities, Volume II

These two volumes are a part of the *Community Participation Series*. Volume I presents case studies of organizations supporting people with disabilities. Volume I was edited by Steven J. Taylor, Ph.D., Robert Bogdan, Ph.D., and Julie Ann Racino, M.A. in 1991). Volume II "presents current strategies and unique ways of thinking about supporting people to live in their own homes and participate in community life. Divided into three resource sections, this forward-looking book lets you explore supportive living efforts on the local, state, and federal levels...discover the powerful personal

perspectives of people involved in different aspects of housing and support...and examine case studies of organizations following new principles of assisting people with disabilities in community life....Revealing discussions give you insights on dealing with the many aspects of housing options... inclusion and integration...staff roles and support relationships...mutual problem solving...personal futures planning...choices and decision making...and other factors involved in an agency's efforts at change." Edited by Julie Ann Racino, M.A., Pamela Walker, M.A., Susan O'Connor, M.S., and Steven J. Taylor, Ph.D.,(1993), Paul H. Brookes Publishing Co.

The Center on Human Policy makes the following reports (as well as many others) available at cost:

### More Than Just a New Address: Images of Organization for Supported Living Agencies

This publication discusses the changes agencies must make in moving to a "supported living" approach to community living, and is based on in-depth work with a number of agencies and individuals across the United States. By John O'Brien and Connie Lyle O'Brien (1991). \$3.10

### Down Stairs That are Never Your Own: Supporting People with Developmental Disabilities in Their Own Homes

This paper discusses the historical and current meaning and dimensions of "house" and "home" for people with

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developmental disabilities. By John O'Brien (1991). \$2.00

## What Can We Count On To Make and Keep People Safe?

Shares a variety of perspectives on creating effective safeguards for people with developmental disabilities, including an analysis for increasing people's safety, and options for action. Edited by John O'Brien, Connie Lyle O'Brien and David Schwartz (1990). \$2.95

## What's Worth Working For? Leadership for Better Quality Human Services

Looks at leadership practices that contribute to organizational capacity to support people, build alliances, and incorporate skilled assistance into ordinary settings. By John O'Brien (1989). \$2.45

## Members of Each Other – Perspectives on Social Support for People with Severe Disabilities

Thoughtful discussion on how community life is made better from the inclusion of people with disabilities. "Civic life depends on citizens' willingness to recognize and support one another's membership despite apparent differences. All people will live better lives when the knowledge that we are all members of each other shapes everyday life and collective decision. By John O'Brien and Connie Lyle O'Brien (1991).

## Principles of Whistleblowing

Contains a list of suggestions for "whistleblowers," staff and others who want to call public attention to rights

violations at service agencies. By Douglas Biklen and Milton Baker (1979). \$2.10

The above publications can be ordered through: Center on Human Policy, Syracuse University, 200 Huntington Hall, 2nd Floor, Syracuse, NY 13244-2340, (315) 443-3851.

## It's About Learning

This is an excellent book about teaching, learning, listening, and community. It is based on a concept they refer to as student centered learning. This "...approach involves starting with the person who wants to learn, not a predetermined curriculum – who is the person, what is he or she interested in, what does he or she want to be able to do, where do we start?" It's about much more than teaching and learning. It is about relationships, listening, and community and celebration. By Marsha Forest with Bruce Kappel (1988), available from Frontier College Press, 35 Jackes Avenue, Toronto, Ontario, M4T 1E2

## A Video....And Then Came John

A colorful portrait of the triumphant life story of John McGough from his birth with Down Syndrome thirty years ago – through societal rejection and prejudice in urban America – to his rebirth as an artist, musician and much loved personality in the warm and accepting cocoon of a small community on the Northern California coast. Telesis Productions, P.O. Box 948, Mendocino, CA 95460, (707)937-3048

# Other Resources

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## Supporting People with Severe Reputations in the Community

A handbook presenting a variety of tools to develop better community capacity to support people with severe reputations (behavior challenges). The handbook is divided into three components: How to plan with the individual for community services; How to recruit and develop the supports needed to implement the plan; and how to sustain flexible and responsive on-going supports. By Michael W. Smull and Susan Burke Harrison, (1991). Community Support & Access Unit, Department of Pediatrics, UMAB, 630 W. Fayette Street, Baltimore, Maryland 21201, (410) 328-2140

## Get Me the Hell Out of Here. Supporting People with Disabilities to Live in Their Own Homes

This paper tells the story of an agency which converts their services from the traditional residential service models and institutional settings to providing supported living with people living in their own homes. It is the story of the agency's transformation through the lives of three woman they support. It provides a helpful reflection on the struggles and what was learned along the way. A chapter by Jay Klein in *Natural Supports in School* by J. Nisbet, Brookes Publishing, 1992.

## Tao of Leadership – Leadership Strategies for a New Age

"John Heider's The Tao Of Leadership provides the simplest and clearest advice on how to be the very best kind of leader: be faithful, trust the process, pay attention, and inspire other persons to become their own leaders." (Quote

from Assemblyman John Vasconcellos) By John Heider (1985), Bantam Books Publishing.

## Truth or Dare – Encounters with Power, Authority, and Mystery

This book provides an indepth examination of the nature of power. Starhawk distinguishes three types of power: "power-over," referring to domination and control; "power-from-within," meaning personal ability and spiritual integrity; and "power-with," pertaining to social power or influence among equals. This book is helpful reading for any individual or group struggling with power. By Starhawk (1987), Harper & Row, Publishers

## Sexual Abuse Prevention and Sexuality Education

The Wisconsin Council on Developmental Disabilities offers the following four publications for under \$3.00 each. We haven't reviewed these materials but judging from the other work published by the Council which we have reviewed these are probably really great resources.

Doubly Silenced: Sexuality, Sexual Abuse and People with Developmental Disabilities  
by Patricia Miles Patterson, MSSW

Stars: Skills Training for Assertiveness, Relationship-Building and Sexual

# Other Resources

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## Awareness

by Susan Heighway, Susan Kidd  
Webster & Marsha Shaw

## At Greater Risk: Legal Issue in Sexual Abuse of Adults with Developmental Disabilities

by Roy Froemming and Joyce Feustel

## Sexual Abuse of Adults with Developmental Disabilities: Legal Issues and Proposals for Change

by Roy Froemming

You get obtain the above four  
publications from:

## Wisconsin Council on Developmental Disabilities

P.O. Box 7851

Madison, WI 53707-7851

(608) 266-7826

## Supported Employment

### Getting Employed, Staying Employed: Job Development for Persons with Severe Handicaps

This is considered a classic text on supported employment. A number of strategies for job development can be adapted to the work of supported employment service providers. Edited by C.S. McLoughlin, J.B. Garner and M.J. Callahan, Paul H. Brookes Publishing, P.O. Box 10624, Baltimore, Maryland 21285-0624, (800) 638-3775.

## Supported Parenting

### NCAST, Nursing Child Assessment Satellite Training

by Georgina Sumner, RN, MS  
Director

University of Washington

CDMRC, WJ-10

Seattle, WA 98195

(206) 543-8528

A non-profit organization in the School of Nursing at the University of Washington. For the past fifteen years, NCAST has been developing training programs for professionals (nurses, physicians, psychologists, social workers, therapists, educators, researchers) working with young children. These training programs are nationally and internationally known for their effectiveness in preventing and/or ameliorating problems in families with young children. Some of the supported living agencies which provide support to parents with developmental disabilities have found their training and evaluation tool on parent/child interaction to be helpful. They are using the materials as a tool to help mothers and fathers identify the subtle interactions and cues between them and their infant which effect the bonding process and the child's developmental growth.

# Other Resources

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## Teaching Parenting:

### A Curriculum for Parents with Special Learning Needs

This curriculum is a good resource for supported living agencies providing support to parents with developmental disabilities. Lesson plans are divided into four broad teaching areas: health and safety, nutrition, child development, and parent-child interaction. The curriculum was developed by people working in a supported living agency. It is designed to be used in a class setting but would be a helpful reference for instruction in a person's home as well. Written by Rebecca Herbers and Kathy Ramirez (1990) and published by Becoming Independent, Inc. Family Life Support, 6555 Hunter Drive #7, Rohnert Park, CA 94928, (707) 584-1655.

The Wisconsin Council on Developmental Disabilities offers several highly recommended publications including the following:

### Helping Parents Parent: A Practice Guide for Supporting Families Headed by Parents with Cognitive Limitations

This is a small (71 pgs.) easy to read and follow manual. It begins with a respectful discussion on the challenges of parents with developmental disabilities. "The overall goal in supporting families is to promote safe and healthy child development, as well as to enhance the parent's level of self-esteem and level of independence." Part Two offers good information on getting to know the

family, recognizing that this is an ongoing comprehensive process and not something that happens with a standardized assessment. Part Three provides information on: using intuitive knowledge for helping, the critical elements of intervention, and suggestions for establishing priorities for helping and implementing a plan with the family. Part Four identifies common barriers for families obtaining health care services as well as effective interventions in the areas of: health, injury prevention, nutrition, and stimulation of development. Part Five provided information on the responsibility for protecting children from abuse and neglect. By Susan Heighway (1992). \$3.00

### Cultivating Competence

A national resource directory presenting brief program descriptions of 31 models of Supported Parenting in 15 states. By Dolores Ullmer, Susan Kidd Webster & Mark McManus (1991) \$3.00

### Discovering the Parent's Language of Learning

Describes an approach that can increase the effectiveness of the teaching that is involved in support offered to parents with developmental disabilities. By Mark Sweet, PhD (1990) \$2.00

### Facing the Challenge

This guide is written for human service workers, family members, and guardians assisting families headed by parents with disabilities. This guide presents an overview of the law and the workings of the court. Vignettes

# Other Resources

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illustrate how laws intended to protect children from neglect or abuse are applied when children's parents have disabilities. By John Franz (1990) \$3.00

**Building the Foundation: Public Policy Issues in Supported Parenting**  
This series of issue papers addresses the obstacles of the current service system, describes innovative options in designing and funding communication and coordination among agencies. Guiding principles for supporting families headed by parents with disabilities are proposed. By Howard Mandeville and Dolores Ullmer (1992) \$3.00

The publications above may be ordered from:

Wisconsin Council on Developmental Disabilities  
P.O. Box 7851  
Madison, WI 53707-7851  
(608) 266-7826

**Child Abuse Prevention Handbook**  
The purpose of the Handbook is to heighten public awareness and understanding of child abuse. It also serves as a practical aid for those who work with children, those who are in the field of child abuse prevention, and those who are mandated to report under the California Child Abuse Reporting Law. Ordered from the Crime Prevention Center, Office of the Attorney General, P.O. Box 944255, Sacramento, CA 94244-2550

## For Children's Sake – The Promise of Family Preservation

This book provides a good introduction to family preservation programs and their values and methods for providing support to families. The values for family preservation are similar to the values of supported living services. By Joan Barthel (1991), for copies write to the Office of Communications, the Edna McConnell Clark Foundation, 250 Park Avenue, New York, NY 10177-0026. Enclose a self-addressed label.

## Supporting Diversity

### Fiesta Educativa

This organization was founded in 1978 to educate and assist Latino families in obtaining services and in caring for family members with special needs. Fiesta Educativa is one of the few organizations in the entire state of California that is dedicated to empowering Latino families of persons with special needs through education, training, referral and information. For more information, please call or write: Fiesta Educativa, Inc., 3839 Selig Place, Los Angeles, CA 90031, (213) 221-6696.

# Other Resources

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The Hesperian Foundation  
P.O. Box 1692  
Palo Alto, CA 94302

This organization has published a number of very useful materials on disabilities, and ways to supporting individuals and families around the world. Illustrative of this tradition is David Werner, *Disabled Village Children* (Palo Alto: Hesperian, 1987).

## Social Security

A Summary Guide to Social Security and Supplemental Security Income Work Incentives for the Disabled and Blind

Call your local Social Security office and request a copy "The Red Book." The full title of the publication is (Be sure the publication was printed in July 1987 or later.) There are many other publications which may be helpful as well.

Social Security Work Incentive Training Manual

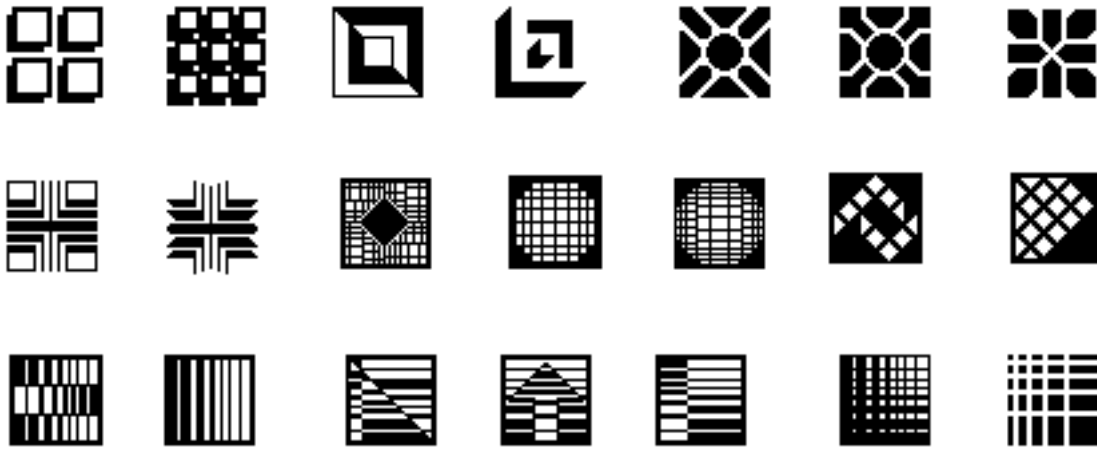
A how-to guide to Plans for Achieving Self-Support (PASS) and Impairment Related Work Expenses (IRWE). You can obtain a copy of at low or no cost by calling or writing Margaret Lamb, Department of Rehabilitation, 830 K Street, Sacramento, CA 95814, (916) 323-0319.



# Other Resources

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*Patterns of Supported Living*

Words &  
Terms



# Words and Terms

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## Accessible housing

Housing which meets accessibility standards.

## Adaptable housing

Housing which is generally barrier-free, and physically accessible, but not adhering completely to accessible standards. The appearance is more typical of traditional housing, as a result, and often attractive for people with (or without) physical limitations. To illustrate, 32" interior doors and typical of most homes; 36" may be the accessible standard; and the adaptable standard may be 34", a compromise.

## Area Board

Created by the Lanterman Developmental Disabilities Services Act to monitor the protection of legal, civil and service rights of persons with developmental disabilities. There are 13 local area boards across the state and their responsibilities include: individual advocacy; distributing information on disabilities; and reviewing the policies and practices of publicly funded agencies. If you don't already have the number, you can find it in the phone book (usually in the front of the *White Pages*) under —

**State Government Offices  
California State Of  
Developmental Disabilities**

## Break Even Point

A Social Security term which indicates the level at which the SSI recipient is earning enough money so that he or she is no longer eligible to receive any 1619(a) payments. The break even point is determined by formula based on an individual's current SSI payment, amount of unearned income and earned wages.

## California Department of Developmental Services (DDS)

Provides policy, regulation and funding for regional center services and state developmental centers.

## California Department of Rehabilitation (DR) - Vocational Rehabilitation

VR counselors refer persons to Supported Employment services and help plan and fund job training and support services. If you don't already have the number, you can find it in the phone book (usually in the front of the *White Pages*) under —

**State Government Offices  
California State Of  
Rehabilitation Department**

# Words and Terms

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## California Department of Rehabilitation (DR) - Habilitation Services Section

Habilitation counselors work with persons who use regional center services and help plan and fund follow-along support as well as Work Activity Centers.

## Circle of Support

A committed group of community members who spend time with a fellow community member with a disability to share common experiences and support each other in establishing relationships.

## Co-housing

A concept, built on experience in Scandinavian countries, whereby people work together toward creation of a development involving private space for individuals (and families), such as a small house or apartment, complete with kitchen and other facilities, combined with common (or communal) space with a variety of purposes: dining with the larger group; child-care; reading rooms/libraries; physical fitness; overnight guests; etc. The group works toward a design sensitive to the agreed-upon needs of the group.

## Community College/Adult Education Instructors

Employed by a component of a local school district to provide support or assistance in job seeking skills, e.g. interviewing, resume writing.

## Community Development Block Grant (CDBG)

A major federal program, administered through HUD, involving grants for a variety of housing and community development activities, including a limited amount for public services (e.g., battered women's shelter and services), with an emphasis on neighborhoods and people with low to moderate incomes.

## Community Mental Health Clinics

Under the Short-Doyle Act, counties are responsible for providing mental health services to local residents with state funding. At present, there are 58 county and 2 city community mental health clinics. The California Mental Health Plan (88-89) states that a "balanced mental health system must include services to enhance mental health and help prevent the need for treatment of mental illness." In terms of supported employment, mental health workers can assist persons with chronic mental illness in a number of ways, e.g. therapeutic services, development of community support networks, identification of appropriate referrals. If you don't already have the number, you can usually find it in the phone book (usually in the front of the *White Pages*) under —

# Words and Terms

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## **County Government Offices or City Government Offices Mental Health Services**

### **Community Reinvestment Act**

This federal law, 1977, encourages banks to respond to the lending needs of communities from which savings are drawn. In fulfilling the mandate, banks often seek to work closely with community groups (especially private, non-profit agencies) around housing and community development efforts. Assistance can take several forms: relaxed standards in judging credit worthiness; a different type of loan (e.g., loan-to-value ratio, fixed or variable, duration); technical assistance; or a slight reduction in the interest rate.

### **Community Supported Living Arrangements (CSLA)**

#### **What is CSLA (Community Supported Living Arrangements)?**

CSLA is a new set of flexible supports and services designed to assist adults with developmental disabilities to live in their own homes with on-going support as needed. At this juncture, CSLA is a four-year federal and state demonstration project, through October, 1995, involving eight States, including California.

#### **How does it differ from Independent Living Programs?**

It differs from most ILS (Independent Living Skills) program services in at least three ways. First, while paid

support may fade over time (as the person learns to live with less paid support), services need not be time-limited. Second, for people who want (and need) personal assistance, adaptive devices or assistive technology, or help in establishing and maintaining relationships and community connections, CSLA can respond to such needs. In other words, habilitation or training is not the only service available through a CSLA agency. Third, while motivation to live independently may be a key factor in accessing CSLA services, a person who requires a lot of support can be considered. Whether a person is “ready for independent living” is no longer a determinant of who will be served.

#### **What services can be provided by a CSLA agency?**

CSLA services can be used, upon successful application and selection, by an individual, two people living together, or as many as three adults sharing the same household.

The array and sequence of services is expressed in an ISP (Individual Support Plan), which is to reflect the hopes, dreams, and needs of the person served, ideally with input from the person’s CPC (Client Program Coordinator), involved family and friends, and a personal advocate.

A CSF (Community Support Facilitator) helps the person plan services, assists in brokering such services as Section 8 housing subsidies or IHSS (In-Home Support Services). Beyond such facilitation, the CSF will typically play some coordination role,

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and may provide habilitation and training services.

Over and above whatever generic services can be accessed, CSLA may be used to provide (or help pay for)

- personal assistance;
- habilitation and training;
- 24-hour emergency assistance;
- support services to aid community integration; and,
- assistive technology and adaptive equipment.

## **What services can CSLA not pay for?**

CSLA cannot be used to cover (1) housing costs (e.g., rent, utilities, cost of vacancies, etc.); (2) vocational services, such as day training or employment services, (3) adult or postsecondary education; or (4) Medi-Cal services funded through use of 'sticky labels.'

## **Who is to be served?**

A person must be federally-eligible for Medi-Cal and motivated to live in their own home. Motivation has no single, limited meaning. A person who has very limited verbal skills may be 'motivated' if by actions or the existence of an extensive support network, supported independent living is seen as what the person wants and needs.

California's application to the federal government identified three priority needs: (1) adults who use wheelchairs or need other assistance with ambulation, have good communication skills through some means, and live in

licensed settings; (2) adults in supported employment or other regular jobs, and live in licensed settings; and (3) adults who are parents whether their children also have developmental disabilities.

To provide each regional center with flexibility to respond to community needs, a fourth priority are adults who would benefit from CSLA services, as determined by each participating regional center with input from the community.

In the first year (1991-92), only adults in seven regional centers were scheduled to receive CSLA services: Alta, North Bay, East Bay, Tri-Counties, North Los Angeles, Westside, and San Diego. In subsequent years, other regional centers may be encouraged to participate. If the ILS program vendor category were used flexibly, there is nothing to prevent any regional center from providing the array of CSLA services right now.

## **Other features of interest:**

Each person served is expected to choose a Personal Advocate from among unpaid family and friends. If not, the area board will be asked to provide one. Circles of support are encouraged, and may be formal or informal, and if formal, organized by the person receiving services or someone else (e.g., a friend, personal advocate, personal team)

Each person served is expected to have a choice of CSLA agencies. Community Monitoring Teams, involving neighbors and others,



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organized through Area Board, have a responsibility to see that the person is getting needed and wanted services, and a decent quality of life.

## Developmental Disability

The State of California defines a developmental disability as a disability which originates before the age of 18, continues, or can be expected to continue, indefinitely, and constitutes a substantial disability for that individual.

## Earned Income

A Social Security term which refers to money a person earns by performing work.

## Employment Development Specialist/

### Job Developer

Staff of a Supported Employment service who complete all of the up-front work involved in finding a job.

## Employment Training Specialist/Job Coach

Staff of a Supported Employment service provide on-the-job training, ongoing assistance and follow-along support for persons with disabilities who are working in the community.

## Follow-Along/ Follow-up

After initial job training in supported employment is completed and someone is performing a job to the standards of the employer, follow-along/follow-up support services begin. Some Independent Living Programs refer to Follow-Along as the services people get when they have lived in their own homes for two years and continue to need ongoing support. It was a term used prior to the development of supportive living service.

## Group Placements

An employment option where a small group of persons with disabilities work in a community business alongside people who are not disabled with a supervisor who assists them.

## Habilitation Specialist

Department of Rehabilitation staff who provide and fund a plan for follow-along services for persons who are eligible for regional center services and are working .

## HCD

California Department of Housing and Community Development, a State agency with overall responsibility for State and local housing, including local housing elements, zoning and other regulations, preservation of the housing stock, expansion of housing to meet the needs of Californians. The agency can be reached at 916-444-9210.

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## Housing Development Corporation

A corporation which promotes, assists or sponsors housing for low and moderate income people. The housing is not "public," but "assisted," and can be for rental or home ownership. Predevelopment ("seed") money can come from foundations, corporations or banks, HUD, HCD, California Housing Finance Agency (CHFA), Community Development Block Grant (CDBG) funds, and the like.

## HUD

The U.S. Department of Housing and Urban Development, a cabinet-level agency responsible for a variety of housing programs.

## Impairment Related Work Expenses

Work expenses which can be deducted from earnings. If approved by Social Security, *IRWEs* may include: follow-along support services; job training; medical devices; certain attendant care services (to get ready, and to get to or from work); out of the ordinary transportation costs; work-related equipment; drugs and medical services; some home modifications; and, other expenses (e.g., cost of keeping a guide dog, expendable medical supplies). An *IRWE* helps reimburse someone 50% of the cost of these services.

## Independent Living Skill Instructor

Staff of an Independent Living Skill Center who provide services to persons

who require support and assistance in order to live in the community.

## Independent Living Skills (ILS) Training

A service category within the regional center system used to purchase individual (or group) training in independent living skills (e.g., money management, shopping and food preparation, paying bills, etc.).

## Individual Job Placement

The placement of one individual with a disability into a community job.

## In-Home Supportive Services

A program of non-medical attendant services, funded through a combination of Title XX, federal Social Services Block Grant funds, and State General funds, to enable individuals with disabilities to live safely in their own homes, where this would not be possible in the absence of such in-home support (attendant services). If you don't already have the number, you can usually find it in the phone book (usually in the front of the *White Pages*) under —

## County Government Offices Social Services Department InHome Support Services

## Job Development

The process of finding jobs in the community and consisting of job market surveys, employer contact, job analysis, etc.

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## Job Placement

The process of matching what the employer needs with what a person has to offer as a worker.

## Job Related Skills

Skills needed to obtain or maintain a job but not necessarily related to the performance of a specific job duty. Such skills may include learning to ride a bus to and from work, dressing for the job, appropriate break-time behavior or depositing a paycheck in the bank.

## Job Site Training/On-site

### Job Training

A component of supported employment services involving the direct instruction of job tasks and related skills by a job coach. This takes place on a worksite in the community.

## Medicaid/Medi-Care

Government-subsidized programs which provide assistance with health care expenses for eligible persons who are aged, blind, or disabled. If you don't already have the number, you can usually find it in the phone book (usually in the front of the *White Pages*) under —

### County Government Offices

### Social Services Department

### Medical Services

or

### United States Government Offices

### U.S. Government

### Health and Human Services

### Social Security Administration

## Mental Health Worker/Case Manager

Community mental health staff who assist in providing resources or ongoing support and advocacy for persons with mental health concerns.

## Natural Supports

Personal associations that everyone makes like family relationships, friendships with neighbors, other club members, fellow workers, community organizations.

## Plan to Achieve

### Self-Support (PASS)

A work incentive for SSI recipients. A plan, which must be approved by the Social Security Administration, is designed to achieve an approved vocational goal. Certain income and resources may be excluded from being counted against SSI cash payments if such income and resources (e.g., savings to buy a business) are needed to achieve an approved vocational goal.

## Regional Center

Regional Centers are non-profit, case management agencies which have contracts with the California State Department of Developmental Services. Twenty one centers assist persons with developmental disabilities in obtaining a variety of residential, day program and other needed services.

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If you don't already have the number, you can usually find it in your local phone book listed under —

## **Developmental Disabilities Regional Center**

## **Regional Center Case Manager/Client Program Coordinator/Counselor**

Regional Center staff who to assist or fund ongoing support and advocacy for persons with developmental disabilities. Case managers are responsible for coordinating the overall support service plan.

## **Section 8 Housing Subsidy**

A program, funded by HUD and administered by public housing authorities, to assist low- and very-low income families in obtaining decent, safe, and sanitary housing in private accommodations. Eligible tenants typically must pay 30% of adjusted gross income. The housing authority pays the difference between what the tenant must pay and the maximum approved rent for the area as determined by HUD. With a voucher, rather than a certificate, the tenant can pay more than the maximum approved rent, although the subsidy remains the same. If you don't already have the number, you can usually find it in the phone book (usually in the front of the *White Pages*) under —

## **County Government Offices or City Government Offices Housing Authority**

## **SSDI (Social Security Disability Insurance)**

A Social Security income support program administered to provide a minimum cash income for workers who are disabled and who have paid into Social Security through their own or their parent's payroll deduction. There are certain instances where a person with a disability may receive both SSDI and SSI, usually in the event the person is a dependent child of a person receiving SSDI payments.

## **SSI (Supplemental Security Income)**

SSI is a federal social security program that pays monthly cash payments to persons who are aged, disabled and blind who have limited income and assets. The aim of the program is to provide a minimum income for rent, food and clothing. The payment can vary according to formula. If you don't already have the number, you can usually find it in the phone book (usually in the front of the *White Pages*) under —

## **United States Government Offices U.S. Government Health and Human Services Social Security Administration**

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## Supplementary Security Income/State Supplemental Payment (SSI/SSP)

A program of income support for people who are blind or disabled, have little or no income or resources, and are unable to work or are working but earning less than a 'substantial gainful activity' level. In California, the State supplements the federal SSI payment.

development, placement and initial training and support for persons who need Supported Employment services.

## Work Incentives

There have been changes in the Federal law that provide incentives to people who receive SSI and SSDI and want to work. These incentives have removed some of the fears of losing essential cash and medical benefits.

## Sweat equity

An assisted housing project, in which individuals (and families) devote time to working on construction of their owner-occupied dwelling. By reducing out-of-pocket construction costs, the individual (or family) develops an ownership interest (equity) from their "sweat," or contribution to the work effort. If, upon completion, the dwelling has an appraised value of \$125,000, cost (ignoring labor contributed by the owner) \$100,000 to build, and has a \$100,000 mortgage, the individual (or family) would have \$25,000 in sweat equity.

## Transition Specialist

School district personnel who develop and implement a transition plan which facilitates the movement of a person with a disability from school-based to adult services.

## Vocational Rehabilitation Counselor

Department of Rehabilitation staff or a private insurance company staff who develop and fund the plan for job

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## Index of Key Concepts

As you have already noticed, each chapter in the catalogue is numbered separately using initials and numbers, like **VPD 13** for page 13 of the *Values, Philosophy and Definition* section. Here is a guide to those initials:

<b>VPD</b> Values, Philosophy and Definition	<b>S</b> Stories
<b>PS</b> Patterns of Service	<b>OR</b> Other Resources
<b>CR</b> Community Resources	<b>WT</b> Words and Terms
<b>CE</b> Community Employment	

The page numbers listed below are not an exhaustive listing, but will give you a good idea of where most of the major concepts in this catalogue can be found.

**Americans with Disabilities Act**, Cr 19, CR 23, CE 15-CE 17, OR 5

**Area Boards**, CR 23, CE 17, WT 3

**Behavioral challenges**, PS 122-PS 124

handbook on, CR 10

lifestyle planning for, PS 124

story of, PS 123

**Celebration**, S5-S6

story of, S6-S11

**Circle of Support**, PS 47

and celebration, S 5

definition of, WT 4

elements for maintaining, PS 52

Joshua Committee, PS 48

organizing tips, PS 49-PS 51

stories of, CR 5, CR 6

**Community**, PS 65-PS 90

acceptance, PS 80

and gifts, recognition, PS 78, PS 82, PS 83, PS 90

and supported living services, PS 67

books on, OR 5-OR 6

bridge-building, PS 70-PS 72, PS 74-PS 75

building, PS 69-PS 72

participation versus presence, PS 67-PS68, PS 73-PS74

stories of, PS 8, PS 72-PS 90

value of, 10, PS 65-PS 66

**Community Supported Living Arrangements (CSLA)**, PS 54, WT 5

**Conceptual revolution**, 9, 10

books on, OR 8

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- Continuum**, VPD 8, VPD 9, S 10
- County Departments of Social Services**, CR 15-CR 16
- Developmental model**, VPD 8, VPD 9
- Employment, Supported**, CE 1-CE 10, CE 23-CE-28
- access to, CE 24
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  - books on, OR 11
  - definition of, CE 23
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- Ethnic and Cultural Diversity**, PS 114-PS 118
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  - importance of understanding, 12
  - organizations about, CR 27, OR 14
- Home**, VPD 12, VPD 13, PS 35-PS 44
- and professional decisions, PS 37, PS 40
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  - subsidized and emergency, CR 7-CR 8, CR 31-CR 34, WT 10
- Independence, interdependence**, VPD 13, VPD 14, PS 95
- story of, S 9
- Independent living programs**, 11, VPD 18, VPD 19- VPD 21, PS 66-PS67, WT 5
- Individual Program Plan (IPP)**, VPD 11, PS 23
- In-Home Supportive Services (IHSS)**, PS 54, CR 8, CR 37-CR 40
- definition of, WT 9
  - problems with, PS 119
  - stories of, CR 5
- Institutions**, VPD 7, VPD 8
- Lanterman Act**, VPD 11, VPD 12
- Medical services**, CR 11-CR 14
- Parents with developmental disabilities**, PS 109-PS 118
- books on, OR 12-OR 14
  - professional relationship with, PS 113
  - risk factors, PS 109



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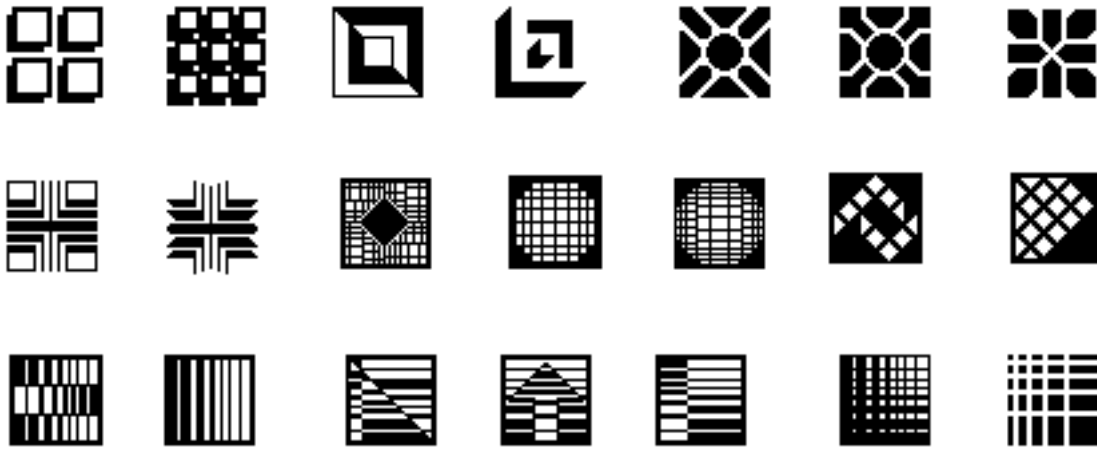
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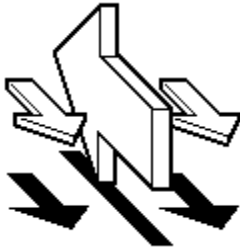
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# References



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In this section, we've listed references that we looked at in developing this guide. So that we don't duplicate our efforts, materials you find in this section are not in the *Other Resources* section and vice versa. **References** includes:

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Remember, you can ask your local library for assistance in accessing these reference materials.



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