

Supported Living Services Your SLS Training Tool Box



Part Two: Principles of Supported Living Services

Connections for Information and Resources
on Community Living (CIRCL)

April, 2001



Supported Living Services Training Tool Box

General Information for SLS Staff

Developed for

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

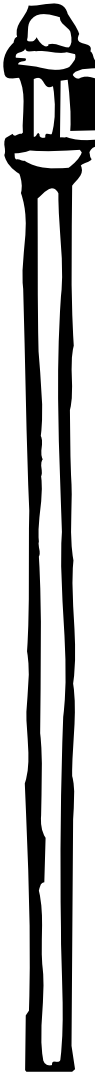


Introduction

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

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

In this section, you will find information on each of the five principles or outcomes of supported living services and resources for getting more information.



Principle Street

Supported Living Principles

Supported living services are based on a set of principles or expected outcomes that set the service apart from any other vendored service. These principles give direction to the mission, policies and practices of the agency.

1. A Home of One's Own

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

2. Choice and Self-Directed

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

3. Relationships

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

4. Community Membership

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

5. Flexible, Tailored Services and Supports

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

This figure was adapted from [Developing Supported Living Services: A Guide to Essentials for Service Agencies and Regional Centers](#); see References for complete citation at the end of Part Two.

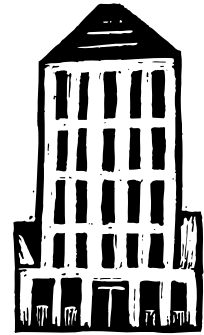


Principles of Supported Living

1. A Home of One's Own

Introduction

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



1. A Home of One's Own

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

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

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

This following 5 sections were adapted from [Developing Supported Living Services: A Guide to Essentials for Service Agencies and Regional Centers](#); see References for complete citation at the end of Part Two.



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

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

Wow, Do We Have a Place for You!

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

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



Individuals Control the Character and Appearance of their Home

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



Individuals Choose Who, if Anyone, They Live With

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

Individuals are Secure in Their Homes

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



Putting the Principles into Practice

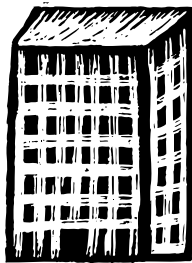
This manual is intended to be a “toolbox” to help you implement the principles of supported living services. Part Four includes some practical tools that you can use to help you do this.

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

A Home of One’s Own

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

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



See *Part Four: Tools and Applications* for a sample titled the **Housing Resource Checklist..**



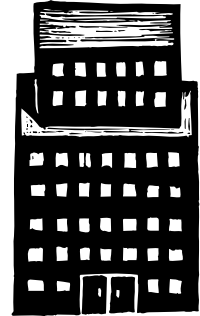
The individual should participate to the fullest extent possible in the search for a home. You will want to help them decide:

- Who will make the inquiry phone calls and talk to prospective landlords? Will they do this, will you or will someone else? If the individual is going to make the calls, how will you help them prepare to make these calls?
- How will they participate to the fullest extent in finding a home?
- How will they introduce themselves and you to a potential landlord?
- How much will they tell the landlord about the kinds of services they receive and about their disability?
- What else?

Individuals Control the Character and Appearance of their Home

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

- Find out about their hobbies and interests. Help them decorate around these themes.
- Support their decisions about who they invite into their home. You may need to help them make the plans and you may have to help with transportation.
- Support them to maintain their own routines and rituals (i.e., What is their morning routine, what do they want to do in the evenings?).
- Support them to maintain their home. You may want to help them develop a housekeeping checklist, and a maintenance checklist (with things like changing the air filters), You may also help them communicate their maintenance needs to their landlord if they rent.



For more about routines and rituals you may want to find out more about [Essential Lifestyle Planning](#).



Find out more about Section 8 and subsidized housing in *Part Two: Information Briefs*.



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

Individuals Choose Who, if Anyone, They Live With

- Does the individual want or need a housemate? Why?
- How would they afford to live by themselves if this is their choice?
- Do they have subsidized housing? If they need live in support can they get a two bedroom certificate?
- How do they get along with others when they live with someone else? What does it take for this to work well for them? For example: Do they need a lot of privacy? Do they like their home quiet or do they like a lot of activity? Do they need to have control over a lot of things in their home like where things are placed, the TV station, the lights being on or off, etc.
- What are the characteristics of people they like to spend time with and what kind of people don't they like.

Individuals are Secure in Their Homes

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



Things to Think About For Your Agency

- Does your agency keep a list of apartments that take subsidized housing?
- Does the agency have any kinds of tools or lists for evaluating apartments? For examples look in Part Four, Section 1 of this handbook.
- How does the agency help someone decide if they need a housemate?
- When does the agency support someone, when it is their preference and need to have a live-in paid housemate?
- How is live-in support arranged? For example, is there a standard contract for a paid roommate and how are the roommate's wages and benefits determined? How is each job description individualized?
- If your agency owns, or holds the lease to the places people live, how does the agency make sure that people experience the value of it being **their** home?
- What is the agency's relationship with landlords, the local house authority, and non-profit housing development corporations?



Summary

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



Building your Toolbox: A Home of One's Own For More Information/Resources

A Home Of Your Own Guide

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

Fannie Mae's HomeChoice

An affordable mortgage as well as information about other affordable mortgage products: **1-800-7-FANNIE (1-800-732-6643)**.

National Home of Your Own Alliance

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

How To Plans: Home Furnishings for Supported Living

Adult and Supported Living Services, State of California, Department of Developmental Services (1996), (916) 654-1956.

Renters Rights

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

Tenants Rights

By Attorneys Myron Moskovitz and Ralph Warner, Nolo Press, 1-800-846-9455.



2. Choice and Self-Direction

Introduction

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

2. Choice and Self-Direction

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

Individuals Make Their Own Everyday Choices

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



begin to discover what their preferences are. You will want to know what is important to them in the areas of:

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

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

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

Individuals Direct Their Services

Individuals who receive supported living services are at the center of planning the services and supports they receive. While their family and friends, their regional center case manager, and the SLS agency participate in the planning process, the individual who receives services has the loudest voice. When an individual is not able to communicate in

*Our quality
of life
everyday is
determined
by the
presence or
absence
of things that
are important
to us – our
choices, our
rituals.*

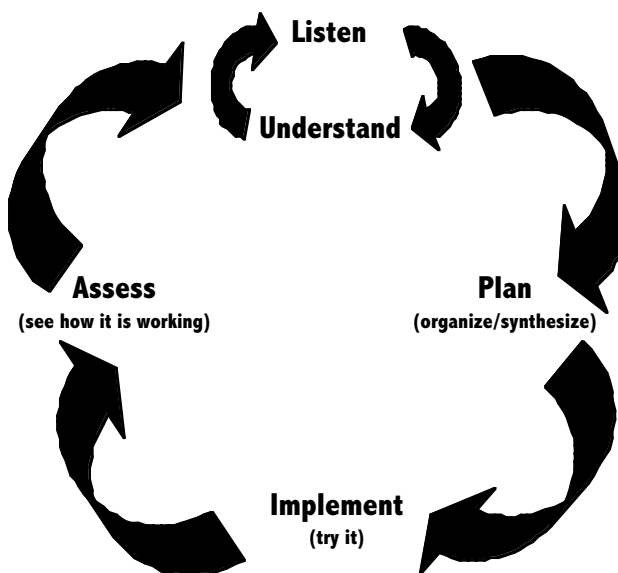
Michael Smull
1996



typical ways (i.e., they don't use words to talk) , the agency learns about his or her needs and desires by spending time with them observing their preferences and the things that work and don't work for them. The agency also listens to the people who know and care about the individual to find out how to support him or her.

First, the individual selects an agency (assuming they have decided to use an agency- they could choose to become vendored to manage their own services or their family could become vendored). Then the agency develops an Individualized Service Plan with the individual that reflects the services he or she wants and needs. The service plan describes what services (e.g., cooking, budgeting, hiring of personal assistants), will be provided, who will provide services (e.g., live in roommate, come in personal assistant, community support facilitator), when services will be provided (e.g., time of day, frequency), and how (e.g., instruction, facilitation, supervision) services will be provided. Just as the individual and their needs will be constantly changing the service plan will be continually changing to reflect the current needs and desires.

Person Centered Planning - Learning Wheel





Always remember that people's preferences, likes and dislikes will change over time as they have more experiences and learn and grow. Do not get discouraged if you help someone achieve a goal like moving in with a friend only to have them decide a few months later that they would rather live by themselves. We all make decisions, try things and then change our minds. Part of your job will be to help the individual with problem solving, decision making and learning about consequences. The same things we all struggle with throughout our lives.

Individuals Choose Who Provides Services to Them

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

- 1) A person centered planning and assessment process is used to get to know the individual being referred for services.
 - 2) The individual's preferences and needs drive the development of job descriptions and employment agreements.
 - 3) The individual is assisted to develop an interviewing and hiring process that works for them. When the individual is not able to participate in interviewing in regular ways (i.e., a sit down question and answer interview) the family or others who know and love the person may help with interviewing.
-
- 1) SLS agencies will usually have serious applicants spend some time with the individual who would receive their services. This is the best way for the service recipient to make an informed decision about whether or not they want the person to work with/for them. Also, the applicant has an opportunity to experience spending time with the individual so they can be sure they want the job.



People who are hired to provide supported living services understand that their employment with the person they are supporting is contingent on the person's continued desire to receive services from them.

Individuals and their families are regularly asked by the SLS agency and their regional center case manager how satisfied they are with their services and with the staff who work with them.

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

Everyone communicates through their behavior, especially people:

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

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

A Process for Supporting Individuals Who Make Risky Decisions

One of the serious challenges that supported living agencies face is supporting individuals who make decisions that jeopardize their health and safety (e.g., choosing to employ someone through IHSS who is negligent in providing the assistance the person needs). Supported living agencies struggle with the tension that can come from having two roles in people's lives. One role is to support and encourage the individual to make their own life choices. The other role is to support the person to live a healthy and safe lifestyle.



Supported living agencies work hard to have a partnership with the individual and a relationship based on mutual respect and trust. Then, they can feel comfortable having some influence over the individual if the individual is making risky decisions. They do not take control away from the person but they may offer increased direction and try a variety of strategies to support the person to stay healthy and safe. They recognize their obligation to try whatever they can to help people make fully informed decisions. It is not appropriate to shrug off responsibility with the justification that “people learn from their mistakes” because not everyone does. Nor is it appropriate to say that there is “dignity in risk taking”. There is no dignity in experiencing pain or tragedy.

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

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

With rights come responsibilities

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

Part Four, Section 2 Tools to Support Decision- Making

includes a process titled *Considerations for Increased Staff Support in the Face of Risky Decisions*. Your agency and the individual’s Circle of Support can use it to determine the level of risk the individual is taking and to help figure out if more control and direction should be provided to help the person stay safe and healthy.

See **Helping Staff Support Choice** (by M. Smull) in **Part Four, Section 2**.



See **Revisiting Choice, Parts 1 and 2, Positive Rituals and Quality of Life** (by M. Smull) in **Part Four, Section 2..**

You need a life before you have a dream.

M. Smull

job to help the individual recognize all of their options and the possible results of any decisions they may make.

Individuals Plan for Their Futures

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

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

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



Things to Learn About Your Agency

- How does your agency support an individual to make their own choices if they do not express themselves in regular ways? For example if someone does not use words to speak or if someone has a limited vocabulary?
- How does your agency support individuals to get assistive technology (i.e., communication devices)?
- How does your agency get to know an individual who is referred for services.
- How does your agency honor both the small everyday choices and the big life changing choices individuals make?
- What is your agency's process for supporting individuals who make decisions that jeopardize their health and safety or the health and safety of others?

Summary

Having choices and control over our lives in everyday little decisions (like what to do, and where to go) and in large decisions (like where to live, who to spend time with and where to work) gives each of us the quality of life that we want. Individuals with disabilities have the same desire and need to have control over their lives. Supported living services offer them this opportunity.



Building your Toolbox: Choice and Self-Directed For More Information/Resources

Accessing Assistive Technology

by Protection and Advocacy, Inc. (PAI), (1995), 100 Howe Avenue, Suite 235-N, Sacramento, CA 95825, (916) 488-9955.

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

By John O'Brien, Connie Lyle O'Brien, & David B. Schwartz (January 1990) Responsive Systems Associates.

David's Discovery

A video about "Choice". It is listed on the DDS web site at <http://www.dds.gov/OW/videos01.htm>. An order form is linked to this site.

Getting to Know You:

Planning for Services in Supported Living

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



Technology links for people with disabilities on the web:

Apple's Worldwide Disability Solutions Group <<http://access.berksys.com/>>

Visit Apple's home page to review some frequently used access devices and software compatible with Macintosh computers.

Berkeley Access < <http://access.berksys.com/>>

The goal of Berkeley Access is to develop inexpensive software-only products that provide mainstream computer access for people with disabilities.

IBM Special Needs Solutions

<<http://www.austin.ibm.com/pspinfo/snshome.html>>

Visit the home page of IBM's Special Needs Systems.

Microsoft - Accessibility and Disabilities Group

<<http://www.austin.ibm.com/pspinfo/snshome.html>>

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

Prentke Romich Company <<http://dialup.oar.net/~Pprco/>>

PRC provides quality language and assistive technology products and services to people with disabilities, their families and professions.



3. Relationships

Introduction

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

3. Relationships

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



Supported Living – Entering into a Relationship of Support and Commitment

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

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

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

John O'Brien, 1991

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

Relationships and Obligations (John O'Brien, 1993)

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

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



Obligations to the Person

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

- ... treating you with respect and listening carefully to you so that we can keep getting to know you better
- ... learning with you about your interests and preferences and identifying the kind of home that will offer you a safe, decent base for your participation in community life
- ... learning with you about the kind, amount, and style of assistance you need to live successfully in your home and your community
- ... working with you, and your family and friends, to establish the home life you desire and the assistance you need
- ... recognizing the social, financial, and personal barriers to the kind of home life you want and assisting you to work to overcome them
- ... understanding the vulnerabilities to your well being that result from your disability and your personal history and carefully negotiating safeguards with you that balance risk and safety in a responsible way
- ... being flexible and creative with all the resources available to us to respond as your interests, preferences, and needs change
- ... keeping responsibilities clear so that, in every area in which we work together, you and we know what you will contribute, what your family and friends will contribute, and what assistance and support we will contribute





- ... minimizing our intrusion in your life by periodically checking to make sure we are not doing unnecessary things or doing necessary things in intrusive ways
- ... sticking with you in difficult times
- ... learning from our mistakes
- ... following through on our commitments to you and not making promises to you that we can't keep

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

- ... provide you with information
- ... invite and encourage you to try new experiences
- ... invite and encourage you to widen your circle of friends and contacts
- ... hold high expectations for the quality of your life as a full citizen and community member
- ... stretch our own awareness of possibilities by actively seeking contacts with people involved in building up our communities and with people who are developing more effective and practical ways to assist people with disabilities



We know that you could find yourself in conflict with others: neighbors, landlords, other service providers, or the law. In these conflicts we recognize our responsibility...

- ... to be on your side, in the sense that we will assist you to achieve the best resolution of the conflict possible in the circumstances
- ... to assist you to understand the conflict and to consider alternatives for its resolution
- ... to assist other parties to the conflict to understand your position
- ... to consider adjusting the kind or extent of assistance we offer you if that adjustment will help to achieve a satisfactory resolution of the conflict

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

- ... to negotiate openly with you in search of mutually satisfying outcomes
- ... to try new ways to assist you and then check to see if the new approach has good results
- ... to work hard to understand your communications about the adequacy and acceptability of assistance, especially when you can express yourself better through your behavior than in words
- ... to assist you to explore other sources of assistance if you want to do that





We recognize that you might find close friends among our workers and, while we neither expect or require this kind of relationship, we gladly accept the potential difficulties that this might involve.

Obligations to the Person's Friends and Family

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

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

- ... respond to your concerns about the person's safety and well being
- ... negotiate openly with you in search of mutually satisfying outcomes

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

- ... to uphold the importance of mutually respectful relationships among family members
- ... to assist you to negotiate a satisfactory resolution to the conflict if our help is acceptable to you and to the person we assist
- ... if the conflict is serious and you cannot resolve it, we will maintain respectful contact with all parties but honor the choice of the person we assist. (O'Brien, 1993)



Conclusion. Mutually respectful relationships are often hard to develop and even harder to maintain over time. These obligations point out the serious commitment a supported living agency makes to stand by an individual through life's ups and downs and through disagreements and tension. Honoring these obligations takes a considerable amount of commitment to the relationship and endless energy, communication, teamwork, negotiation and collaboration.

Circles of Support

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

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

At times when an individual is making decisions that place his or her health or safety in jeopardy the supported living agency may want to pull together the individual's circle of support. They may talk individually or over the phone or they may all come together and have a formal meeting. During these times the circle is invaluable for supporting the individual's right to make decisions while at the same time providing increased direction or intervention to assist the individual to be safe.



An effective circle of support works together within a culture of mutual trust and respect to share responsibility for supporting the individual. Because relationships are so tenuous and the relationships in supported living have a high degree of obligation and commitment you can expect that they will be continuously tested for their durability.

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

Things To Learn About Your Agency

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

- How does your agency facilitate and support the relationships and the services that might be provided by the individual's family, friends and other community members?



- How does your agency facilitate “Circles of Support”? What are some examples you can learn from.?
- How does your agency view the support that individuals receive from their family and friends?
- What are some examples of collaborative relationships that you can learn from?
- What relationships have been challenging for the agency to support?
- Does the agency have any policies or practices about the relationships between staff and the individuals they support? For example do staff give out their home phone numbers? Are staff allowed to visit with individuals when they are not working?
- What are some stories or examples of how your agency honors its responsibilities and obligations to the individual and their family and friends?

Summary

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

It is important to start with figuring out what the individual’s relationships are like now and what they were like in the past. A good person centered planning process can help. Part Four, Sections 3 and 6 include some tools that can help learn more about the person’s important relationships. Part Four, Section 4 includes some tools you can use to help the person develop new relationships.



Supported living agencies struggle with the tension that naturally comes as a result of their relationships with the individuals they support. It is hard work. Sometimes it feels like it has no beginning and no end. Not every agency and not every staff person have the qualities that it can take to hang in there with someone, or someone's family, when things get tough or confusing. Staff of supported living agencies frequently struggle with defining their role in a person's life. John O'Brien's article in this section can help guide an agency and its staff. Also, the tools to support decision making in Part Four, Section 2 may be useful when the agency is struggling with the agency's obligation to the person when they are making risky decisions.



Building your Toolbox: Relationships For More Information/Resources

It's about Learning, A Student Centered Approach to Adult Learning

by Marsha Forest with Bruce Kappel (1988), Frontier College Press, Toronto, Ontario

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

by Jack Pearpoint (1994) Inclusion Press, Toronto, Ontario

What's Really Worth Doing and How to Do It, A Book for People Who Love Someone Labeled Disabled

by Judith Snow (1994) Inclusion Press, Toronto, Ontario

Assistance with Integrity, The Search for Accountability and The Lives of People with Developmental Disabilities by John O'Brien and Connie Lyle O'Brien, Responsive Systems Associates, Lithonia, Georgia

What We are Learning About Circles of Support. A collection of tools, ideas, and reflections on building and facilitating circles of support

By Beth Mount, Pat Beeman, George Ducharme (1988).
Communitas, P.O. Box 374, Manchester, DT 06040





4. Community Membership

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

David B. Schwartz, 1992

Introduction

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

4. Community Membership

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

Community membership is especially rewarding for the individual and the community when the individual is a contributing member. For example, the individual may be a volunteer at a local food bank or regularly help their elderly neighbor mow their lawn. Sometimes community members and organizations naturally welcome an individual without the assistance of the SLS agency, while other times the agency must be thoughtful and purposeful at facilitating the individual's participation.

Community presence is not community membership.

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



We often make the mistake of assuming that when individuals move into their own homes in regular neighborhoods that they will naturally meet their neighbors and be welcomed into community life. The experience of people doing this work is that far too often this process does not happen on its own. Our ignorance, or neglect, can result in isolating people and although it is true that some people may enjoy or prefer solitude to being with other people, we may justify this isolation by saying that the person is not very “sociable” or that they’re choosing to spend time alone. Some people become depressed or suffer from other kinds of problems when they are lonely and isolated.

SOME THOUGHTS ON OPENING UP THE DOORS OF COMMUNITY LIFE

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

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

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

ADAPTED FROM **THE GIFT OF HOSPITALITY**



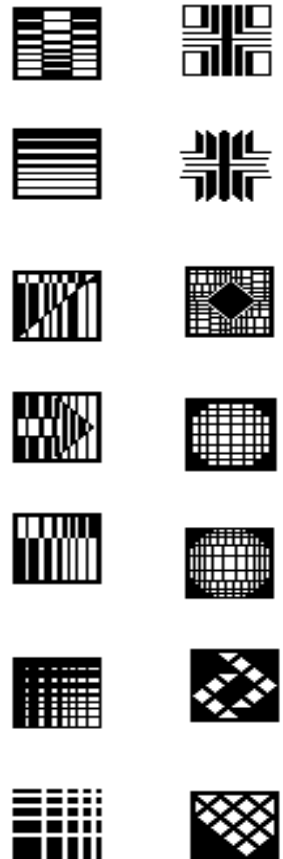
As you work in supported living services, you will constantly be struggling with a balance between offering enough and the right kinds of supports with offering too much support. This is a healthy struggle. Many leaders who have been providing supported living services for a long time say that when a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

Learning from Community Builders

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

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

This section was excerpted from [Patterns of Supported Living](#).





Patterns of Community Building

1. Focus on a specific geographic neighborhood. Learn about the neighborhood. Spend time hanging out with the people who are part of the community.
2. Find out about organizations and associations which exist in the neighborhood. Figure out which associations are working on building a better community. Find the people who are the welcomers. Every group has some. Get to know them. You can't do community work by yourself. You have to open yourself up to the community members and ask for help, ideas, and contacts.
3. Ask, Ask, Ask! Ask the association to welcome back someone who has been excluded. We have been afraid to ask. Community builders' experiences tell us that community members are waiting to be asked.
4. Pay attention to natural cues to figure out how much and for how long to lend support. Every situation is unique and there are no rules. Pay attention to when you should back out and let the regular community process take over. Be available if problems and conflicts occur but trust the community to work things out. Don't be quick to jump in and intervene in the natural process. Provide support to both the person with disabilities as well as the community members.
5. Stand alongside the person with disabilities and alongside community members as well. Join in. Be a member. Be a regular person. Don't feel like you have to go in as a professional with the answers. In fact, if you do, you will make the community people feel incompetent and they may back off.
6. Establish circles of support around a specific person. Involve community members. Let them know how they can help.





7. Remember that nothing about relationships is fixed and permanent. Informal relationships will change over time. They may grow, fluctuate, or die.

8. Community building work is rarely ever over.

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

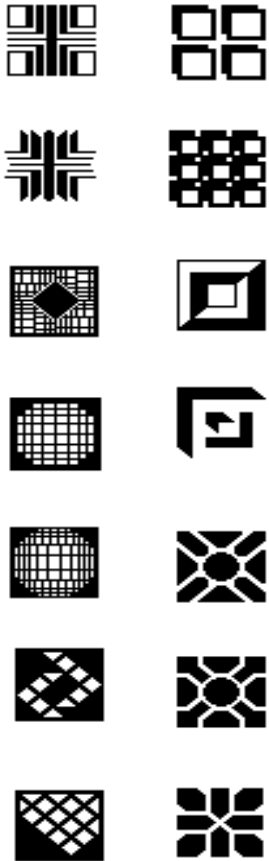
- They work through trust networks—a network of people who know each other and can open doors on behalf of the person with a disability. If a bridge-builder does not have a network, then she/he is taking the time to build one.

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

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

- All bridge-builders are starting small. They work with no more than 10 people at one time. They receive administrative support to start small.





- Bridge-building takes time and patience before things occur. Bridgers work in their own time and in their own way.
- Bridge-builders spend most of their time in the community. If they work for human service agencies, they have been freed from the demands of human service systems and are exempt from paperwork and other distractions.
- Effective bridge-builders are not "professionals." They are small business owners, beauticians, local politicians, church members, neighbors. They use common language to describe their feelings and experience.
- Bridge-builders who have been human service workers have difficulty giving up control, letting things happen. They have to learn to trust community people to know what to do and to follow-through.
- Bridge-builders do not "fix" or "change" the focus people. They accept and introduce the focus person as she is. They find people and places in the community who also accept the person as she is now.
- Bridge-builders do not teach the community how to integrate. They tell stories about inclusion. They model effective interactions and acceptance by example. They learn a lot about acceptance from people in the community who are naturally inclusive people.
- Bridge-builders must be responsive, present, and they must listen a lot. They are opportunity seekers, and they seize and support every possible opportunity they see to make connections for people. Circles of support provide a unique opportunity for bridge building. Circle members make a personal commitment to the person with a disability. They do their part to make a dream or a goal come true. They extend the circle of support by making new connections.



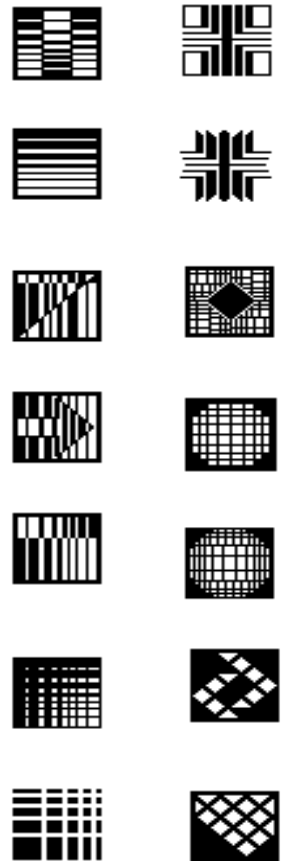
- Many bridge-builders feel very isolated. They are constantly making creative decisions and judgments along the way, and this level of innovation is stressful. They reach across many cultural lines and settings. They sometimes work closely with a partner.
- Most bridge-builders have unclear roles. They are learning as they go. They are trying lots of things.

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

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

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

In 1985 the agency for which I worked led a complex effort to "spring" these eight people from institutions to life in a community. The community picked was the little town with the funny name.



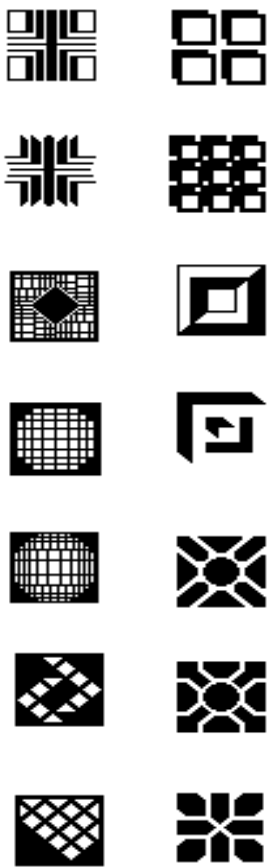


December 23rd, 1985 was liberation day. The whole thing took a tremendous amount of energy, persistence and probably audacity. Oh, it was a great feeling to see them leave. Exhilarating in fact—for the people who moved and for the people who played a part in making it happen. One of the public entities that had made it possible was the state Developmental Disabilities Planning Council. They had initiated a project to get people with disabilities out of nursing homes. They had provided money for people to set up their households.

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

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

About this time the state Developmental Disabilities Planning Council made funding available for a new kind of project called "Citizen Participation." We wrote a proposal, and were awarded a grant. It was just a small grant in terms of money. With this tiny little





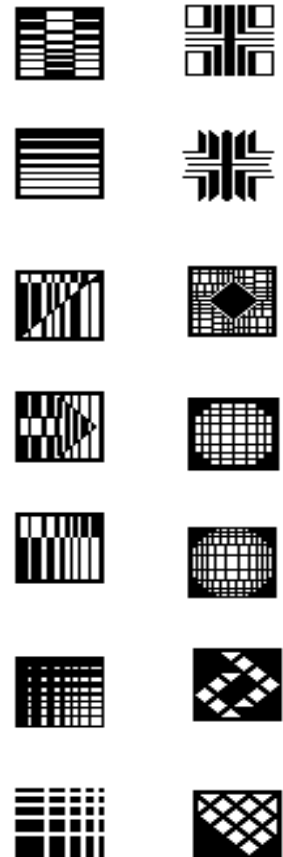
grant we began. I was hired to figure out what this new approach would be. As it turned out, I didn't know what I was getting myself into. I was used to things like developing policies, designing programs, making assessments, writing reports, supervising staff, counting units of service, coming up with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

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

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

Sophie

I found out that Sophie was a hairdresser who had run a shop in town for many years. She was also the mayor. Would she be well known? If you think about a small-town beauty shop, chances were high she would know just about everybody and everything in town. Would she be well-respected? Well, after all, someone had elected her mayor and trusted her enough to be the top-ranking leader of the community. And finally, she had no ties to the human service world. Perhaps she could help. I needed to call her and ask.





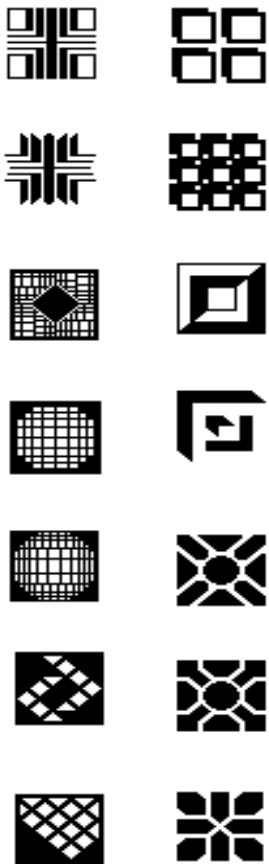
I was given Sophie's telephone number. I want to be perfectly honest here and tell you that I looked at Sophie's telephone number on my bulletin board for many days. As I struggle now to understand my hesitancy to call her, several things come to mind. How could I ask a perfect stranger to get involved? What if she just said no? Would her "attitude" be right? Finally I called.

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

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

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

Sophie went on to say that if we were going to be working at getting people involved in the community we needed to talk to Frank. She



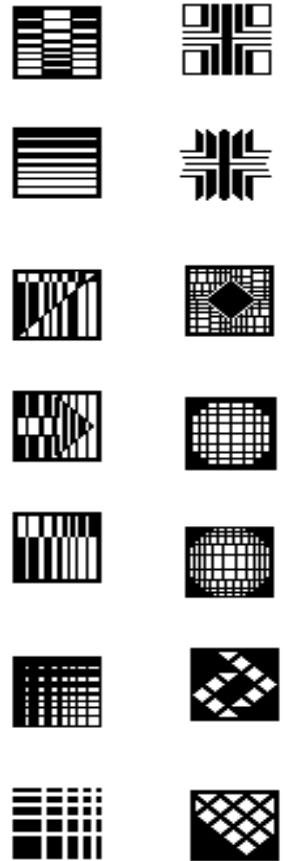


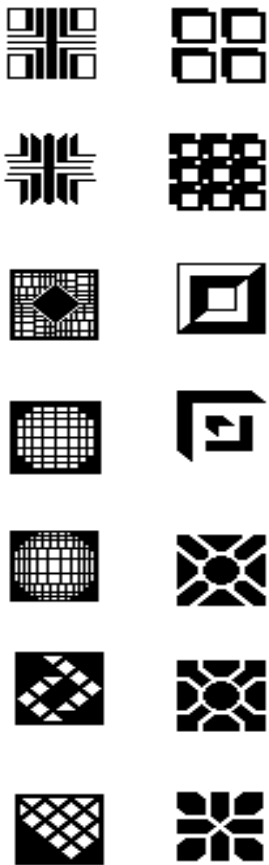
said Frank knew everybody in a thirty-mile radius and belonged to every association, group, and club. In fact, Frank had probably started most of them. I made arrangements to come back again to meet Frank. On the way out, Sophie asked me again if she had done something wrong when the new people in the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

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

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

Sophie and I talked with Frank about what we wanted to do about getting people whom I supported in their apartments more involved in community life. Frank said he thought it was a good idea, but didn't want to commit himself right that minute. He said he had so many activities that he didn't want to say he could help until he had thought about it. Frank pulled out a folded piece of paper from his breast pocket and showed it to me. On the paper were notes of meetings and times—Lions Club, Festival Committee, Food Pantry and so on. I thought it was interesting that he didn't have an appointment book.





Frank started to tell me a story about when he ran a band group of kids that marched in area parades. Frank is very involved in parades. A girl who couldn't use her right arm wanted to be on the flag team. Some parents of other kids began to complain because she was the only one who carried a flag in her left hand and it messed up the flag formation. The parents said the group wouldn't be judged well in parades. Frank told them he didn't care; the girl was marching and she would carry her flag in her left hand. He said the girl is about thirty now and when they run into each other in town he feels good because she always talks about the band group, and how happy she was carrying the flag. Something inside me felt good, too. Then Frank said he didn't care who a person was, what problems they had, or what people couldn't do. What was important was, if someone wanted to be included then there was something important that he could find for them to do. Frank told Sophie he could help if we wanted him to.

Meeting Frank and Sophie and spending time with them sensitized me in an unexpected way, as a person as well as a human service worker. They taught me in small ways, never intending to change me as I may have initially meant to change them. Although I didn't realize it at first, I came to them expecting that I would be the teacher, the educator, the expert who would instill in them and their community

how to go about "community integration." While I was busy explaining about people's physical limitations, they were already brainstorming about what people could do. I sensed in Sophie and Frank this enormous capacity for caring. It didn't have anything to do with "disability." It had to do with how they felt about all people. They sensed utility and worth in everyone. They wanted their community to be a good place to live. Over the years they had been willing to invest in making it that way.

I initially worried because Sophie and Frank didn't know about word usage and terms I used. "Social Role Valorization," goal plans and units of service meant nothing to them. Someone at my agency asked me if they were really qualified to do what we wanted them to do. I labored over that thought for a great while. Eventually I



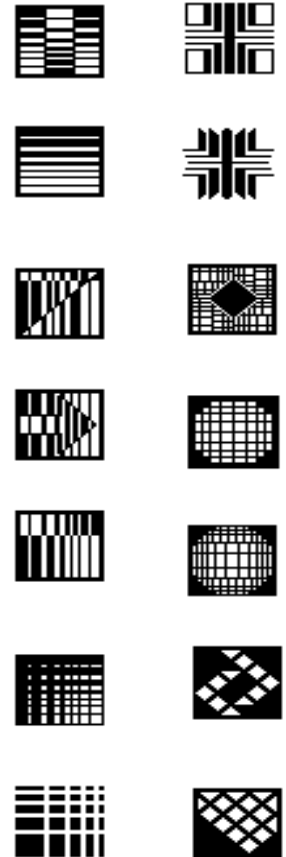
came to just know that their "professional" qualifications were not an issue. The only way I can describe having come to this conclusion is that my heart told me. Inviting people into community life was already their life's passion. They had shown me their capacity to welcome and embrace people. I didn't worry any longer about what words they knew. And finally, when I went to the deli to talk and have coffee with Sophie and Frank, I no longer carried my briefcase. Once we agreed upon what we wanted to do together, we arranged for Frank to receive a small "retainer" to help defray some of his expenses. The first person he started to connect with the community was Albert.

Albert

Albert is a rather 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.



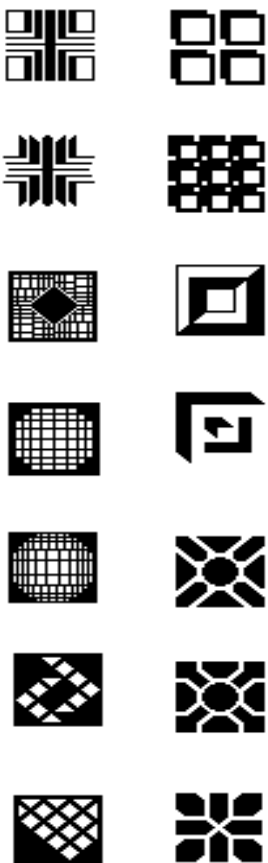


When Albert lived in the nursing home, he got in the habit of securing his most prized possessions by wrapping them in many layers of handkerchiefs, socks and bags and keeping them close to his body. Each week at the food pantry, someone asks Albert if he'd like to put on his name badge, at which time 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 pantry this is just known as Albert's ritual. One of the workers there told me that the ritual means that Albert feels proud to be a part of their group. It never occurred to them that there was anything wrong with it.

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

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

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





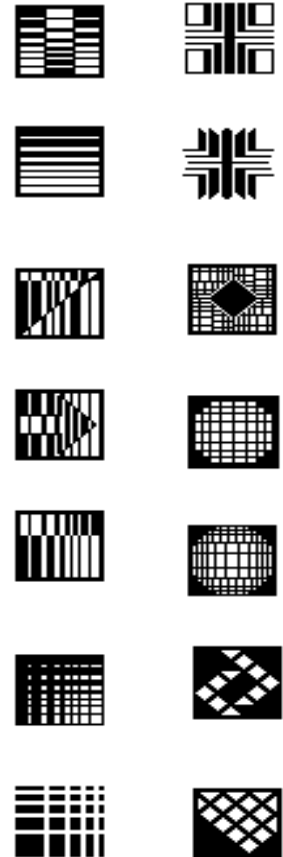
Pete

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

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

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

Sometime after Pete had become a regular member of the Bible study his day program came to a halt. The agency that had been funding his program had decided he was not capable of working, so they gave up trying to prepare him. Now Pete had absolutely nothing to do with his days. He came down to our agency building and tried to help out but usually ended up just sitting around. By this time I had met Gene, who was a good friend of Frank's. Gene was a helper at the food pantry and had taken a liking to Albert.



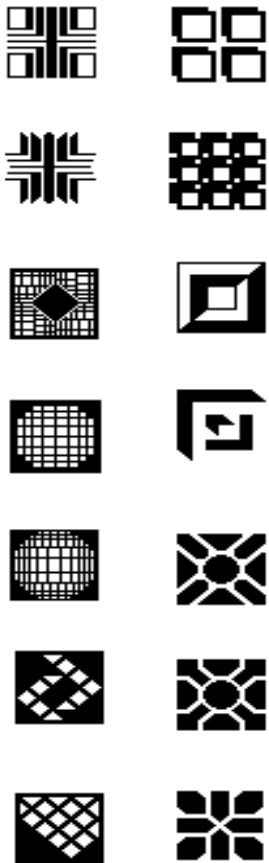


Gene told Frank and me that he wanted to get involved in helping our citizen participation efforts. Gene was a lifelong resident who had been an executive in the sales field. When I met Gene he was between jobs and had pretty much given up on wanting to be a part of the sales field any more. He was looking for something different in his life—a way to be of real help to the people in his community. This was what led him to the food pantry, and Frank in particular. As he expressed it to me, he saw in Frank what lived and breathed in his own heart. Frank was a symbol of pure love and an example of how human beings could interact in their world. He started spending time with Frank and learning from him.

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

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

When showing people Pete's book Lynn Ann, with pride, shows how he is getting better and better with organizing it. They saw at first that he was having trouble knowing where to paste the ads in. Their solution was to draw a grid on notebook paper and make lots of copies. Having the lines on the paper has helped Pete to do his job better.





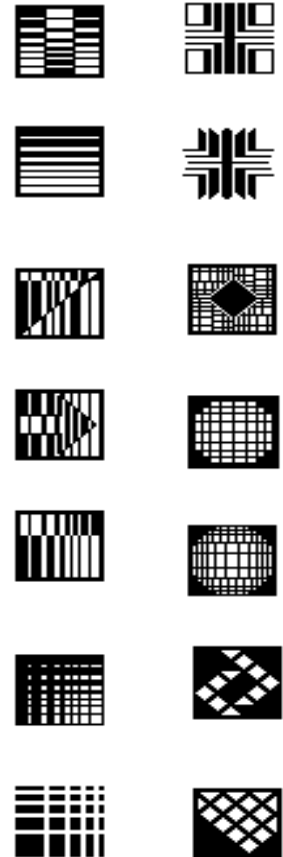
Life in Lynn Ann's office has changed significantly since Pete arrived. There is a new spirit in the office. Lynn Ann says the best thing about having Pete there is simply him being himself. Pete's gift of gab is revered here, especially the jokes. Lynn Ann and Pete have a deal— Pete has to keep telling her jokes because she often gets too serious. In return Lynn Ann's promise is to be a good boss. When Pete yells over "Hey Lynn, I have a joke," the entire office comes to a hush. The punchline is delivered, everyone either laughs or moans—and then they get back to work.

Bonnie

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

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

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





wasn't there. I scanned everywhere for her but she was busy preparing for something else. Soon it was over.

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

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

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





children and bring them home. She decided at that time that she was blessed and from then on decided to make it her business to "do right by people."

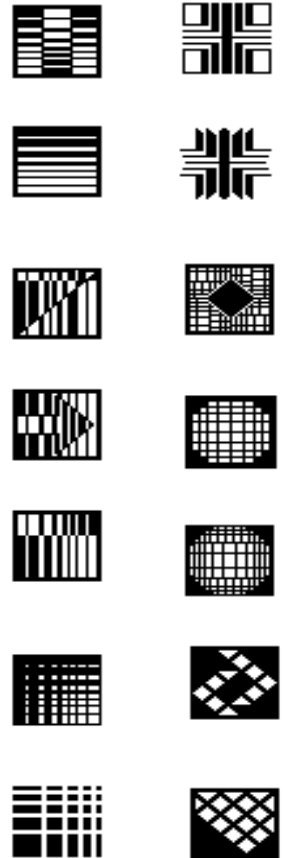
Gene asked Gloria, "Might your church be a place for Bonnie?" Gloria's response was that at her church the doors were open. Gloria asked the church elders, the pastor and the deacons who all in turn asked the congregation to welcome Bonnie. And this they did.

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

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

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

I heard that the day of Bonnie's baptism into the church was quite an event to see. It was different from any other baptism ever performed there. Faced with the problem of taking her wheelchair into the baptismal pool, the deacons conferred and decided on another way. There was some concern about the response of the church elders since they would be breaking down deeply rooted tradition. However, on the day of her baptism, Bonnie, draped in cloaks and doused with water, was met with a resounding eruption of applause.





Community Membership - Getting Started

These stories are not unique to Pennsylvania. Stories of people being included in their communities are being shared all over California by individuals and supported living agencies. Supported living services offer a new opportunity for many individuals to have the support they need to become a valued member. Part Four, Tools and Applications (Section 4) includes *A Guide to Developing Community Connections*. This guide includes several tools that can help you get started in your journey to becoming a community builder.

Community Membership Means Fully Utilizing Community Generic Resources

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

Things To Learn About Your Agency

Supported living agencies work creatively and purposefully to help people become valued members of their communities. You can learn about your agency's work by asking the staff who work there to share stories about the individuals they support and how these individuals are involved in their communities.



- Does your agency have a data base or listing of community places, groups, clubs, organizations and community activities that people may want to participate in?
- Do all of the staff help support people to become active in the community or does your agency have special staff who have this role? For example, in some agencies they have identified one or a few staff who are considered community builders or bridge builders.
- What kind of transportation is available to individuals who want to be active in the community? Are there any limitations? For example, certain days or times of day when transportation is not available? Do staff transport individuals when public transportation is not available?
- How are individuals supported to attend clubs, churches, or activities during a time of day that staff may not usually work?
- What community connections do the staff, volunteers and Board members have that could be useful for helping individuals make connections.

Summary

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



Building Your Toolbox: Community Membership For More Information and Resources

The Art of Welcoming

by Sharon Gretz and Dianna Ploof, Pennsylvania Developmental Disabilities Council, phone 877-685-4452.

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

A Guide to Developing Community Connections

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

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

by David B. Schwartz, 1992, Cambridge, MA: Brookline Books.

Who Cares, Rediscovering Community

by David B. Schwartz, 1997, Westview Press.

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

What About IHSS

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

Supplemental Security Income: Questions and Answers for Persons Residing in Supported Living Arrangements

by Adult and Supported Living Services Section (1996), Department of Developmental Services, 1600 Sacramento, CA, 95814.

IHSS Fair Hearing and Self Assessment Packet

by Protection and Advocacy Incorporated, 100 Howe Avenue, Suite 185 North, Sacramento, CA 95825-8282



5. Flexible, Tailored Services and Supports

Introduction

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

5. Flexible, Tailored Services and Supports

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

Getting to Know the Person and Planning for Services

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

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



3. What routines and rituals are important.
4. What the person can do for themselves and what they will need support to do.
5. How the person would like support provided (i.e., time of day, qualities of staff, frequency, order to doing things).
6. The kinds of support the person will need to stay safe and healthy.
7. How the person communicates their needs and desires.
8. What the agency and others will need to know and do to help the individual live in a way that makes sense for them.

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



Individual Service Plan

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

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

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

- | | |
|--|--|
| 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 | |



Flexible, Tailored Services: New Patterns of Staffing, New Job Positions, and New Wage and Labor Laws

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

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

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

Personal Support Services

Personal Support Services are one type of supported living service that can be provided to do the things for an individual that they can not do for themselves because of the nature of their disability. These services should always be provided in the way the individual receiving the service wants. Even individuals who communicate with no or very little language or who use their behavior to communicate have preferences over when and how personal support is provided. This makes it critical



that the SLS agency know the person's preferences, routines and rituals in order to provide respectful services. Many kinds of assessments and planning processes will help the agency gather this information. *Getting to Know You*, in Part Four (Section 6), is one tool that may be helpful.

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

Responsive Services

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

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

The reasons that individuals need on-call support vary. Some need back-up support if a personal support assistant does not show up. Others need emotional support, crisis prevention support or someone with whom to talk. Supported living agencies may use pagers, cell



phones, a 24-hour answering service or a combination of technology all arranged so that someone is always on-call.

Developing A Pattern of Support

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

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

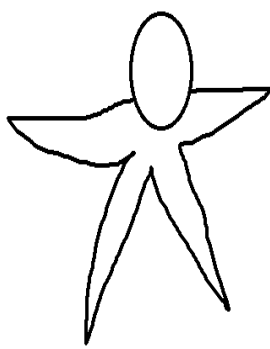
Here is an example of how someone put everything together to develop a pattern of support for Sharon. We're presenting Sharon's story because it offers many challenges.

Getting to Know Sharon

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

At one time, we would have looked at Sharon's record to find out more about her, but it only told us about the things she couldn't do. To find out about things that Sharon could do, we 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



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

**Get to
Know
Someone**

ISP, Schedules,
IHSS, Family and
Friend Support

**Figure
Out a
Pattern of
Support**

**Recruit
and Hire**

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

**Use
Generic
Services**

Home Adaptations,
Equipment,
Section 8, IHSS

Personal Assistance,
Facilitation/Instruction,
Emergency Assistance,
Community Support,
Family and Friends

**A
Preferred
Lifestyle**





find out from doing some sort of assessment. For example, we found out that Sharon was bothered a lot by the violence that she always saw on the evening news. (In time, she joined a local peace organization to help "end violence in the world.")

Figuring Out Support Needs and Desires

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

Assisting in Locating and Securing a Home

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

Developing Formal and Informal Support

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



a lot, but between her and a neighbor and our agency support staff, we figured out a good plan.

Getting Connected to the Community

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

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



Things To Find Out About Your Agency

Individualized Service Planning

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

- How does your agency get to know people (assess their needs and desires)?
- How does your agency help people plan for their futures?

Individualized patterns of support

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

- How does your agency schedule staff so that individuals receive the services during the time of day and in the location that makes sense for the individual?
- How does your agency assist individuals to use IHSS? How will you help them recruit, screen, hire, train and supervise?

Full array of services

- If your agency currently provides instructional services like independent living services: How does your agency support people who are not able to learn to do a skill and instead need someone to do it for them?
- How does your agency support individuals with special needs like individuals who need assistance with parenting or individuals who need personal assistance services?



Responsive Services

- How does your agency organize the staff to be responsive during unusual working times? (e.g., evenings, overnight, weekends, holidays)?
- How does your agency organize agency staff and resources so that the agency can be responsive if someone needs unplanned, unscheduled help in a hurry? For example what kind of on-call system is set up? How will on-call staff or others be reached when they are not in the office or it is after office hours?

Summary

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

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



The Many Roles of a Supported Living Service Provider

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

Adapted from [Learn the Basics, Learn the Process, Apply What You Learn: Service Coordination Orientation and Training Curriculum](#) (1999). Developed for the Southern California Training and Information Group. See the Reference Section for a full citation.



Advocate

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

Problem Solver

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

Teacher

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

Community Organizer/ Resource Developer

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

Facilitator

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



Friend/Companion

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

Personal Assistant

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





Team Leader

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

Record Keeper

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



Building Your Toolbox: Flexible, Tailored Services and Supports For More Information and Resources

A Workbook for Your Personal Passport

by Allen, Shea & Associates (1996) with special thanks to: Patsy Davies, Claudia Bolton, Mark Rice and Steve Sweet

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

All My Life's A Circle

Using the Tools: Circles, MAPS & PATHS

This booklet (1994) was written by Mary Falvey, Marsha Forest, Jack Pearpoint, and Richard Rosenberg.

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

Developing First Plans! A Guide to Developing Essential Lifestyle Plans

by Michael Smull & Bill Allen; Self-Published (1999)

Essential lifestyle planning is one form of person centered planning. It is a way to learn how what is important to each person in everyday life. This manual is intended for use by those who have completed training in how to develop plans. It is **not** a substitute for training and should not be used without training. For more information about training, visit www.allenshea.com and click on *M. Smull and Friends*.



It's Never Too Early, It's Never too Late!

by Beth Mount and Kay Zwernik (1988) from the Governor's Planning Council on Developmental Disabilities

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

Listen, Understand, Plan, Support: A Resource Guide on Individual-Centered Planning

developed by Allen, Shea & Associates for CARF . . . The Rehabilitation Accreditation Commission (1996); available from CARF (www.carf.org).

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

My Life Planner; Letting Go; Dream Deck

by Emilee Curtis and Milly Dezelsky (1993)

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



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Direct Support Professional Training Year 1 (1999).

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Supported Living Services Training Tool Box

**Part Two:
Principles of Supported Living Services**

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

April, 2001