A Guide to Developing Community Connections

Compiled by
Patsy Davies and Claudia Bolton
October, 1996
A Guide to Developing Community Connections

Assisting people feel connected to their neighborhoods and communities can be both exciting and difficult, simple and mysterious. In spite of these complexities, we believe that it is one of the most important things we can do in our work in supporting people with disabilities. This workbook is a compilation of tools and information gathered from people across the country who do the work of community building. What we have included is not inclusive, and does not contain a sure to succeed method. The tools and exercises are to be used as a starting point in your work of connecting people. Each situation is different; what works for one person will probably not work for another. We want you to use these exercises as one way of exploring ways to connect others.

We encourage you to do these exercises for yourself first. Regardless of whether you are an extrovert or an introvert, strongly connected to your community or a loner, it is important to be conscious of the ways in which we are connected to people and places in our own lives. This consciousness is critical as you work to connect people and help them develop relationships.

Use this guide creatively and thoughtfully. We hope you will find it useful as you study, think, learn, discuss and search for ways to assist people develop ties to their communities and deepen their relationships with others.

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Ties and Connections

There are a number of important ways that people relate to each other. The list below includes a number of types of ties and connections, all of which can lead to a greater sense of community and belonging.

• **Friendship:** having friends, relationships, including a “best friend”. Mostly these can be described as “strong ties”

• **Acquaintance:** having a network of acquaintances

• **Membership:** being a member of associations and organizations

• **Keeping in touch:** with trends and movements of interest; subscribing to them; belonging to “social worlds”

• **Being part of a family:** having an active connection with family life

• **Having a partner:** or someone to whom a long-term commitment has been made

• **Being a neighbor:** living next door to, or at least near to someone (down the street or across the road)

• **Knowing or being known in a neighborhood:** using the resources of the neighborhood (usually the area within easy walking distance from where you live) and recognizing and being recognized by others who use them too

Four main themes to consider which impact all relationships are:

• **Time:** The amount of time people spend together and the length of time they have spent together in the past

• **Intensity:** Some ties and connections are invested with a lot of emotion. They mean a lot to us, perhaps more than anything or anyone else. Others are less important, and some not very important at all.

• **Intimacy:** We share confidences with some people more than with others. Some of our ties and connections involve a lot of trust.

• **Reciprocity:** The exchange of services between people. This may range from simply following the rules of politeness, to providing practical help, to sharing major parts of our life and work.

(Adapted from Friends: A Manual for Connecting Persons with Disabilities and Community Members, Amado, Conklin and Wells, and Ties and Connections, Ordinary Life Working Group, King’s Fund Centre)
The People We Know

Another way to look at the people we know is to think about their role they play in our lives. These descriptions were developed by John O’Brien as he studied successful circles of support in Connecticut.

Anchor: personal commitment to...
- a source of continuity by sharing life over time
- stands by the person in difficult times
- growing knowledge of the person
- includes the person in life decisions
- protects the other person

Allies: personal relationships in which people...
- share time and activities
- share knowledge of person’s gifts & challenges
- share knowledge of the community
- make contacts for one another
- lend practical help
- enjoy one another

Associations: formal and informal groups organized...
- to animate civic life by promoting member’s interests
- to develop member’s skills
- to work for change in policies & practices members see as unfair or unjust

Assistance: cash transfer and organized services which make available...
- money with option of person control
- personal assistants
- devices, adaptations, redesign of activities
- teaching
- advice
- representation

Agendas: political action to insure just and effective public policies such as...
- personal assistance services
- inclusive school classrooms
- individual ownership of home
- safe and accessible transportation

Name people in your own circle on the exercise on the following page.
Helping individuals with disabilities get better connected to their communities would be much easier if the staff who worked with them were themselves connected to their communities. Unfortunately, it is not always possible to hire staff who already have strong community ties. It is possible, however, to train staff about the importance of community connections and relationships, and to encourage them to use their existing connections as well as to develop personal connections in the community.

- Have staff do their own relationships maps. This can help staff see opportunities within their own networks of relationships for connecting people with disabilities. If staff people within an agency begin thinking about their own connections and brainstorming ideas for connecting various individuals served by the agency, they might find that a wide variety of opportunities are already available.

- Identify staff people who are natural “connectors”. Some staff people are more comfortable in roles as “community connectors” than others. These people are generally the outgoing, sociable types. Some are already active in their neighborhoods and community organizations, and know lots of people through their activities. Some may be new to the community, or unfamiliar with particular activities or opportunities, but have no hesitation calling up, asking questions, finding out information, and meeting new people. These staff people can act as resources to other staff, can take the lead and help other staff learn about community building, can inspire others to try. When one staff person discovers that “It never hurts to ask”, and help someone make a connection, others see that it can be done.

- Encourage staff to get involved in community themselves, and recognize this involvement. One way to encourage involvement is to make information about various community organizations available to staff using a bulletin board, newsletter, or information presented at staff meetings. Acknowledging staff who participate in community organizations is one way to let them know that their participation is valued and to encourage others to get involved. Often, when one staff person joins or becomes involved, others follow.

- Encourage people learning to be more self-generative, curious, outgoing, and to take more risks. With continuing encouragement, staff will become more willing to ask more people to become involved and to investigate more possibilities. Staff become more of a part of their own communities just by helping others do so.

(Adapted from Friends: A Manual for Connecting Persons with Disabilities and Community Members, Amado, Conklin and Wells.)
A community life exists when one can go daily to a given location at a given time and see many of the people one knows.

Philip Slater

From a book by Ray Oldenburg The Great Good Place: Cafes, Coffee Shops, Community Centers, Beauty Parlors, General Stores, Bars, Hangouts, and How They Can Get You Through the Day

In his book The Great Good Place, Oldenburg writes about what he refers to as “Third Places”, those places in every community where locals gather to visit, share news and be among others. Such places are a great spot to meet the neighborhood “connectors” (those people who know everyone else) and to assist someone to become a “regular” in a neighborhood place. Oldenburg describes the characteristics of Third Places in this way:

**They must be on neutral ground** - places where individuals come and go as they please, none are required to act as the host, and in which all feel comfortable and at home.

**They act as a leveler** - a place that is inclusive, accessible to the public and does not set criteria for membership and exclusion.

**Conversation is the main activity** - a place where the “talk is good”, lively, colorful and engaging. You can see it in the smiles of others, handshaking, back-slapping, and pleasurable, entertaining conversation.

**There are regulars** - a place where the customers are a source of attraction, giving the place its character and the assurance that on any given visit someone will see someone they know.

**They have a low profile** - the place is typically plain, sometimes looks unimpressive, and do not attract a high volume of strangers and transient customers. This discourages pretense and people “come as they are”.

**The mood is playful** - there is laughter, which is the magical element that warms the insider. The urge to return is there, to recreate the good time and to recapture the experience.

**They can feel like a home away from home** - people feel rooted, see familiar faces, and may have special privileges because they are a regular.
Looking at Life Behind the Counter

by Sharon Gretz

Rock’s Cafe is no slick, glamorous, Tiffany lamp or ferns place. In fact, it is best described as “nondescript.” Rock’s lies in a small shopping strip hidden off the intersection of two busy state routes in a small, rather rural community near my home. One can barely notice the small sign or detect its presence beside a video rental place and the convenience store. I am on a mission early in the morning, with specific intent and purpose.

The impetus for my visit to Rock’s is my excitement and anticipation of a scheduled visit to Pittsburgh by author and sociologist, Ray Oldenburg. Oldenburg wrote a book a few years back that I am fond of and that got me thinking a lot about community life. The book is called, The Great Good Place: Cafes, Coffee Shops, Community Centers, Beauty Parlors, General Stores, Bars, Hangouts and How They Get You Through the Day. In his book, Oldenburg illuminates the importance of what he calls “Third Places”, the informal spots, neither home nor work, where locals gather on neutral ground to associate, share good cheer and converse with a diverse group of others. Oldenburg writes, ‘There must be places where individuals may come and go as they please, in which none is required to play host, and in which all feel at home and comfortable. If there is no neutral ground in the neighborhoods where people live, associations outside the home will be impoverished.’ It was and is obvious to me that these “third” places and their hospitality are key as we seek ways for people who have been labeled and exiled from community life to find places of belonging. My mission at Rock’s is quite clear - is this a “third place” or not?

I first heard of Rock’s when I was discussing the notion of the third places with a friend. She too had spent many years working in human services. After giving her my best description of third places, my friend launched into a story about Jim, a man she knows who has mental health labels. Jim, as it turns out had lived in the vicinity of Rock’s for a number of years (as did my friend). She told me how Jim, on his own, had come across Rock’s Cafe and became one of it’s “regulars”, stopping in periodically in the day. Over time, Jim could be found behind the lunch counter serving coffee, both to himself and to other regulars at busy times. At yet other times, Jim helped out by washing dishes and clearing tables. It was a place where he found belonging; where others came to know him; and where he was appreciated for being a regular and for helping out when needed.

I asked my friend if Jim was still there. She reported that not long ago, Jim moved from the community to another, which was some 20 miles away. The reason for his move was that in order to receive certain services he needed he had to go (translated - he entered a residential program that required he fit into a “slot” or “bed”). In ending, my friend said that if I was checking out third places; I might do well to stop by at Rock’s.

As I pulled into the parking area, I wondered to myself why I had never noticed Rock’s Cafe. After all, I don’t live far from here. I have gone to the convenience store 2 doors down any number of times. I had stopped for food at the McDonald’s and Taco Bell down the road. Yet, I had never even known that Rock’s Cafe existed. Getting out of my car, I wondered if I would stand out like a sore thumb going into Rock’s. I knew from my friend that it was quite small. Would it truly be a third place? Would I know it even if it was? The litmus test for third places can be found in Oldenburg’s book. Before I entered, I reviewed my mental checklist:

• Must be on neutral ground
• Is a “leveler” - an inclusive place where one’s station in life is insignificant and where one’s personality is the most important characteristic.
• The main activity is conversation, regardless of the functional purpose of the setting.
• Regulars are trusted
• One can become a regular if one wishes to be.
As I entered Rock’s, I found it to be even smaller than I had imagined. In front of me was the lunch counter. To the left were six, maybe seven small tables, many of them filled. One group appeared to be retired senior citizens, predominantly men but one couple also included. At another table was a group of employees from the gas company across the road. They were easy to identify by their company logo emblazoned on their shirts. Nearly everyone looked up at me as entered. I was sure they were looking for a familiar face. I smiled at them. Several folks smiled a somewhat cautious smile back. One man nodded a greeting to me. I chose a table near the gas company table. Then came a call from the small kitchen beyond the counter, “I’ll be right there!” As it turns out this call came from the woman who owns Rock’s. Wiping her hands on a towel, she arrived at my table with a “good morning, what can I get for you”. She was a robust pleasant woman who quickly went off to prepare my breakfast order.

Back to my mission - is this a third place or not. It took all of about 15 minutes for me to come to a conclusion. The answer was an undeniable, an unequivocal - yes.

As I sat at my table, the buzz of conversation and laughter abounded. Good natured quips were exchanged between tables of folks who obviously knew each other. Soon the door opened again and a gentlemen in a suit entered. The owner from the kitchen looked out and yelled, “Tom! Hi! Hey, I’m busy back here. Go behind the counter and get your coffee. The cream’s down below and don’t forget your spoon!” The man did exactly as she said, obviously familiar with the scene “behind the counter”. The man, Tom, took his coffee in the company of the retired group and quickly inserted himself in the conversation. A short while later, one of the retired men yelled out, “Hey, what does it take to get some more coffee in this place?” Out of her kitchen came the owner, who yelled back, “Hey, you’re a big boy. Get it yourself! !!” Everyone laughed aloud - the banter was most certainly made possible by the familiarity in the cafe.

When the owner came out of the kitchen with my breakfast in tow, she commented as she passed her regulars, “Hey guys, give me a break today. Cindy can’t come in ’til later. Her baby-sitter is sick and she has to get her son off to school. This is help yourself day.” She went through the story again when she placed the food on my table with an apology that it had taken too long.

Moments later the gas company employees sauntered to the counter to pay their checks. Again, friendly quips were exchanged. Once man had a large bill. The owner said, “You’re going to leave me stuck if I have to break that bill. Pay up tomorrow.” While she’s talking, one of the retired men goes behind the counter and pours coffee for himself - “When do I get on your payroll?”

I had a warm feeling at Rock’s that morning. When I paid my check, the owner told me this was prime time for her regulars and again at lunch time. She chuckled as she added, “My regulars are great! They solve all the world’s problems over their morning coffee.” She thanked me for stopping in and asked that I come back sometime. You know what? She really meant it. Her comments weren’t like the robotic “thank you and have a nice day” phrase that I have encountered in so many places of business - where the person doesn’t even look up at you and they’re already ringing up the next customer. She was genuine. Her place was genuine - the real thing - a welcoming place, a belonging place, a third place.

To finish this paper I have stopped at a Burger King on my way to a meeting. I always seem to write better over a cup of coffee. There is no “group” here at the Burger King. Individuals fill individual tables, all absorbed in themselves. As I coolly look through this place, I notice a rather disheveled looking man busily writing notes on a piece of paper. At the same time, the man is talking to himself in a loud voice - loud enough for all the patrons to hear his confused words. I wonder if this is his “place.” Not one of the other patrons seems to notice him at all. They must hear him yet they certainly do not SEE him. It’s as if he is invisible.

I think again about Jim - the other man with a mental health label. Jim had found his place at Rock’s Cafe. He was not invisible there. After all he was trusted behind the counter. I wonder about Jim’s new community. Was there a “Rock’s” there? Had he found it? Or did he now take his coffee alone, in a Burger King - where he would be arrested for going behind the counter. I think it tragic that Jim no longer has his place - tragic that to receive services he had to abandon his place - the place where he was somebody - where he helped to solve the problems of the day and of the world, over coffee.
Associational life is rich in all of our communities. Learning about where the community networks are is useful information to have on hand. This is a guide to help you learn about the possible associations in your community. Use this list to think about the various organizations people belong to. You can identify groups in your area in a number of ways - talking to others, looking in the phone book, reading area and neighborhood newspapers, surveying churches and existing groups, checking with the Chamber of Commerce, etc. Make your own listing and use it as a resource as you think about connecting specific people.

<table>
<thead>
<tr>
<th>Associations (examples)</th>
<th>Your Area</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Artistic Organizations</strong></td>
<td></td>
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<tr>
<td>choral, theatrical, writing</td>
<td></td>
</tr>
<tr>
<td><strong>Business Organizations</strong></td>
<td></td>
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<tr>
<td>Chamber of Commerce, business associations</td>
<td></td>
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<tr>
<td><strong>Charitable Groups &amp; Drives</strong></td>
<td></td>
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<tr>
<td>Red Cross, Cancer Society, United Way</td>
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<tr>
<td><strong>Church Groups</strong></td>
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<tr>
<td>service, prayer, men’s, women’s, youth, seniors</td>
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<tr>
<td><strong>Civic Events</strong></td>
<td></td>
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<tr>
<td>July 4th, art fair, festivals, Halloween</td>
<td></td>
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<tr>
<td><strong>Collectors Groups</strong></td>
<td></td>
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<tr>
<td>stamp collectors, flower dryers, antiques</td>
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<tr>
<td><strong>Community Support Groups</strong></td>
<td></td>
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<tr>
<td>Friends of the Library, nursing home, hospital</td>
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<tr>
<td><strong>Elderly Groups</strong></td>
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<tr>
<td>Senior Citizens</td>
<td></td>
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<tr>
<td><strong>Ethnic Associations</strong></td>
<td></td>
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<tr>
<td>Sons of Norway, Black Heritage Club, Hibernians</td>
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<tr>
<td><strong>Health &amp; Fitness Groups</strong></td>
<td></td>
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<tr>
<td>bicycling, jogging, exercise</td>
<td></td>
</tr>
<tr>
<td><strong>Interest Clubs</strong></td>
<td></td>
</tr>
<tr>
<td>poodle owners, antique car owners</td>
<td></td>
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</tbody>
</table>
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<table>
<thead>
<tr>
<th>Associations (examples)</th>
<th>Your Area</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Local Government</strong></td>
<td>town, fire department, emergency units</td>
</tr>
<tr>
<td><strong>Local Media</strong></td>
<td>radio, newspaper, local access cable TV</td>
</tr>
<tr>
<td><strong>Men’s Groups</strong></td>
<td>cultural, political, social, educational, vocational</td>
</tr>
<tr>
<td><strong>Mutual Support (Self Help) Group</strong></td>
<td>Alcoholics Anonymous, LaLeche League</td>
</tr>
<tr>
<td><strong>Neighborhood &amp; Block Groups</strong></td>
<td>crime watch, beautification, Christmas decorations</td>
</tr>
<tr>
<td><strong>Outdoor Groups</strong></td>
<td>garden clubs, conservation clubs</td>
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<tr>
<td><strong>Political Organizations</strong></td>
<td>Democrats, Republicans, caucuses</td>
</tr>
<tr>
<td><strong>School Groups</strong></td>
<td>printing club, PTA, child care</td>
</tr>
<tr>
<td><strong>Service Clubs</strong></td>
<td>Zonta, Kiwanis, Rotary, AAUW</td>
</tr>
<tr>
<td><strong>Social Cause Groups</strong></td>
<td>peace, rights, advocacy, service</td>
</tr>
<tr>
<td><strong>Sports Leagues</strong></td>
<td>bowling, swimming, baseball, fishing, volleyball</td>
</tr>
<tr>
<td><strong>Study Groups</strong></td>
<td>literary clubs, bible study groups</td>
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<tr>
<td><strong>Veterans Groups</strong></td>
<td>American Legion, Veterans of Foreign War</td>
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<tr>
<td><strong>Women’s Groups</strong></td>
<td>cultural, political, social, educational, vocational</td>
</tr>
<tr>
<td><strong>Youth Groups</strong></td>
<td>4H, Future Farmers, Scouts, YMCA</td>
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</tbody>
</table>
In addition to formal and informal associations, learning about the places in your community is an important exercise. The following map was developed by Allen, Shea & Associates as a way for you to explore the various places in your own community. It is helpful to do this exercise with someone else who lives in your community (two heads can be better than one!). Consider the various places, setting, activities and gathering places that are part of your community.

**Where do people gather?**

**What do people go for fun?**

**Where do they go?**

**What clubs do people join?**

**Where do people go on the weekends?**

**Take a walk around your**
| What are the major streets for shopping, services, entertainment? |
| What are the public places (library, community center) that people go? |
| Where is the center of the community? What's there? |
| What are favorite places to shop? |
| What is unique to your community? |

**COMMUNITY, WHAT DO YOU SEE?**
Characteristics of a Community Connector

• has confidence in his/her understanding of the person with disabilities

• trusts in community members

• someone with high expectations

• someone who can trust people to work out problems on their own and at the same time,

• sensitive to and gently assists when there are problems or difficulties

• has no hesitance in calling on and requesting others’ willingness

• is well connected themselves and understand the value of community connections

• focuses on the gifts and capacities of people with disabilities

• believes that the community is filled with hospitality for strangers

• is a “people person” - an enduring confidence in the capacity of people to do what is right, knowing they will not always live up to their ideas

• has replenished capacity to forgive others for mistakes; yet remembering that people with disabilities cannot afford to have more mistakes made in their lives

• has flexibility, maturity and a willingness to laugh when things go wrong
Person centered planning

is a way of getting to know a person, learning about who they are and what their life is like now, as well as helping someone think about how they would like their life to be different. There are various methods to do this planning, including Personal Futures Planning, Essential Lifestyle Planning, PATH, and MAPS.

Regardless of the method used, information gathered about a person’s interests, skills, potential skills, and preferences are critical to understanding how to begin assisting someone build community ties. Just as important is to know what doesn’t work and things to avoid.

Here are some areas to think about when exploring what a person’s interests and skills are. Remember, what you are looking for is what a person likes to do, what creates energy and motivation for them, what skills, identities, environments, settings, habits and qualities they have that we can build on.

- activity levels
- using one’s body and hands
- artistic abilities
- analytical thinking
- leadership abilities
- work identities and interests
- ethnic and religious identities
- interests
- appearance
- noise levels
- familiar places
- health issues
- disability issues
- routines
- personal qualities

The activity on the next two pages was developed by Beth Mount as a way to match interests to opportunities in the community. If you have done the preceding exercises, you have already identified people in your life (or someone you are supporting), formal and informal organizations, and places in the community. Now you can begin to brainstorm places that can enhance interests, gifts, and personal qualities, and develop strategies for getting started.
These Are The Opportunities In My Community

**Brainstorming Places That Enhance Community Contributions.** Be creative and develop a wide variety of opportunities. Consider all of the possible sites, settings, and roles in which people can contribute.

<table>
<thead>
<tr>
<th>Summarize the interests, gifts, qualities and identities you hope to develop.</th>
<th>List the community opportunities, settings, associations, networks and places where people come together with similar interests, talents and values.</th>
</tr>
</thead>
</table>

Adapted from Capacity Works: Finding Windows for Change Using Personal Futures Planning, Mount, 1995
Five Action Steps for Getting Started

Identify several ideas that seem most appealing and then outline five specific strategies for getting started. Remember to include who you will contact, when, and any additional information you may need to get started.
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Community Groups, Organizations and Places

Thinking about how to connect a person to a place requires: knowing the person well; knowing the place; thinking about the supports everyone involved will require; providing support in the most effective, flexible manner; and, thinking, rethinking and evaluating your approaches.

The next exercise was adapted from one developed by Kathryn Kemery McClain as a way to think through the characteristics and rituals of a particular place or organization. It is designed to assist you to explore the various possibilities for involvement in a particular activity or place. It is important to know about the setting, the demands and the opportunities it may place on the person. This activity helps us remember the progression of activity one would go through in order to participate. The next step for you after this exercise is to consider the supports a specific person will need during each stage of interaction.

THE STAGES OF INTERACTION.

**Arrival:** List things related to how other people arrive at the group or place.

**Entry:** List things related to how people actually get into the building or location. Do people have to walk up steps, knock, open the door?

**Getting started:** List anything that happens from the point that you get into the building until the activity actually starts. This could include things like finding a seat, knowing to be quiet when the meeting begins, greeting other people, introducing yourself, etc. Sometimes the atmosphere is very informal while other situations have more formality. Are there unwritten ground rules?

**Participation:** List anything that occurs during the main portion of the situation or meeting. This varies greatly. Look for the unwritten rules, types of interaction, types of conversation, as well as the "things" that are required. For example, you would want to go to a coffee house with money.

**Finishing up:** How can you tell the activity is winding down? Are there specific things that occur? Again, remember the unwritten rules.

**Exit:** List whatever is required to leave the building. Pay attention to whether people talk with one another on the way out, whether folks go out for coffee after the activity, etc.

**Departure:** List how people leave.

**Characteristics.** A running description of anything relevant that occurs at that particular stage. This can include things like how people are dressed, seating arrangements, or anything else that seems relevant given the setting and the person you will be supporting.

**Expectations and Demands.** Includes anything that the setting demands during a particular stage. It could be a response such as shaking hands or saying good-bye, an ability or skill, etc.

**Describe the people who are part of the social setting.** This can include a variety of things such as age, sex, “type” of person, anything that strikes you as relevant or defining about the group.
Name of Group or Place: __________________________________________

Location: ______________________________________________________

<table>
<thead>
<tr>
<th>Stages of Interaction</th>
<th>Characteristics</th>
<th>Expectations and Demands</th>
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<tbody>
<tr>
<td>Arrival</td>
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<tr>
<td>Entry</td>
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<td>Getting started</td>
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<tr>
<td>Participation</td>
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<tr>
<td>Finishing up</td>
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<tr>
<td>Exit</td>
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<tr>
<td>Departure</td>
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Describe the people who are part of this place or group:
________________________________________________________________________________________________________________________________________________________________________________________________________________________
________________________________________________________________________________________________________________________________________________________________________________________________________________________
________________________________________________________________________________________________________________________________________________________________________________________________________________________
More on Building Connections

Another way to think about this work of connecting is to look at it as occurring in several stages.

**Exploring:** Get to know the community and search for social settings. Having identified them, fully explore some of them with a specific person in mind.

**Strategizing:** Develop support to include a specific person by fully knowing the community settings and by knowing the person. Think about the various interests, gifts and skills of the person, and the possible places they can contribute.

**Engaging:** Carry out the support plan you have developed to introduce the person to the setting.

**Analyzing:** Consider how effective you were in supporting the person and supporting others in include the person. What can you differently?

**Investing:** Is this a setting the person enjoys? Does he/she want to spend time continuing to be involved? How can you continue to support the person in building relationships in this particular setting?

**Including:** Consider the ways in which you can support the person in their relationship to others. Relationships take time and effort to evolve and to mature. Think of ways in which you can support others in their relationship with this person.
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Resources on Community Building and Relationships

**The Community Place.** 730 Main Street, Manchester, CT  06040; (860) 645-3178  
(formerly The Communitas Communicator) A catalog and newsletter based on the vision of community inclusion.  A great source for materials related to circles, inclusion and community building.

Especially:

- **Circles of Support: Building Inclusive Communities.** Describes the experiences of developing circles around people living in the U.K.

- **Building Communities from the Inside out.** Written by John Kretzmann and John McKnight, this book features effective and practical ways for people to make meaningful contributions to their community.

- **Stories of Circles/Circles of Stories.** Reflections on one person’s experiences with several Circles of Friends formed in support of people in the Milwaukee area.

- **Capacity Works.** Written by Beth Mount, this workbook summarizes the values and principles of Personal Futures Planning, circles of support and community building by providing the reader with six tools for reflection.

- **The Whole Community Catalogue.** A guide for building communities and supporting inclusion. Full of ideas, resources and quotes.

**Center on Human Policy.** Syracuse University, 805 South Crouse Avenue, Syracuse, NY 13244-2280; (315) 443-3851; fax (315) 443-4338; e-mail: thechp@sued.syr.edu. A source for a variety of reports and resources on the integration of people with severe disabilities into community life.

Especially:

- **Personal Relationships and Social Networks: Facilitating the Participation of Individuals with Disabilities (1991)** by Zana Marie Lutfiyya. An information package which includes three articles and an annotated bibliography.

continued
Resources, continued


**Inclusion Press**, 24 Thorne Crescent, Toronto, Ontario, Canada M6H 2S5; (416) 658-5363; fax (416) 658-5067 A resource of books and videos about full inclusion in school, work and community.

Especially:

**All my Life's a Circle: Using the Tools: Circles, MAPS & PATH.** Written by Mary Falvey, Marsha Forest, Jack Pearpoint and Richard Rosenberg, this book describes all you want to know about these three tools.

**What's Really Worth Doing & How To Do It!** A book about dreaming, inclusion and giftedness written by Judith Snow.

**From Behind the Piano: Building Judith Snow's Unique Circle of Friends.** Written by Jack Pearpoint, this book describes Judith's journey from living in an institution to traveling around the world.

**The Common Thread**. A periodic newsletter written by Sharon Gretz and Dianna Ploof, and published by the Community and Relationship Building Project at United Cerebral Palsy of the Pittsburgh District. Available from The Community Building Project, 17 Eisele Road, Cheswick, PA 15024.
Resources, continued

Friendships and Community Connections between People with and without Developmental Disabilities. A collection of articles creating a perspective of the principles in successful experiences to help others build relationships of their own through social connections. Edited by Angela Novak Amado and available through Paul H. Brookes Publishing Co., P. O. Box 10624, Baltimore, MD 21285-0624.

A Guide to Developing Community Connections

Compiled by
Patsy Davies and Claudia Bolton
October, 1996

Connections for Information and Resources on Community Living (CIRCL)
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Challenges in Coordinating and Managing Services and Supports in Secondary and Postsecondary Options

By Debra Hart, Karen Zimbrich, and Teresa Whelley

**Issue:** Current practices and policies, including differences between youth and adult service delivery systems and the lack of interagency collaboration, complicate service coordination for youth with disabilities. How can service coordination become more flexible, youth-centered, and culturally responsive?

**Defining the Issue**

As youth with disabilities prepare to leave secondary school, they and their families face the challenge of finding services and supports appropriate for adult life. Even youth with a strong sense of self may find the task of coordinating adult services and managing supports confusing, if not overwhelming (National Center for the Study of Postsecondary Educational Supports [NCSPSES], 2000). First, they have to identify what services they want and what to call them, presumably learning new, adult services terminology along the way. Second, they have to find the services they have identified and decide how to fund them, hopefully gaining new advocacy and access skills in the process. Third, they have to know how to manage services and supports and what to do when circumstances, wants, and needs change. Individuals may gain self-determination skills, but will they ever figure out how “the system” works?

For example, arranging transportation to and from college or employment can be a complex and confusing issue. Will the student use public transportation or para-transportation? Will the student drive? Does the campus have a shuttle service? Is it accessible? Does the employer support car-pooling? Will the local vocational rehabilitation agency provide a vehicle and driver? Is the student...
eligible for medical transport? Each of these possibilities may require investigation into eligibility criteria, driver’s license and disability documentation requirements, application procedures, and identification of a funding source.

Even when services and supports can be located and secured, managing them still poses a significant barrier to satisfactory postsecondary options (NCSPES, 2000). Educators, adult service agencies, and service providers face barriers to collaboration, including a lack of knowledge regarding each other’s systems as well as bureaucratic constraints resulting from long waiting lists and limited financial resources.

There is growing recognition that the complexity of service systems is an impediment to developing comprehensive state and local service coordination for individuals with disabilities once they leave high school (Stodden & Dowrick, 1999). Federal laws and related policies have been implemented to address barriers to postsecondary education and employment for individuals with disabilities. These include the Americans with Disabilities Act of 1990, Amendments to the Rehabilitation Act of 1973, the Workforce Investment Act of 1998, and the Ticket to Work and Work Incentives Improvement Act of 1999. Additionally, in February 2001, President Bush launched the New Freedom Initiative (NFI), a comprehensive plan to reduce barriers to full community integration for people with disabilities. In order for new and existing initiatives to be as effective as possible, they must be implemented in a coordinated, streamlined, consumer friendly, and culturally responsive manner.

**Current Practice**

Whereas the Individuals with Disabilities Education Act (IDEA) of 1997 requires that services for students be coordinated, the law does not specify how service coordination should be provided. Current models of service coordination described in the literature typically fall within four paradigms (see Figure 1).

Current practices and policies, including differences between youth and adult service delivery systems and the lack of interagency collaboration, complicate service coordination. As students with disabilities move from secondary education to postsecondary education and/or employment, the first challenge they face is the use of different terminology across various settings. The resulting confusion may prevent students and professionals from recognizing service gaps. The lack of common terms across service systems further contributes to a lack of understanding among service coordinators and poses an additional barrier to collaboration. Bureaucratically, these systems are well established and are likely to be inflexible in their approach due to their own internal processes, cultures, and histories.

Another major difference is that postsecondary services are not mandated, as they are within public education systems under IDEA 1997. Instead, they are based on eligibility determination and on availability of funding from an adult service agency. In addition, an individual may be eligible for services from more than one adult service agency, and different agencies have different rules, regulations, and eligibility requirements. Adult services are available from a myriad of service providers.

![Figure 1: Current Service Coordination Models](image)

1. Independent/dedicated: the agency providing service coordination is independent (does not provide services other than service coordination) and the service coordinator has no other role or responsibilities beyond providing coordination of services;

2. Independent/not dedicated: the agency providing service coordination is independent from service provision but the service coordinator has other responsibilities;

3. Not independent/dedicated: the agency provides service coordination and direct services to consumers but the service coordinator has no other role or responsibilities beyond providing coordination of services; and

4. Mixed: any combination of above three models (Research and Training Center on Service Coordination, 2001).
providers, with no designated coordinating agency, unlike service coordination requirements by the Local Education Agency (LEA). Without interagency partnerships, students and families, as well as adult service workers, may have difficulty planning and locating funds for needed services and supports.

Postsecondary educational institutions do not typically accept an Individualized Education Program (IEP) from a high school as documentation of a disability or an academic accommodation. However, colleges may be able to use high school testing results, if the information is current and disability-specific. For example, after consultation with the college, a student with a learning disability might submit the psycho-educational evaluation from eleventh grade as documentation of the learning disability. If a student needs additional documentation, it is the student’s responsibility to obtain this information. The student’s school files and medical records, if appropriate, need to be collected and maintained by the student after leaving high school. As a result, it is imperative that high school students learn self-determination skills, including IEP and other record-management skills, so that they have the ability to assume responsibility for their records and for other aspects of adult life.

Finally, there are genuine gaps in services. In some human service agencies, for instance, eligibility criteria is less stringent for children/adolescents than for adults, so individuals considered to have a disability while in school may be deemed ineligible for services and supports as adults. Among other arguments (e.g., the often-cited rationale that an agency cannot work with students until six months before they leave school), the question of adult eligibility may contribute to delays in service provision for students still in high school. This is particularly true for vocational services and supports, ideally in place a year or two before students leave school, which provide a base of experience vital to making informed decisions about potential career paths. Individuals with disabilities may find that services and supports are not available in their local community (e.g., interpreters, job coaches, and public transportation), or that services, such as individually supported jobs, do not match their interests. They may find long waiting lists for the more desirable community-based services. In addition, they will find a system in which no state or regional agency is responsible for tracking cross-system services or locating service gaps among agencies.

It is important to note that the barriers described above are exacerbated for students with more significant disabilities. These students often remain in special education programs well beyond their eighteenth birthdays. Usually, youth with significant disabilities are relegated to segregated programs while their non-disabled peers go to college or technical school, develop social networks, and start careers (Hart, Zaft, & Zimbrich, 2001). Activities provided in isolation rarely reflect individual student needs and preferences, nor do they provide the type of in-depth study and practice that allow a student to develop and pursue a chosen career path.

New federal initiatives may improve service delivery by enhancing existing and creating needed services. These include IDEA 1997, with its emphasis on creating access, participation, and progress in the general curriculum for all students; Medicaid Infrastructure Grants to support the competitive employment of people with disabilities; One-Stop Career Centers, with employment services that are to include individuals with disabilities; and the New Freedom Initiative, with its commitment to reducing barriers to equality for Americans with disabilities. Service gaps may begin to be addressed as these initiatives are implemented.

**Summary of Challenges**

An examination of current practices by secondary education and adult service systems reveals challenges to service coordination that particularly affect students with complex needs, who may look to multiple agencies for a range of supports. In summary, there are five major barriers to effective service coordination and management of supports (see Figure 2).

**Recommendations**

To be effective, services and supports must be individualized, flexible, and supportive of consumer choice, change, and control. The following are recommendations for resolving the major barriers summarized in Figure 2.
1. Build partnerships that establish interagency cooperation at state and local levels:
   - Research service coordination strategies that effectively build interagency partnerships, foster consumer self-determination, and are flexible enough to allow consumer choice.
   - Develop and implement state and local interagency teams and publicize interagency agreements that address issues related to service coordination.
   - Establish unified policies and streamlined practices for intake and referral procedures, eligibility determination, communication, and service planning.
   - Develop and implement ongoing evaluation strategies to determine effectiveness of new models.

2. Develop clear and uniform mechanisms for information sharing, communication, and coordination of services and supports across agencies and audiences:
   - Develop a state-level, Web-based clearinghouse with a searchable, online database of information on resources, services, eligibility requirements, and expected outcomes, available to consumers and families, postsecondary institutions, advocacy organizations, human service agencies, and workforce development sites. Include an “Ask the Expert” section, to allow users to post questions and receive immediate responses.
   - Translate information into languages spoken in the communities served by agencies, and address issues of cultural competencies important to family and community cultures.
   - Develop a glossary of common terms pertaining to supports and services that are consistent across secondary education, postsecondary education, and employment systems, to use in future national and state legislation.
   - Consider electronic formats, multimedia stories and diaries, multicultural/multilingual outreach, and other platforms for students, parents, and professionals to become proficient in the use of terms related to transition and adult service delivery. Evaluate effectiveness frequently.
   - Develop, promote, and consistently offer a Transition Coordinator/Specialist option for teachers in training, which meets specific certification standards, to be determined by the state department of education in coordination with adult service systems.

3. Conduct resource mapping and alignment on state and local levels:
   - Fund demonstration grants that will research and develop effective resource mapping and alignment strategies, including creative flexible funding options, within and across systems and agencies. Conduct effectiveness evaluation and disseminate results nationally.
   - Support resource-brokering for postsecondary students and adults with disabilities at state and local levels. Pool
case management resources of adult, medical, Vocational Rehabilitation, Department of Labor, and postsecondary educational agencies to create structures for support-brokering across disciplines.

4. Identify and develop services to address gaps:
- Include cross-system service gap identification as part of resource mapping.
- Ensure that generic resources, including natural supports, are included.
- Enlist consumers and their families to help locate and address service gaps.
- Develop innovative strategies, such as time-sensitive service provision and cultural competence (defined as a set of behaviors, attitudes, and policies that promote effective cross-cultural work), to enable generically available service providers to be user friendly, culturally responsive, and knowledgeable about services that are most desirable and most timely for individuals with disabilities.
- Develop policies that support provision of adult services prior to students exiting secondary education.

5. Build student- and family-professional partnerships using student- and family-centered strategies:
- Provide adequate information about adult options, services, and supports for planning and decision-making.
- Promote empowerment through active participation in team meetings, using strategies such as person-centered planning, pre-planning meetings prior to IEP meetings, and the development of self-determination skills for youth.
- Learn about the culture of families and communities and conduct outreach strategies, such as partnering with community-based minority organizations, to ensure recruitment and active participation of families of diverse cultures and linguistic backgrounds throughout the IEP process.

To prepare youth with disabilities for adult life, service coordination must be a flexible, youth-centered, culturally responsive process that assists individuals and family members to secure supports and services that they want and need, when they want and need them. A service coordinator, sometimes referred to as an independent support coordinator, independent broker, or personal agent, can assist individuals to develop career paths (e.g., through person-centered planning). The role of the service coordinator may also include securing and implementing support services, assisting individuals at managing their own services and supports, and providing ongoing evaluation of the effectiveness of these supports. Services should include formal and generic services, and natural supports within the youth's family and the community at large.

References


Debra Hart and Karen Zimbrich are with the University of Massachusetts, Boston. Teresa Whelley is with the Center on Disability Studies, University of Hawaii at Manoa.
Getting from Where I Am to Where I Want to Be!
Bridges Version

What’s this all about? Your answers to these questions can help you put together a transition plan. A plan to help you reach the best possible future.

The questions are written in the first person, so that the focus is always on you, the person in transition. You can use this in several ways: (1) you can fill it out by yourself; (2) someone can ask you the questions and write down your answers; (3) you can work on it with a teacher, counselor, or someone else; or (4) family and friends can help you with it.

When you work on it with other people and they give you ideas for your plan, make sure you put their initials next to their ideas. That way, you will remember what you said and what others said.

1. Who is this about?
2. What are some great things about you?
Getting from Where I Am to Where I Want to Be!

Things About You

3. What do you like to do? around town? at home? for fun?

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

5. What makes you happy?

6. What makes you sad or mad or frustrated?
Getting from Where I Am to Where I Want to Be!

About Work

7. What are you doing now? going to school? working? something else? If you’re not working now, please go to question #9.

8. How’s your job?
   - Is it the kind of job you like? □ Yes □ No
   - Are the hours and days okay? □ Yes □ No
   - Do you get job support you need? □ Yes □ No
   - Does the pay cover your bills? □ Yes □ No
   - Do you get benefits? □ Yes □ No

   How do you get along with people at work?
   □ great □ okay □ not very well

   When you think about your job (check the one that shows how you feel most of the time):
   □ you’re glad you got it
   □ it’s okay that you got it
   □ you’re sorry that you got it

9. Do you want a job, or a different job than you have right now? If so, what kinds of jobs have you had?

   If working or a different job is not important to you now, please turn to the page called About How You Live and Would Like to Live.

10. What kinds of jobs or careers interest you?

11. Do you need support in getting a job?
   - Are you looking for your first job? □ Yes □ No
   - Does it take you a long time to learn a job? □ Yes □ No
   - Do you get Social Security benefits? □ Yes □ No
   - Do you need support in things like using money or getting to work? □ Yes □ No
   - Do you need any specialized training or work experience? □ Yes □ No

   If you answered yes to any of these questions, you could probably use some support in getting and keeping a job.
Getting from Where I Am to Where I Want to Be!  
About How You Live and Would Like to Live

12. How do you live now?
   - Alone? □
   - With a roommate? □
   - With your parents? □
   - With other relatives? □
   - In a group home? □
   - Other? □

13. What are the best things about where you live right now?

14. What could be better about where you live right now?

15. What kinds of support do you need where you live right now?

16. Are you living where you want to live and with whom you want to live?

17. All things possible, where would you like to live and with whom?

If you’re living where you want to live for now, please go to question #18.
18. What are your dreams and hopes for the future?

19. What worries you about your future? What worries those around you (family, friends)?

20. All things possible, what do you see yourself doing 3-5 years from now?

21. What support would you need to get to where you want to be?
22. What are some first steps to take towards your desired future?

23. Looking back at what you wrote for #22, which things would you like to discuss at your next transition meeting?

24. Who should be at your transition meeting (family, friends, teachers, agencies) to help you plan?

25. Who worked on this with you?
Getting from Where I Am to Where I Want to Be!

Moving towards your desired future, what do you need, want, or hope to happen in the next 1-3 years?

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<th>Who can do what?</th>
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How will we know if your plan has worked?
Author: Michael Kendrick
Title: SRV As A Resource for Seeking and Shaping the Good Life
Original Source: Families for Change
Publication date: Spring 2008
Publisher information: Families for Change, Spring 2008, Volume 3, Issue 7, pages 3 - 5, Family Advocacy, Australia

Abstract:
Social Role Valorisation or SRV is a theory that the majority of people have not encountered. Michael Kendrick observes that those who have been fortunate enough to immerse themselves in SRV find it very helpful in assisting people with disability to have a good life and describes some of the potentially positive impacts.
The theory of Social Role Valorisation (SRV) is not one that families and most ordinary citizens will have come across, quite apart from seeing its usefulness and applying it. In fact, even a majority of professionals in the sector may have only heard about it and may themselves lack any meaningful comprehension of or competence with it. However, those that have had the good fortune to have been able to immerse themselves in it, typically find it to be hugely helpful to their efforts in regard to assisting people with disability to create and obtain a good life for themselves. In the interests of helping curious people gain the beginnings of an appreciation for what SRV can do to help with ‘life building’, a series of brief descriptions of the ways that SRV theory can help people make progress are offered. Each of these draws upon specific elements of the theory of SRV and illustrates how it can help impact on ‘life-making’ in practical ways. Nonetheless, what is offered here is a description of its potentially positive impacts, not a description of the theory itself.

The Importance Of Acquiring And Being Supported In Valued Social Roles

The world is full of experiences, opportunities and possibilities that, if they are properly tapped into, can mean that a person gets to enjoy life more richly and to fulfil their greater potential. However, if they cannot get to these experiences, then all of this will be lost. The means to get to these life giving experiences and opportunities are valued social roles. Roles are the vehicle through which a person gets to be part of community life and enjoy what community life might offer. These roles can include, for example, friend, neighbour, club member, employee, sports fan, adventurer, athlete, relative, companion, travel mate and so on. These roles are usually not available, or in extremely short supply, in segregated settings for people who have disability. Consequently, a person who is segregated will never have the extent of life opportunities that one who is out and about in the larger community will have. Such roles can be consciously created for a given person even if they do not exist at present, as long as there are people who are supportive of this happening. The more one has a diversity of valued social roles, the more of life they can taste, embrace and reject depending upon whether these experiences are to their liking.

Being Granted Full Humanity And Personhood

One of the ways that people with disability get cheated out of a good life is that we act as if they do not deserve nor want as full a life as their non-disabled peers. Though we may be unaware of it, we extinguish countless life possibilities for people when we set our expectations for them too low because this conveys and confirms the message that ‘less than’ will have to do for them because, after all, they have a disability and the bottom line is that they should settle for less. This constitutes a profound and damaging mistake because it crushes a person’s life and possibilities. On the other hand, if one starts from the assumption that, irrespective of the person having disability, this person is as fully human.... in all ways..... as anyone alive today, then we can properly appreciate all of the hope and possibility that comes when the fullest potential of all of life awaits to be tasted.
It is important to not forget that being fully a person is a great gift, because it means that it is always possible to conceivably enjoy and appreciate any aspect of life providing that the appropriate support to do so is present. Taking up this view, that a person with disability is fully capable of enjoying any aspect of life that suits them, is much better than to take the opposite view that they should give up on life and settle for less. One road leads to a narrow diminished life and the other leads to the hope of a daily richness in living.

**Proactively Pursuing Life Possibilities; Not Over-Fixating On The Person’s Impairments**

When we focus on what people are not, or on what they cannot do, it blinds us to who they are and, even more importantly, who they might yet be. Most impairments that people live with can be offset to a large degree by good supports that take care of the things that the person cannot do for themself. So, while people may be constrained to some extent by their disability, it is important to not become overly focused on this, as it will make it hard to concentrate on what could be possible in life for the person, particularly if the person gets the support they need. By focusing on a person’s gifts, assets, potentials, capacity to enjoy life and their many passions and interests, it is only a matter of time and diligence before some kind of lifestyle will begin to emerge for the person. On the other hand, by constantly using the presence of disability as an excuse for not having or expecting a good life, we will talk ourself and others into a self defeating hopelessness. This is why it must become a habit with us to not give undue energy to the ways that disability creates limits for a person and instead shift our focus and energy towards what is still possible in the person’s life and what we can do about realising that potential. By doing so, life and its many enjoyments become closer rather than farther away.

**Seeing And Meeting The Person’s Needs In Typical Ways**

A great danger exists when we make the mistake of believing that people with disability cannot get their needs met in largely the same way that other people do. This is because it leads to us setting people with disability aside from others in so called ‘special’ places and programs, as if these are the only way that they will get what they need in life. More often than not, they will get much less. Further, they will be harmed if they are denied the chance to get the ‘real thing’. Why we must look to using the same resources as people without disability, is that these actually do meet the needs of countless ordinary people. It is true that people with disability may require some support to take advantage of these, but this should not be a reason not to take advantage of them. For instance, we do not need special clothing stores for people with disability when we have perfectly good shops already. The same could be said about ‘regular’ gyms, choirs, sports leagues, knitting groups, churches, airlines, homes, jobs and all manner of other ‘regular’ solutions to our needs and that of millions of others. This is because they can actually meet our needs and so, therefore, it is crucial that people with disability get to take full advantage of these.
Undoubtedly some of these regular and normal ways of meeting one’s needs will lead us to some people who are less accepting and welcoming of people with disability, but these kinds of people can change in time as they relax and come to be more comfortable with the newcomer who happens to have disability.

**Sharing Life With All People**

There is a theory that claims that people with disability could only be comfortable and secure if they lived out their lives ‘with their own kind’. This overlooks the fact that most people with lifelong disability actually grow up and live quite comfortably within families in which they are the only person with disability. They most certainly can and do enjoy their lives and relationships not only with family, but also with all manner of people that they like and feel comfortable with. So, the real issue in whether people can get along with others is not disability, but rather compatibility. People with disability are people like everyone else and so will quite naturally feel comfortable with and enjoy people that they find likeable and good company.

The more we emphasise this, the more we will begin to realise that it is the qualities of people that matter in congenial relationships, not whether they have or do not have disability. Whether these relationships occur in work, leisure, home or community groups may not matter as long as the time spent with people is pleasant and supportive. In fact, there are all sorts of instances where people with disability do not get along with other people with disability. This is not because of their disability at all, but rather their lack of compatibility. So, when we focus on this, we will see that congenial and friendly people of all kinds are actually ‘their own kind’ if they end up getting along well. Since there is obviously a wealth of lovely people in this world, it is important to be sure that people with disability get all the chances possible to meet people whose company they enjoy.

**Belonging To Groups That Share One’s Interests And Passions**

People with disability can usually have and enjoy any life interest that others also are attracted to. Similarly, when people share in a common passion or interest, they naturally gravitate to groups that are engaged in that interest. In the process, they not only get to share a passion, they also form bonds of friendship and comradeship stemming from the things they love and place considerable personal importance on. In this way, they find a place of belonging amongst others and the ability to say that they are a member and one of many. This helps form identity, can often provide status and typically, leads to various valued social roles within the group - and possibly in relation to others who are not part of the group. Further, others will also get to know and appreciate them and this will provide for all manner of relationship ties, including many lasting friends. It is true that
facilitating such opportunities has its challenges, particularly in regard to groups that are wary of newcomers and slow to welcome them, but these are natural enough inhibitions that may be overcome with time and dedicated facilitation.

**Contributing To Life**

Life need not only be about what others may do or not do. It can also be about discovering within yourself ways that you can give back to life and to the people and communities with whom you live. When we concentrate upon the gifts of people, we enable these to be noticed and to find expression in everyday life. All people have qualities and capacities that can add value and enrichment to the lives of others. When these gifts of people with disability are overlooked or remain undernourished and underdeveloped, we will be the poorer for it. So, it is important that we focus on people with disability and the contributions that they both want to and can make to life.

**Having A Unique Life, Well Suited To The Person**

It is a paradox that we are all so similar as human beings and yet, at the same time, we are all distinctly unique people. People with disability are every bit as unique and diverse and when their uniqueness is fostered and allowed its natural expression, then it becomes possible for a person to seek out and embrace a life and lifestyle that most optimally suits them as a person. Of course, the better the fit of one’s lifestyle to one’s personality and preferences, the happier most people will be. It is important to most people to be the designers and decision-makers of their own lives and to be able to pursue the directions in life that most closely align with one’s ultimate purposes in life. It is no different if you have disability and the satisfactions are exactly the same when you can be your own person.

**Not Allowing Vulnerabilities To Be The Reason To Deny A Person A Good Life**

It is true that many people with disability may live with vulnerabilities that are more intense and worrisome than others might face. It would also be irresponsible to neglect these vulnerabilities. Fortunately, it is also possible to constructively offset such vulnerabilities with intentional safeguards that are well matched to the precise concerns that are present. Should this happen, then most of normal life can and should go on for the person much as it does for others. However, if such vulnerabilities are ignored, supported poorly or are overly emphasised, there is a risk that the healthy, satisfying and vibrant lifestyles that can be lived, even if one lives with serious vulnerabilities, will be threatened. Vulnerability is not a reason to not pursue a full life, as the enjoyment of life is the same in its essence whether you have or do not have vulnerabilities to contend with.
SRV Theory As A Guide To Assembling A Good Life

SRV theory is not a panacea, nor was it ever said to be. Life will be a challenge whether one has disability or not. However, if one is poorly advised on what it takes to make a good life, then it is possible to miss many of the real opportunities that exist to do this. So, the best way to see the role of SRV, is as a body of advice about how people with disability can obtain fulfilling lives and address their diverse and unique potentials as human beings. In this, SRV theory has much to offer, as can be seen in the results it can lead to if employed properly. In this way, SRV theory is wise counsel.

Michael Kendrick is an independent, international consultant in human services and community work. He has worked in the disability, mental health and aged care fields for nearly thirty years and occupied a variety of roles. He is an active public speaker and trainer as well as evaluator, consultant, and advisor to advocates, governments, agencies and community groups. He also writes extensively and many of his articles are available through Family Advocacy’s Inclusion Collection Library. He resides in Massachusetts.
Supported Living: What’s the Difference?

John O’Brien

Supported living is a simple concept in danger of being complicated until its power to help people with developmental disabilities gets lost. Its simplicity is elegant.

a person with a disability
who requires long term, publicly funded, organized assistance
allies with an agency whose role is to arrange or provide
whatever assistance is necessary for the person to live
in a decent and secure home
of the person’s own

Because people with developmental disabilities have different ideas about what a decent and secure home of their own would be like, different requirements for assistance, and differing abilities to communicate their preferences and needs, and because their ideas, requirements, and abilities change as they grow and develop, the promise of supported living lies in its potential to deal creatively with the complexities arising from the lives of many different individuals. Supported living focuses at the scale of individual lives, where there is the best chance of understanding the problems and possibilities in each person’s situation: many people over extended time equals much variety in living and support arrangements. Increasing variety challenges common assumptions and structures for management, which typically aim to reduce variety.

The capacity to generate a variety of types of assistance is the essence of supported living. Potentially destructive complications arise from at least two sources:

• Supported living expresses a fundamentally different relationship to people with developmental disabilities than most other approaches to service do: instead of controlling people with disabilities in order to fix (train, habilitate, rehabilitate, treat) them, supported living workers seek to cooperate with people with disabilities in order to develop the assistance they need to get on with their own lives. This contrast

This paper is based on a two day retreat with California leaders in the development of supported living convened by Allen, Shea & Associates in January 1993, meetings with the staff and the board of Jay Nolen Services, Los Angeles, CA, and a half day meeting with members of Oregon’s Supported Living Network in February 1993. Thanks to Charles Galloway, Connie Lyle O’Brien, Jack Pealer, Pat Puckett, Connie Saverino, and Doug Watson for their comments on an earlier draft.

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creates dissonance for service workers and managers accustomed to services based on control; the least difficult resolution of the dissonance is to practice the habits of control and call it support.

- Supported living is developing in a time when scarcity, lack of public consensus on the management of scarcity, and rapidly escalating complexity and uncertainty haunt public managers at every level. Decades of rising expenditures on services to people with developmental disabilities (mostly present or former institution residents) have accumulated frighteningly large waiting lists (mostly of people who have been cared for by their families) for costly services. This demand has grown as hundreds of pages of statutory, regulatory, and procedural commitments have accumulated. This situation frightens many public managers into a futile search for greater and greater administrative control. Supported living, even more than other innovations, needs slack to develop and can never be uniform and predictable in the way that services based on standardized control of clients can be. This makes supported living an attractive but threatening anomaly. It’s attractiveness tempts administrators to load it down with untested promises (for example, supported living will be much cheaper because every participant will be required to make extensive use of ‘natural support,’ which is free to the developmental service system). Its threat tempts administrators to hedge it in with increasingly detailed requirements.

The challenges come from these complications: Can those who want to provide supported living step outside of the habits of thought and practice that govern most existing services to people with developmental disabilities? And, can those who want to sponsor supported living create more effective ways to manage public resources on behalf of people with developmental disabilities?

These notes attempt to communicate some of what is different about supported living as it emerges in the sustained work of a small number of agencies whose staff have been learning the hard and happy lessons of providing personalized assistance since before anyone coined the term “supported living” or established a funding source by that name. Focus on the differences that supported living wants to amplify offers a base from which to negotiate the challenges of distinguishing supported living from other forms of service and evolving effective means of public accountability.
**Understanding Supported Living Depends On Personal Experience**

Effectively providing supported living calls for a commitment to understanding the work from two perspectives: the perspective of unique individuals who have developmental disabilities; and the larger, social perspective of people with developmental disabilities as a devalued group. These perspectives develop from reflection on personal experiences with people with disabilities. How well you understand supported living depends on where you stand in relationship to people with developmental disabilities. If you stand over people, assuming that you know best and that people with disabilities will be better off if they do what you say, you will miss the point of supported living. If you stand away from people with developmental disabilities, assuming that they are dangerous, shameful, pitiful, or unacceptable, you will miss the point of supported living. If you see no need to reconsider your own assumptions about and behavior toward people with developmental disabilities, you will miss the point of supported living. Only when you stand with people with developmental disabilities, recognizing their common humanity, honoring their desires to make a life for themselves, and struggling with them to create new opportunities, can you begin to understand supported living.

A group of leaders in agencies pioneering supported living identified some of the experiences that have enabled them to step outside the assumptions and practices that usually govern service providers. It will be easier to understand what is different about supportive living if you can draw on personal experiences like those described here.

<table>
<thead>
<tr>
<th>Experience</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Being surprised to discover that people with disabilities are able to do things that experts have told you are impossible for them to do (especially when you believed the experts).</td>
<td>Running a marathon with people who weren’t supposed to be capable of running a mile. Listening to someone for the first time through augmented or facilitated communication Learning to teach someone a complex assembly task.</td>
</tr>
<tr>
<td>Sensing injustice and wanting to act when people underestimate or exclude people with disabilities whom you know.</td>
<td>Seeing people in an institution and knowing it was wrong for them to be there. Deciding to break rules that required demeaning treatment of people with disabilities. Seeing kids go from an integrated pre-school to a segregated kindergarten and deciding to work for change in schools. Being outraged to discover how many people with disabilities have been sterilized.</td>
</tr>
<tr>
<td>Feeling confusion, loss, and anger when others exclude a person you know because they see a disability as the most important thing about someone you know as a friend.</td>
<td></td>
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<td>---</td>
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<tr>
<td>Missing a childhood friend institutionalized after a car accident and continuing to wonder why it had to happen that way.</td>
<td></td>
</tr>
<tr>
<td>Wondering how other people could just assume that a neighbor with a severe disability belonged in segregated settings.</td>
<td></td>
</tr>
<tr>
<td>Feeling very uncomfortable with the hierarchy of status imposed on “staff” and “clients.” Thinking that things like separate staff toilets and rules and procedures about how “we” should interact with “them” seem like apartheid.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sharing personal time and activities as an equal with people with disabilities – not being a caregiver or a supervisor or a trainer.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Going camping with a person with a severe disability and discovering new ways to just be with her.</td>
</tr>
<tr>
<td>Watching late movies and eating popcorn with people (against the rules of the facility).</td>
</tr>
<tr>
<td>Spending time with a person with a severe disability who is dying well.</td>
</tr>
<tr>
<td>Finding yourself helped and supported through a hard time by a person who was supposed to be a “client”.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Purposely choosing to change your usual role and learning from the change.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being an active member of a support circle for someone who is neither a relative nor a client.</td>
</tr>
<tr>
<td>Providing personal assistance to someone instead of supervising their program.</td>
</tr>
<tr>
<td>Being part of the creation of an innovative service either as part of a planned effort or because no one knew what to do for a particular person and you decided to do what-ever it took to make things work for that person.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Discovering big differences in life experiences between oneself and some people with disabilities.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being reminded over and over how little money people get to keep.</td>
</tr>
<tr>
<td>Having someone you have known for 15 years continue to seek reassurance that you are their friend.</td>
</tr>
<tr>
<td>Studying the history of services to people with developmental disabilities and the theory of normalization and finding a frame of reference for understanding the systematic pattern of negative experiences imposed on socially devalued people.</td>
</tr>
</tbody>
</table>
Recognizing similarities between oneself and people with disabilities which are much deeper than apparent differences.

Enjoying the results of the challenges and conflicts that come from embracing diversity

A Negative Way Toward Definition

It is helpful to define the edges of supported living by saying as clearly as possible what it is not.

<table>
<thead>
<tr>
<th>Supported Living is NOT...</th>
<th>Supported Living IS...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ø A “program” to fix or change people</td>
<td>• A safe &amp; decent home of your own</td>
</tr>
<tr>
<td>Ø Isolation &amp; loneliness</td>
<td>• Choice</td>
</tr>
<tr>
<td>Ø Segregation by disability or income</td>
<td>• Personalized assistance</td>
</tr>
<tr>
<td>Ø Forcing people to live the way we think is good for them</td>
<td>• Support from others who care about &amp; respect you</td>
</tr>
<tr>
<td>Ø A way to avoid responsibility for careful decisions about threats to people’s vulnerabilities</td>
<td>Ø Another stop on the service continuum</td>
</tr>
<tr>
<td>Ø An excuse for letting bad things happen to people</td>
<td>Ø An incentive or reward for good behavior</td>
</tr>
<tr>
<td>Ø Targeted at a particular (dis)ability group</td>
<td>Ø A curriculum or list of skills to master to remediate deficiencies</td>
</tr>
<tr>
<td>Ø (Benign) abandonment to whatever consequences follow problems</td>
<td>Ø Expecting that the amount of assistance necessary will always decrease</td>
</tr>
<tr>
<td>Ø Another name for “downsizing” existing facilities into smaller units or otherwise renaming existing services</td>
<td>Ø Just getting an apartment to live in</td>
</tr>
<tr>
<td>Ø Compatable with services that congregate &amp; control people</td>
<td>Ø Being grouped on the basis of disability</td>
</tr>
<tr>
<td>Ø A funding stream for use to do more of the same kinds of services</td>
<td>Ø Being assigned roommate(s).</td>
</tr>
<tr>
<td>Ø Segregation by disability or income</td>
<td>Ø Having permission to live in an agency controlled apartment</td>
</tr>
<tr>
<td>Ø Just getting an apartment</td>
<td>Ø Signing a lease on a place that staff control</td>
</tr>
<tr>
<td>Ø A fixed amount of assistance forever</td>
<td>Ø A set of uniform requirements &amp; procedures</td>
</tr>
<tr>
<td>Ø Isolation &amp; loneliness</td>
<td>Ø Justified because it is always or necessarily cheaper than group living</td>
</tr>
</tbody>
</table>

Discovering that a group of people with developmental disabilities share your personal experience of surviving childhood abuse.

Feeling the continuity between a family tradition of work for social justice and the personal struggles of people with developmental disabilities.

Thinking over and over again about a teacher’s comment: “There is less difference between any ordinary person and a person with a profound disability than there is between any person and their potential.”

Getting an entirely different approach to a difficult personal problem from someone whose culture and experiences give them a completely different way to look at the world.

Becoming best friends with someone who is as different from you as can be.
Notice that the misunderstandings express several contrasting themes.

<table>
<thead>
<tr>
<th>Common Assumption</th>
<th>Better Assumption</th>
</tr>
</thead>
<tbody>
<tr>
<td>The existing service system just needs improvement through the addition of another service element or minor reforms (e.g., making service settings smaller)</td>
<td>Supported living is compatible with the goals of public policy for people with developmental disabilities (e.g., concern for individualization, integration, and choice). But it is a fundamentally different way to work toward those goals. It challenges, and overturns, the logic of any service continuum and most current forms of regulation.</td>
</tr>
<tr>
<td>People with developmental disabilities need professional people to define their problems, prescribe solutions, and exert control to insure compliance with their recommendations.</td>
<td>People with developmental disabilities need allies who will… …help them define what matters to them. …help them develop the system of personal assistance necessary for them to pursue what matters to them. …help them resist intrusive and disrespectful regulatory and service practices.</td>
</tr>
<tr>
<td>People with developmental disabilities should either be in a program (under staff control) or on their own (with minimal or no assistance).</td>
<td>People with developmental disabilities can be in charge of their own lives and get the assistance they need to live in safety and dignity.</td>
</tr>
<tr>
<td>Service providers are primarily responsible to insulate people from risks. Often this will mean controlling a person’s access to opportunities and activities.</td>
<td>Service providers are responsible to assist people to deal constructively with their vulnerabilities. Sometimes this means sticking with people through very difficult and confusing experiences and sometimes it means working hard to negotiate a safer situation with a person.</td>
</tr>
<tr>
<td>It doesn’t really matter who controls the home of a person with developmental disabilities</td>
<td>When given the opportunity, many more people with developmental disabilities than anyone ever thought want the assistance necessary to be in control of their own homes.</td>
</tr>
</tbody>
</table>
One of the biggest challenges to established providers who want to convert their services to supported living lies in the unfamiliarity of many of the problems they will encounter. Existing services have evolved as a set of habitual solutions to common problems, forming a kind of culture. Serious engagement with supported living raises the problems beneath these habitual solutions into uncomfortable awareness and calls for new solutions.

People involved in the work of supported living have identified the complex mix of problems identified in the following paragraphs.

**Poverty**

As people move into their own places and rely on SSI, Food Stamps, and rent subsidies for their living expenses, the reality of their material poverty becomes more apparent. They, their families and friends, and staff become more aware of the quality of housing, transportation, and health care available to poor people. The issues arising from people’s poverty demand substantial problem solving effort.

**Loneliness & Isolation**

For some people, moving away from a congregate setting increases loneliness. With adequate opportunities and help, a person can respond to loneliness as a motive to develop connections to other people and activities. If staff and important others ignore or interpret the person’s loneliness as unavoidable, the person may well slip from a transitional state of loneliness into long term isolation.
People who enjoy their relationship with paid staff may express little interest in expanding their personal connections, preferring instead to hang out at home with staff. Staff with positive relationships need to be particularly conscious of the benefits of a growing social network and active in offering people opportunities to try new things and meet new people.

Successful matching of people with disabilities and paid assistants results in a positive, personal relationship. Some people with disabilities will come to see their assistants—particularly paid roommates—as friends. This can create problems when the assistant performs necessary tasks poorly, especially when other staff are concerned about performance problems that the person supported is willing to overlook because of feelings of friendship.

Staff must re-think the principles which have guided practice in agency controlled settings. Some agencies have organized teaching activities to shape independent performance to a ‘normal’ standard: their goal has been to move the person from disability (doing different things differently from ‘normal’ people) to normalcy (doing the same things the same way as ‘normal’ people do them). Some agencies have standards for physical environments that are incompatible with the kinds of places and furnishings usually available to people who are just starting out in their own homes. Assuring that people have safe and decent accommodation and providing effective ways for people to develop relevant skills are important contributions of supported living. But the ways these contributions are made and the standards for judging performance shift when services respect and work to increase people’s autonomy.

Instead of referring to standard procedures for solutions to problems, supported living workers learn to refer to their understanding of the person’s life. What to do about a person whose refrigerator isn’t clean depends on the person, the expectations of other important people like landlord or roommates, and the kind of relationship the person has with the worker and the agency. Understanding context is essential to good problem solving.

Some agencies have grown accustomed to thinking about their obligations to their clients primarily in terms of meeting regulatory requirements and avoiding legal liability. In our litigious society, this impersonal and defensive way of dealing with people is reinforced by insurance companies and some regulators. As an agency shifts from providing a total program to clients in an agency facility to supporting people in their own homes the nature of the agency’s responsibility shifts in uncertain ways. It becomes less clear where the person’s responsibility for choice begins and the agency’s sole responsibility leaves off.
Agency preoccupation with avoiding liability blocks the development of responsible ways to strike an individualized balance between personal vulnerability and individual autonomy.

Creating Community Opportunities

Much of what people with developmental disabilities need most, they need from other members of their communities. Because historical patterns of discrimination have excluded people with developmental disabilities from many aspects of community life, supported living workers have to be active in developing community opportunities with the people they assist. If supported living workers are passive, exclusion and isolation will continue. Because many services have responded to people’s exclusion by attempting to simulate community life within services, workers will find themselves dealing with many situations where the presence and active involvement of a person with a developmental disability is a new, and possibly a strange, idea.

Some community members may believe that service agencies exist to contain and control people with developmental disabilities. Re-positioning the agency as a support to people may call for education, negotiation, and perhaps conflict. Conflict can be threatening if it involves politicians, the media, or the police.

Collaborative Relationships With Family Members

Some family members believe that services that control people with developmental disabilities are necessary for their safety and that choice would be dangerous. Some family members believe that congregating people with developmental disabilities together is necessary to prevent isolation and loneliness. Some family members believe that professionally prescribed treatments are the most important things for people with developmental disabilities. Because supported living is based on beliefs which may be different from those held by family members, supported living workers must become skillful at listening to family members’ concerns, negotiating agreements with them, and, sometimes, balancing the concerns of family members with the choices of competent people with developmental disabilities. Negotiations with some family members will be more difficult because they have received, and followed, contradictory advice from professionals committed to controlling people with developmental disabilities.

New Ways to Plan For People

The service system plans for people in a linear, rational way. Annual objectives and regular periodic reviews are supposed to control the amount, direction, and means of assistance a person receives. This assumption is built into the regulation and review systems. But people’s real lives change differently. Needs for more or less support or the discovery of a new area of need or interest doesn’t follow an orderly pattern. Supported living agencies end up working around and amending formal individual plans much more than implementing them.
New Ways To Deal With Dangerous Situations

Some people with developmental disabilities may be dangerous to themselves or to other people. The basic image of supported living — keeping up with changing needs for assistance in ways that put the person’s choices first — may need to give way to managing a person’s life: taking purposeful action to limit the person’s choices. It is very challenging to deal with both these kinds of assistance but, if an agency chooses not to do so, some people — for example people who get into conflict with the law or people whose judgment is dangerously poor — will lose their place in their community.

This problem is compounded when service system managers define supported living primarily as a response to people whose needs are extremely challenging to understand and meet. Narrowing the availability of supported living in this way not only discriminates against the many people with developmental disabilities now contained by group living arrangements, it distorts the development of supportive living agencies by multiplying the number of very complex situations they must deal with.

New Means to Find Flexibility in Funding

Individualized funding may reduce the slack an agency can use to respond flexibly to changing needs. Administrators who have learned creative ways to save and shift funds within group home budgets to allow for innovation or exceptional circumstances have less room to maneuver as support funds are controlled by person/hour of assistance.

New Forms of Supervision

As people move into their own homes, direct, “eyes on” supervision of front line staff is virtually impossible. Staff must become much more autonomous in managing their schedules and in making decisions about people’s well being and the best uses of agency time. In order to sustain effective alliances, all staff have to learn to make judgments consistent with agency values. Every worker will deal with community members. Some workers find this much expanded role challenging and interesting; others find it a greater responsibility than they want to manage.
Managers have to learn to be effective consultants in problem solving and effective mediators in complex relationships. The agency must develop ways to insure that staff don’t feel isolated and unsupported, and these must be thoughtfully created so that staff don’t feel distrusted or manipulated.

The Need For Sustained Creativity

Typically, agencies value stability in residential arrangements. The need for creative effort seems highest at first, as the agency learns a new way of serving people. Creativity then drops off as people settle in to routine expectations and practices. Once the service model is standardized it can be replicated with little added effort. Supported living requires a much longer period of creative activity. New ways to relate to people with developmental disabilities and their families and friends take sustained creative effort. Effective routines develop around many tasks, such as helping people locate housing and dealing with people’s physicians and dentists, but agency leaders need to channel the energy freed by these routines into efforts to increase the responsiveness and flexibility of the agency. Developing new opportunities in the housing market and in neighborhoods takes sustained creative effort. Responding to changing interests and needs in a flexible and economical way takes sustained creative effort. Responding to changing external requirements in ways that preserve agency mission and values takes sustained creative effort. Renewal of mission and encouragement of active problem finding define key leadership tasks in a supported living agency.
As supported living agencies face these problems and consciously develop and share solutions they will develop a new culture to give meaning and direction to their work. Given the difference between supported living and most other forms of service, it is especially important for supported living workers to maintain a strong network of personal connections to others doing the same work in other places.

The Obligations of Supported Living

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 should accept to the person they assist and their families and friends.

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

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

We recognize that you may disagree with us or be dissatisfied with the assistance we provide, we accept responsibility to…
…respond to your concerns about the person’s safety and well being
…negotiate openly with you in search of mutually satisfying outcomes

We realize that you and the person we assist may have different, perhaps even conflicting, ideas about what is possible and desirable for the person; in the event of these differences we agree…
…to uphold the importance of mutually respectful relationships among family members
…to assist you to negotiate a satisfactory resolution to the conflict, if our help is acceptable to you and to the person we assist
…if the conflict is serious and you cannot resolve it, we will maintain respectful contact with all parties but honor the choice of the person we assist.

These obligations make plain an uncomfortable fact at the heart of supported living: to assist people with developmental disabilities in this way is to become vulnerable to them, to their families, and to their communities. Our success depends more on inviting and assisting people with disabilities and community members to do what we cannot do: create satisfying lives and fulfilling community relationships.
Additional information can be found on our Web site: http://apd@myflorida.com

Follow the links to “Supported Living” and download a copy of the Guide to Supported Living in Florida.

Sandy is 68 years old. He grew up on his family’s dairy farm in Pennsylvania. He and his mother moved to St. Petersburg in the 1960’s. In 1979, his mother was diagnosed with a terminal illness. Sandy had no other family, so he left the home and a lifetime shared with his mother to live in an Intermediate Care Facility for persons with Developmental Disabilities (ICF/DD). There, he learned to live without her, surrounded by 46 other people.

His guardian approached Sandy about moving into his own home. No one was sure how he would react to the idea of supported living. Once it was described, Sandy’s response was: “When do I move…before Christmas?”

A house was found that matched Sandy’s vision. He moved in two days prior to his birthday. There, he celebrated 68 years of living and the fact that for the first time, he had a home of his own. Sandy has had countless new experiences as a result of supported living. He sleeps in a double bed, decides what his meals will be and when he will eat them, buys his own groceries, walks nearly one mile daily… and the list goes on. In short, he enjoys the freedom, individuality, and contentment that can be realized through supported living.
WHAT IS SUPPORTED LIVING?

Supported living is an opportunity to choose where, how, and with whom you live. In supported living you receive the supports and services you need to live in your own home, in your own community.

WHERE DO PEOPLE LIVE?

All over the community! People rent, lease or buy houses or apartments that are available through the local housing market and receive the training and assistance they need to maintain their own private homes. Supported living is a residential option that does not include any agency-owned, state-owned, or congregate housing.

WHO IS ELIGIBLE?

Anyone 18 years of age or older who:

☑️ is a consumer of Developmental Services;
☑️ wants to live in his or her own home; and
☑️ needs some supports and services to live there.

WHAT KIND OF SUPPORT CAN BE PROVIDED?

Each supported living arrangement is different, just as each person is different!

Most individuals in supported living receive services from a supported living coach. Coaches assist people in areas where they need some support and help them learn to do new things. This can include finding a house or apartment, setting up a household, using a bank and managing money, planning and preparing meals, using public transportation, shopping, and many other life skills. Coaches help people find and use the resources of the community and make connections with others who live there. An important part of a coach’s job is supporting people to make everyday choices and to be responsible and safe in the community. Supported living coaches also provide emergency assistance as needed 24 hours a day, 7 days a week. Coaches may work with you for up to 90 days prior to moving into your own home.

Some of the other services that might be provided to someone in supported living through the DS Home and Community Based Waiver include support coordination, in-home supports, homemaker, companion, respite, chore services, adaptive equipment, personal emergency response systems, therapies, community employment services, adult day training, and transportation. Some individuals may receive a financial subsidy to help with basic living expenses. Each support arrangement is different and depends on the individual’s needs and desires, as well as available resources.

WHO SHOULD I TALK TO?

Ask your support coordinator (case manager) for more information about supported living and about supported living services in your area. If you need information about becoming a consumer of the Developmental Disabilities Program, get in touch with your local Developmental Disabilities district program office. Ask about the Supported Living Liaison Network. This network is comprised on individuals who live in homes of their own and have volunteered to share their experience with you.
Introduction

Getting ready to leave high school can be both exciting and stressful. Young adults with disabilities need to figure out what their interests are and develop goals for the future. Decisions need to be made about where the young adult might live, what kind of job they might have, or where they may continue their education. New life options create opportunities for more decision-making. Although young adults with disabilities may become more independent during this time, the support and encouragement of others remains crucial for success.

The Institute for Community Inclusion (ICI) interviewed high school students with disabilities and their parents/guardians. ICI asked these families about their plans for the future and how others may have influenced their decisions. In addition, both students and their parents were asked to tell ICI about important decisions they have made as a family, and who they depend on when there is a problem and support may be needed.

Three stories

Many of the students and parents who participated in ICI’s study described how they used and depended upon their personal networks—both formal and informal—to figure out what they need and want, and help them discover, reach for, and achieve their personal goals. In addition, these personal networks helped to develop self-determination in the young adult. The three stories that follow illustrate ways that students used personal networks to help them achieve their goals, and sometimes, how they could be better used to make their goals a reality. These examples also illustrate how personal network members helped to develop self-determination.

(The stories that follow are based on conversations with the students and their parents. Please note that names have been changed to protect their privacy.)

What is self-determination?

People who have self-determination know what they want and how to get it. They know a lot about themselves and have a clear vision for the future. Self-determined people can make decisions for themselves, and know what they have to do to achieve their goals. They feel independent and in control of their life plans. A self-determined person does not need to know all the answers, but they know that there are a variety of options in life that are available for them. They understand their own strengths and weaknesses, try to solve problems, and make their own choices. Self-determination is related to self-esteems and confidence because in order to pursue your goals, you need to feel that you can do it! In addition, self-determined people know how to find help when they need it. This help usually comes from their personal network.)
Heather, a recent high school graduate with physical and special health care needs, expected to have a full-time job, live with her boyfriend, and someday have kids of her own. She felt very strongly about the value of work, as she said, “I want to work 100%. I want to work for my money.” Heather’s personal network exposed her to a variety of employment opportunities. When she was looking for a summer job, a family friend who worked in landscaping helped her find a job in the business. In addition, her brother introduced her to the auto body field by letting her work on his car. This led Heather to take classes in auto body at school to gain more experience. These experiences gave Heather the knowledge to develop work and career goals. Heather gathered the support she needed from her boyfriend and brother who went with her as she collected job applications, helped her fill them out, and provided encouragement. Heather’s brother advocated on her behalf to their mother. “He’s the one that’s fighting with my mother telling her that I should work.” Heather also applied for jobs independently and used school personnel to help her uncover the Department of Vocational Rehabilitation (VR) as an additional resource. She set up an appointment with a VR counselor on her own. All these activities led her to find a job in a field that matched her interests.

**Important points:**
- Heather’s network gives her opportunities to discover her preferences by exposing her to a variety of work experiences.
- Heather chooses to work. Her self-determination is evident in her strong desire to work despite her mother’s concern.
- Heather demonstrates self-determination not only by independently finding VR as a resource, but by gathering support from her boyfriend and brother.
- Heather makes substitutions for gaps in her personal network. Because she feels her mother was not supportive, she finds other people (her brother, boyfriend, and school personnel) to help her out. Positive network members balance out other members who have reservations.
- Heather uses a combination of informal network members (brother and boyfriend) as well as formal network members (school personnel, counselor from VR) to reach her employment goals.
- Heather’s informal network provided both encouragement and specific help (like filling out applications).

**Story 1:**
I found what I needed to move forward.

Heather, a recent high school graduate with physical and special health care needs, expected to have a full-time job, live with her boyfriend, and someday have kids of her own. She felt very strongly about the value of work, as she said, “I want to work 100%. I want to work for my money.” Heather’s mother, however, was concerned that a full-time job would have a negative effect on Heather’s Social Security benefits.

Despite her mother’s concerns, Heather was determined to go forward. Throughout high school, Heather’s personal network exposed her to a variety of employment opportunities. When she was looking for a summer job, a family friend who worked in landscaping helped her find a job in the business. In addition, her brother introduced her to the auto body field by letting her work on his car. This led Heather to take classes in auto body at school to gain more experience. These experiences gave Heather the knowledge to develop work and career goals. Heather gathered the support she needed from her boyfriend and brother who went with her as she collected job applications, helped her fill them out, and provided encouragement. Heather’s brother advocated on her behalf to their mother. “He’s the one that’s fighting with my mother telling her that I should work.” Heather also applied for jobs independently and used school personnel to help her uncover the Department of Vocational Rehabilitation (VR) as an additional resource. She set up an appointment with a VR counselor on her own. All these activities led her to find a job in a field that matched her interests.

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- Heather uses a combination of informal network members (brother and boyfriend) as well as formal network members (school personnel, counselor from VR) to reach her employment goals.
- Heather’s informal network provided both encouragement and specific help (like filling out applications).

**How can a personal network help to develop self-determination?**

Personal networks can guide the self-determined person as they solve problems and support them when important decisions are made. People from the personal network help teach new skills as goals are achieved. The self-determined person learns to plan and coordinate their lives with help from these important people. Members from the personal network provide more and more opportunities for the self-determined individual to make decisions and learn new skills on their own.

**What is a personal network?**

A personal network is basically everyone that a person knows. This includes both formal and informal network members. Formal network members are professionals such as school counselors or teachers. Informal network members are people close to you, like your friends, family members, and others you may have met in social organizations, sports teams, religious organizations, or even in your neighborhood.
Shantelle, a recent high school graduate with a psychiatric disability, worked part-time while living at home. A large, dependable network of both formal and informal network members helped support her as she developed her goals. This included a close friend, teachers, a therapist, and a neighbor who employed her as a babysitter. Shantelle talked to a close friend and teachers about her decisions for a career, and a therapist about more personal problems.

Most importantly, Shantelle has had great support from her mother. They agreed in their hopes and goals for her future. Shantelle said her mother supported her to reach greater independence: “She doesn’t suggest anything. She thinks it should be my concern and my issues what I should do. She thinks I am responsible for myself. She lets me make my own decisions...[but] if I don’t know if it’s a good or bad idea I ask for her opinion.” Shantelle’s mother confirmed this by saying “if she says she wants to try something I don’t stop her.... We let her make her own decisions. The only way you are going to learn is to make the mistake on your own.”

The only challenge Shantelle’s mother saw that could stand in Shantelle’s way was her tendency towards low self-esteem. This motivated her to surround Shantelle with support. Shantelle’s mother gained insight through talking to teachers, the family doctor, church members, and even neighbors. “That’s what it takes, you know. Keeping that self esteem up and saying... ‘We know you can do it.’” Shantelle’s family and friends were quite proud of her. Shantelle’s mother best summed up her philosophy and optimistic outlook for her daughter when she said, “We’re all looking for a bright future for her.”

**Important points:**
- Shantelle’s mother supports Shantelle’s self-determination by listening and making suggestions, and not making decisions for her. Shantelle’s family and friends focus on building her self-esteem and confidence so she can move forward and be more self-determined.
- Shantelle has a large personal network that includes both informal network members (close friend, neighbor, and especially a strong relationship with her mother) and formal network members (teacher and therapist).
- Shantelle uses members from her personal network differently—some she talks to specifically about work (friends and teachers), while others support her more personal concerns (therapist).
- Shantelle’s mother uses her own network to learn how to support Shantelle and encourage self-determination.
- Shantelle’s mother makes sure not only that she is surrounded by support, but uses her own network as an expansion of support for her daughter.
- Shantelle and her mother are in alignment. This means that they agree, and share high expectations for the future. This alignment and shared goals are crucial in maximizing Shantelle’s self-determination.

**More about where this came from**
These stories are based on interviews with high school students and their parents/guardians. Each student and their parent/guardian were interviewed for roughly 45 minutes. Nine students and eight parent/guardians (6 mothers, 1 father, and 1 foster mother) were interviewed in total.

The families who participated in this study were probably much like your own. They had varying racial/ethnic backgrounds, and the students ranged from freshmen to seniors in high school. The young adults had a wide range of disabilities including physical, cognitive, learning, emotional/psychiatric, behavioral, and sensory impairments. Some families lived in suburban locations while others lived in cities.
Carlos, a recent high school graduate with a cognitive disability, had a variety of interests including art and electronics and was very serious about working. However, while he had ideas about careers that would fulfill his interests, he did not know how to make it happen. He had high expectations for his future and didn’t want to settle for any old job. High school frustrated him because he felt that the work experiences and skills he learned there would not prepare him for the working world: “I am not going to get anywhere with those jobs.” Although he advocated to change his situation at IEP meetings, school personnel did not change his program.

Carlos’ mother was also disappointed by his school, and supported his advocacy efforts. However, she was concerned that Carlos’s standards might be too high. “He doesn’t want to take any suggestions... I don’t think he understands [that] he doesn’t get to pick and choose.” She also doubted whether he would be able to pursue the jobs he liked. “It’s kind of, like, out of his grasp, but I don’t say that.”

Carlos and his mother used two formal network members to help him succeed. This included a professional from a private organization and a counselor from the Department of Mental Retardation (DMR). Carlos’s mother coordinated these services. Carlos’ mother also used his monthly SSI check as a “bank account” to give him experience in using money. However, Carlos’s mother reported that they didn’t use their own personal network as a resource: “We’re it, my husband and I.” One result is that, according to Carlos’s mother, Carlos relied on her too much.

While Carlos’s mother wanted Carlos to be independent, she feared that he would make bad choices if left to his own resources. “I don’t think he is mature enough to understand what the big decisions are and how he can handle them.” She didn’t know how to support him to make good decisions on his own without her making them for him. “I kind of guide him.... I kind of sway him, kind of try to con him into it.”

Carlos felt the lack of support. Despite a college course in computers, he didn’t feel confident that he could find a job he liked. Carlos felt stuck. “I don’t want to be alone... for the rest of my life. And I don’t have a good job that I am good at.”

**Important points:**

- Carlos demonstrates self-determination through his strong desire to work, not settling for the limited options offered him by his school program, and self-advocating at school IEP meetings.
- Carlos shows self-awareness in that he had clear interests. Having self-awareness is a crucial first step to being self-determined.
- Carlos’s family helps to develop self-determination by encouraging him access to his SSI checks. Carlos’s mother uses SSI as a tool to increase independence, learn the value of money, and teach financial planning. However, Carlos’s mother is responsible for coordinating the support from his formal network rather than Carlos doing it himself.
- Carlos and his family use formal network members to help him reach his goals. However, Carlos and his mother may not know how useful informal network members such as friends and family could be. A broader range of informal contacts could give Carlos a fuller array of assistance and help him get a clearer focus on his goals, skills, and opportunities.
- There is a **lack of alignment** between Carlos and his mother. This means they did not agree or share the same expectations for Carlos’s future. Although they shared the vision that he would work and live independently in the future, they disagreed about what jobs he is capable of pursuing at that stage. Carlos’s mother thought that Carlos was too picky. Carlos, on the other hand, didn’t want to waste his time on jobs that didn’t match his interests.
- Carlos feels **powerless**, like he was not “in the driver’s seat.” This is the opposite of self-determination. Carlos does not see himself as being on a positive path to a fulfilling future.
What can Carlos & his family do?
Carlos’s mother can begin to give Carlos more responsibility in coordinating the support he receives from formal network members. In addition, while continuing to rely on their formal network members, Carlos and his family could develop their informal network. In this way, Carlos could gain a fuller array of assistance, particularly in areas that he is interested in, with the addition of the personal knowledge and insight that family, friends, and neighbors can give. Their support could help Carlos get a clearer focus on his goals, skills, and opportunities.

Reach out to your network:
- Participate in community events, such as those sponsored by local groups, schools, and libraries.
- Focus on developing relationships. Establish trust. Spend time doing this before you make specific requests of people.
- Think about ways that you can help your network members. Offer your help. Remember, you can be helpful to your network members just as they are helpful to you.

How can a family develop their personal network? It may not be as hard as you think!

Here is what you and your family can do...
You and your family can identify and expand your personal networks and think about ways to reach out to them and practice self-determination.

Map out your current personal network
- Use the diagram on the top of Worksheet #1 to make a list of everyone you know. This should include all people that you know well enough to have a conversation with. Include family members, friends, community members such as neighbors, and professionals such as teachers, counselors, employers, and co-workers.

Build your personal network:
- Go on a few informational interviews. The goal of this type of interview is to learn about a type of job or a certain company, not to get a job. Informational interviews are an excellent way to explore different interests and jobs while making new contacts. People in your network can help you set up interviews where they work.
- Join different community groups such as local neighborhood organizations, clubs, religious organizations, or recreational facilities.
- Volunteer for a cause you believe in, or an activity that interests you.
- Participate in community events, such as those sponsored by local groups, schools, and libraries.
- Focus on developing relationships. Establish trust. Spend time doing this before you make specific requests of people.
- Think about ways that you can help your network members. Offer your help. Remember, you can be helpful to your network members just as they are helpful to you.

Reach out to your network:
- Ask for help when you are facing big decisions in your life.
- Take the time to tell people what you are thinking about, share your goals, and the challenges you may be encountering.
- Be specific about the ways that you would like people to help you.
- Ask people in your current network about career ideas, and explain your interests. Network members may know about employment opportunities or be helpful in exploring job ideas with you.
- Ask people in your network to introduce you, or refer you, to people they know who may be helpful to you. This can lead to new opportunities.
- Don’t be afraid to ask more than once.
- Realize that members in your network will play different roles and you will not get the same thing from each member.
- Realize that network members aren’t always able to help. There may be times when you ask for help and they are not able to give it to you. This is okay!
- Keep your network updated on your progress. People like to help and it will make them feel good to know that you are working toward your goals.

You are already exercising self-determination just by reaching out to those you know. Remember, a self-determined person knows what they want and can find the support to achieve their goals! It’s up to you to find this support.
A good network member:

- Thinks of themselves as a resource.
- Is willing to listen. He/she may offer suggestions or different ways to think about your decision or issue.
- Will make time in their schedule for you.
- Offers encouragement, guidance, and advice when you need it.
- Is a positive role model.
- Should never be someone you feel uncomfortable with or someone who puts you down.
- Is someone you can trust.
- Is someone who is happy to share his/her experience with you.

A good network member supports self-determination by:

- Asking questions but not directing or making decisions.
- Allowing you to experiment with more responsibility, encouraging you to be more responsible for yourself.
- Allowing you to make mistakes in order to learn from them.
- Offering fewer suggestions to encourage independent decision-making.
- Letting you know that they think you are capable and support the decisions you make independently.
- Building your ability to gradually handle your own affairs.
- Boosting your self-confidence.

Ideas for building independence and self-determination

- Schedule an informational interview in an area of interest. Plan and rehearse phone calls and interviews with someone in your network.
- Take responsibility for setting up job interviews and doing job searches. Participate actively in all aspects of your job search.
- Get involved in school meetings. Bring a list of questions and concerns to your IEP meeting. Consider conducting your own IEP meeting with guidance and support from your school personnel. Remember, they are there to help!
- Learn responsibility through household chores, cooking meals, or having a pet. Hard work often produces rewards!
- Experiment with public transportation when you don’t have to be anywhere important. This is a good way to be able to eventually get to a job or friend’s house without having to rely on others.
- Practice opening and managing a checking or savings account. Having a savings account is a good way to begin saving money for college, a first car, or moving out on your own.
- Share in family bill-paying. This helps to understand the value of groceries, clothing, personal items, or rent.

Figuring out what you want:

The first step to self-determination

Start by figuring out what you want for yourself. These should be your dreams, not someone else’s dreams for you. Explore different career options. Think about what you are good at and what makes you happy. Use the bottom of Worksheet #1 to think about who you are and create a personal vision statement. Write this statement down on paper. Remember, a self-determined person understands his/her own strengths and weaknesses, and knows a lot about themselves. Self-determined people may not necessarily know exactly what they want at all times, and their visions may change from one day to the next, but they know how to get what they need.
Going out and getting it:

The second step to self-determination
Once you have figured out what you want, it is time to develop clear goals and come up with an action plan. Use Worksheet #2 to think about where you would like to see yourself down the road. Again, write down your plan step by step. Take out your list of network members and think about how each member might be able to help. Put a star next to the names of those that you feel especially close to, and whom you would be comfortable asking for help. Different people in your network can probably help you in different ways. Be willing to ask for help and be specific. Remember, you don’t need to have all the answers. Self-determined people know how to get what they want and know how to find help when they need it. They can define their goals and take initiative in achieving them.

Starting early
Although the students in these stories are recent high school graduates, you and your family should not wait until then to start building these skills. In fact, it is important to build these skills early in high school. The point is... it is never too early to start practicing self-determination and expanding your network! So get started!

Conclusion
Being self-determined is exciting, although making your own choices can be difficult sometimes. Don’t be afraid to find and ask for help. Reach out to your personal network and ask them to help you reach your goals. Don’t get discouraged if you feel like you don’t know what you want, you change your mind, or you’ve made bad choices in the past. It’s okay to make mistakes. Remember you are capable and you can do it!
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Who am I and what do I want? Solving the puzzle

Who am I?
Subjects I like(d) in school are:
Activities (sports, clubs, volunteer work) that I like are:
Things I like to do in my free time (work, spend time with friends, etc.) are:
My strengths are:
My weaknesses are:

What is my dream?
What types of goals do I have for myself?
What would be my ideal job? Why?
What is important for me to be happy?
How do I envision my life after high school? In 5 years? In 10 years? When I’m my parent’s age?
My goals and dreams for the future are:

Mapping your personal network

Family

Friends

Community members (neighbors, people from clubs or groups)

Professionals (school personnel, counselors, people from jobs)
Going out and getting it! Planning for the future

When filling out this worksheet, think about your goals in four specific areas of your life. These are: work, learning, living situation, and leisure/recreation. Separate each area, and write out goals and steps for each.

Getting it down on paper

Something I would like to accomplish this year is:

   I will take the following steps to achieve this:

   Step one:
   Step two:
   Step three:

My goals for when I graduate are:

   I will take the following steps to achieve these goals:

   Step one:
   Step two:
   Step three:

My goals for when I’m my parent’s age are:

   I will take the following steps to achieve these goals:

   Step one:
   Step two:
   Step three:

Just do it!

What types of decisions do I have to make?

What problems may come up and how do I solve them?

Some decisions I made this week are:

Gathering support

When I have had problems in the past, who has helped me solve them?

Who can help me achieve my goals? And how might they help?

Person #1_________________________How they might help_________________________________

Person #2_________________________How they might help_________________________________

Person #3_________________________How they might help_________________________________

Person #4_________________________How they might help_________________________________