This resource is provided by Northwest Down Syndrome Association www.NWDSA.org. Please contact us for permission to copy or forward this material.



Joe Wykowski

Community Vision, Inc.

© 2009 Joe Wykowski, All Rights Reserved. Published by Community Vision, Inc. Booklet design, Joan Guthrie Medlen

> 1750 SW Skyline Blvd Portland, OR 97221 503.292.4964 www.cvision.org

 $Cover\ illustration\ {\Bbb C}\ www.istockphoto.com/highhorse$

This version prepared for the GRO Project.

A Toolkit for Individual Support

Joe Wykowski

Community Vision, Inc.

Contents

Introduction 4
Guiding Principles5
Creating New Supports6
Person-Centered Planning6
Community Building & Circles of Support8
Individualized Housing10
Helping People Be Safe11
Flexible Support Strategies12
Wage & Hour Companionship Services14
Individual Budgets15
Defining Support Needs15
Person Centered Thinking for Supported Living16

Introduction

Aving the right tools is important for any job. When your job is supporting people, having the right tools is essential. This toolkit is a "how to" guide for individualized agency supports. I have found the process and work included in this booklet essential to creating individualized person centered supports. As providers for supported living, we have learned that it is critical to focus on one person at a time when planning supports. Each person is truly unique.

We found methods other than planning for one person at a time to provide supports and housing dilute choice and control. Our experiences taught us that moving ahead slowly and carefully, while learning from the supported individual and his or her family, is the path to success when striving to support a variety of individuals over time.

The information in this took kit reflects many lessons – some more difficult than others. Use the information in this tool kit to guide you as you, too, plan to support each person, individually.

It's worth the work.

Those who say it cannot be done should not interrupt the person doing it

Chinese Proverb

or any organization, it is important to have a set of Γ beliefs or guiding principles that shape the decisions made by the organization. Refer to your organization's priniciples to guide you as you develop your support agency.

The guiding principles of your organization set the tone and path for supporting people. We have learned that meaningful approaches to supporting individuals with disabilities include the following principles.

- Being surrounded by a rich network of friends and relationships.
- Enlisting people in your life who care about you to help to work through support issues and the complexities of everyday life, if needed.
- Listening carefully, differently, and deeply to people's dreams and desires for their future.
- Maintaining control over ones personal support dollars.
- Deciding with whom you live.
- Controlling one's housing.
- Having the opportunity to hire and fire personal assistants.
- Contracting with a neutral third party concerning issues of payroll and other expenses.
- Participating in and contributing to the community, which leads to full citizenship.

Refer to your organizations guiding principles – update them or write them if needed - to guide you as you develop your organization. Keep in mind these are meant to be visionary. In the end, the specific plan is very personal and different for each person.

Guiding Principles

V The art of seeing things invisible Jonathan Swift



The heart of person-centered planning is empowering each individual to continue to dream about his or her future.



Person-Centered Planning

Including family and friends when planning for supports is a great way to involve non-paid people in the planning process who may already know the person or who have gifts and talents to share with the individual and the circle. Person Centered Planning involves gathering to discuss and plan the future and how to best provide support to the person. This works best in a setting that is comfortable for the person, such as the person's living room. We believe in following the lead of the individual as the expert when planning. We are there to support the individual and in the way they are best comfortable in moving forward.

The heart of person centered planning is empowering each individual to continue to dream about his or her future. It is not a legal document or formal agreement. It is a dream document created on behalf of the focus person with their permission. As with any other planning process the outcomes are only as good as the follow through and commitment of the individuals present. There are many ways to organize the person-centered planning process to capture the spirit of the person's dreams in a logical manner. They are called "maps," which are a graphical way of documenting what the group discusses.

Some of the maps or graphics created for the person include:

- Personal Highlights
- Gifts and Talents
- What Works and Doesn't Work for the Person
- Support Needs
- Dreams for the Future
- Ideal Home and What it Looks Like
- Action Plan or Next Steps

This is just an example of the types of information that are often documented in a person-centered planning meeting. There are many more. The tools, or maps, used and the discussions that take place are determined by the person who is the focus of the planning meeting.



The power of this process is it's focus on the person, their families, and those who care about them.

Community Building Strategies and Circles of Support

9 t takes regular commitment and facilitation of new relationships to help people move beyond their paid support system. \mathcal{A} great majority of individuals with developmental disabilities are often disconnected from their community. They often lack the social networks and friendships that make life exciting, supportive, and adventurous for everyone. We have found that supporting people individually creates a framework from which to build a community with neighbors and meet new friends.

By connecting people with disabilities to new clubs and friendships in their community, a circle of support develops. This goes a long way in building a supportive environment in which friendships are nurtured and continue to develop. All of us can find an apartment or live in a new home. The real sustaining experiences come from the friendships in our lives.

A Circle of Support is a group of people who agree to come together on a regular basis to accomplish personal goals or connections. This circle can include anyone, with whom the person involved is comfortable, who will make a commitment to participate.

What makes this process unique is the support the individual receives from people who are not paid to be in their life. Many people with disabilities depend on an array of paid supports with fewer people who are not paid to be in their life. It takes regular commitment and facilitation of new relationships to help people move beyond their paid support system.

We have found steps to building a circle include:

- Listening to what the focus person's dreams are for the future.
- Empowering and embracing the dream to enable each individual to create a personal vision for the future.
- Gathering interested friends, family, community members, and non-paid people who will commit to being available in a relationship with them.
- Finding connections within existing family, friends, neighbors, and others to create new community for the focus person.



Friendship is the golden thread that ties the heart of the world.

John Evelyn

We have found that traditional planning can lack the excitement and connection to new relationships that comes from circles. Circles are about people coming together to support an individual moving forward with their life without pretense of systems, regulations, requirements, or relationship dependent on paid supports.

Individualized Housing is Separate from Support

Housing and supports should always be managed seprately. This gives the person with the disability control of both independent of each other. **9** n supported living, housing is in the control of the person receiving supports. The purpose is to assist individuals to find housing that meets the specific needs of that *one* person. We have assisted individuals to obtain market rent housing, section 8 housing with their voucher, and to own a home of their own. The key to all of the housing is having the person's name on the lease or home. By doing it this way, if the individual changes the support agency working with them, they do not have to move. They always maintain control over their housing because it is in their name. Housing and supports should always be managed separately. This gives the person with the disability control of both – independent of each other. The role of the individual support agencies is not to own or rent housing, but to assist individuals to obtain the housing they require in the neighborhood of their choice.

Many individuals with a disability do not have a traditional credit history. They may have no credit history because they have been paying room and board to a nursing home or agency. Overall, their credit may be positive, but minimal in scope. To assist with this, an agency may need to initially co-sign a lease, if a person has moved out of a nursing home. However, it is always important to make sure the lease is transferred entirely in the persons name after a period of time has passed. \mathcal{A} ssisting people to be safe in their home is key to helping individuals find the level of independence they desire in their home and community. In supported living, safety is the responsibility of the team of people who support the person, which includes paid support people and the person's nonpaid relationships.

Opportunities for choice and control are achieved when individuals in the circle make a concerted pledge to share responsibility for decisions about safety and making choices. Although the details in a plan, use of technology, and paid support systems are important for a person's safety, the ultimate safety is found in the strength and presence of nonpaid people in a person's life. Assisting People to be Safe in Their Home

. . .the ultimate safety is found in the strength and presence of non-paid people in a person's life. Flexible Support Strategies There is no *one* model or approach to staff support to use in supported living. Instead, a combination of support strategies or opportunities is called upon to meet the appropriate amount of support for each person. Rather than shifts or schedules, flexible, creative approaches, are used which may include support companions, live-in caregivers, roommates, use of technology, and neighbor support to provide the right level of support for an individual.

Support Companions

A support companion is someone who is an employee of the person with a disability. Schedules for support companions vary widely. They may work a fixed or varied schedule, or provide support to a variety of people who live different places. A companion may work longer or shorter hours depending on the schedule of the person.

Live-In Caregiver

A live-in caregiver is someone without a disability who lives with the person for reduced or free rent in exchange for being available over night in case of an emergency etc. Agreements under the live-in model can be flexible and structured differently for each person depending on their needs.

Roommates

Roommates are non-paid people who share a home with the person with a disability and who pay a portion of the rent and utilities. Roommates do not enter into a support agreement for the person with a disability. Rather, they live with the person and share expenses in a similar manner as people with out a disability. They can be as involved or uninvolved with their roommate as they choose.

Technology

Different forms of technology may be used to provide support, allowing the individual to live in their home without 24-hour support. Some examples include emergency call systems, answering services, computer technology, and home adaptations.

Neighbor Support

Neighbors are often willing to be used as emergency back up for support or to check in with individuals when paid staff is not close by. Sometimes neighbors are paid a small stipend to be available at night in case of an emergency.

One approach to providing individual support services is under the federal wage-and-hour rule called *Companion Services*. Under this federal designation, support companions can provide a variety of supports to individuals in their home or the community. The companionship designation is exempt from over time and minimum wage requirements and can be deemed to be any reasonable agreement between the two parties.

Using this federal designation allows ultimate flexibility. Separate living or sleeping quarters are not required as in group homes, and individuals can come and go as needed. This arrangement provides spontaneity. For example, if



Wage and Hour Companionship Rule

person's friends or family schedule a community outing on short notice, the companion can be off work without creating a wage an hour issue.

The companionship service exemption spares the agency from the Fair Labor Standards Act minimum wage and overtime provisions employees who provide in-home companionship services to elderly or infirm persons unable to care for themselves. Companionship services include making beds, washing clothes, and activities of daily living (ADL) in or about the person's home. As stated in two separate Department of Labor ("DOL") regulations, the exemption applies to companions hired directly by the persons to whom they provide services and to those hired through a third-party employer.

Agencies contracting to provide various services under their developmental disabilities contract need to be careful when using the companionship designation for supported living services. For example, if a support staff person changes work routines by moving between companion services and job coaching within the agency, the staff person is not providing support under companionship services when performing as a job coach. Therefore, separate time sheets need to be kept for supported living and supported employment, which is not be exempt from over time. g^n supported living, budgets for support must stand on their own. Therefore, the budget and funding established is for, and belongs to, the person, not the agency. If the person moves their support to another agency, the funding is portable and moves with them to that new agency.

Support agencies receive a fixed amount of the budget to operate the support agency and provide essential supports and services. This is usually about 12% of the individual budget.

Prior to developing an individual budget, a support needs assessment is completed to define the level of support a person requires to live in their home and move about the community. The needs assessment provides an opportunity to think through the person's future life in a systematic manner. This assures the correct level of support is provided and, in this way, the agency is sure the individual is not under or over supported.

Individual Budgets

Defining Support Needs

Person-Centered Thinking for Supported Living	A Home of One's Own
Tools to guide you	\Box Individuals live in homes that they own or lease.
	Individuals choose where to live, with whom they live, and control what happens within their home.
	\Box Housing is separate from services.
	□ Individuals pay their own bills.
	Individuals have the key to the door and control who comes in and out.
	□ The furnishings in the home represent what the person wants in their home.
	Self-Direction
	People work together as a team to support the person using a shared responsibility approach.
	People are generally happy with the supports and services they receive.
	□ There is a planning or approaches that balances risk with choices.
	There is a planning process that assists individuals with planning their future.

□ Individuals direct the supports they receive and have the control to hire and fire.

Community Membership and Relationships

- □ Individuals have opportunities to join clubs, community associations etc.
- □ There are non-paid relationships or attempts to connect people with new non-paid relationships in their life.
- □ Individuals have a circle of support that assists them to create new opportunities they dream about and desire.

Flexible Supports

- □ People's supports and housing are portable.
- □ People's plans reflect the type of support they want.
- □ Individuals receive opportunities to use technology to reduce support when requested.

Summary

A summary worksheet is provided on the following page.

the Will Do 943	
Follow-Up Action or Recommendation	
What Could Work Better?	
What is Working Well?	

Summary Worksheet

Community Vision, Inc. Founded in 1989, Community Vision is the largest nonprofit organization providing individualized housing, supported living, employment and homeownership services to people with disabilities and their families in Oregon. Community Vision has proven that assisting one person at a time to live in their own home provides the stability they need to work, live and thrive in the communities of their choice.

Community Vision, Inc.



Community Vision 1750 SW Skyline Blvd Suite 102 Portland, OR 97219 503.292.4964 www.Cvision.org