A Guide to Developing Community Connections

Compiled by
Patsy Davies and Claudia Bolton
October, 1996
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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 are we 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.

Patsy Davies and Claudia Bolton
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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 the 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.)
Third Places

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>Artistic Organizations</td>
<td>choral, theatrical, writing</td>
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<tr>
<td>Business Organizations</td>
<td>Chamber of Commerce, business associations</td>
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<tr>
<td>Charitable Groups &amp; Drives</td>
<td>Red Cross, Cancer Society, United Way</td>
</tr>
<tr>
<td>Church Groups</td>
<td>service, prayer, men's, women's, youth, seniors</td>
</tr>
<tr>
<td>Civic Events</td>
<td>July 4th, art fair, festivals, Halloween</td>
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<tr>
<td>Collectors Groups</td>
<td>stamp collectors, flower dryers, antiques</td>
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<tr>
<td>Community Support Groups</td>
<td>Friends of the Library, nursing home, hospital</td>
</tr>
<tr>
<td>Elderly Groups</td>
<td>Senior Citizens</td>
</tr>
<tr>
<td>Ethnic Associations</td>
<td>Sons of Norway, Black Heritage Club, Hibernians</td>
</tr>
<tr>
<td>Health &amp; Fitness Groups</td>
<td>bicycling, jogging, exercise</td>
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<tr>
<td>Interest Clubs</td>
<td>poodle owners, antique car owners</td>
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</tbody>
</table>
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<table>
<thead>
<tr>
<th>Associations (examples)</th>
<th>Your Area</th>
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<tbody>
<tr>
<td><strong>Local Government</strong></td>
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<tr>
<td>town, fire department, emergency units</td>
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<tr>
<td><strong>Local Media</strong></td>
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<tr>
<td>radio, newspaper, local access cable TV</td>
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<tr>
<td><strong>Men’s Groups</strong></td>
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<tr>
<td>cultural, political, social, educational, vocational</td>
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<tr>
<td><strong>Mutual Support (Self Help) Group</strong></td>
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<tr>
<td>Alcoholics Anonymous, LaLeche League</td>
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<tr>
<td><strong>Neighborhood &amp; Block Groups</strong></td>
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<tr>
<td>crime watch, beautification, Christmas decorations</td>
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<tr>
<td><strong>Outdoor Groups</strong></td>
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<tr>
<td>garden clubs, conservation clubs</td>
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<tr>
<td><strong>Political Organizations</strong></td>
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<tr>
<td>Democrats, Republicans, caucuses</td>
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<tr>
<td><strong>School Groups</strong></td>
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<tr>
<td>printing club, PTA, child care</td>
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<tr>
<td><strong>Service Clubs</strong></td>
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<tr>
<td>Zonta, Kiwanis, Rotary, AAUW</td>
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<tr>
<td><strong>Social Cause Groups</strong></td>
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<tr>
<td>peace, rights, advocacy, service</td>
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<tr>
<td><strong>Sports Leagues</strong></td>
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<tr>
<td>bowling, swimming, baseball, fishing, volleyball</td>
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<tr>
<td><strong>Study Groups</strong></td>
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<tr>
<td>literary clubs, bible study groups</td>
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<tr>
<td><strong>Veterans Groups</strong></td>
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<tr>
<td>American Legion, Veterans of Foreign War</td>
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<tr>
<td><strong>Women’s Groups</strong></td>
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<tr>
<td>cultural, political, social, educational, vocational</td>
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<tr>
<td><strong>Youth Groups</strong></td>
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<tr>
<td>4H, Future Farmers, Scouts, YMCA</td>
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</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.
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What are the major streets for shopping, services, entertainment?

What are the public places (library, community center) that people go?

What are favorite places to shop?

Where is the center of the community? What's there?

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 hesitation 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 of 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 religions 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.
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.
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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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<tr>
<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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<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.
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


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
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October, 1996

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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 and agencies.

**Figure 1: Current Service Coordination Models**

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.

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


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Creating a Path to Employment
Tips for Parents with Children with Disabilities

Start by exploring the work world together

Start Early
Starting early is a key component to your child’s future success. Start by exploring the work world together and conveying your expectations that he/she can and will work when he/she grows up. Provide opportunities for your child to gain early work experience through volunteer work in your community. Web sites such as Career Voyages (www.careervoyages.gov) and The Office of Disability Employment Policy’s Youth Page (www.dol.gov/odep/categories/youth/career.htm) are useful when exploring career options.

Promote Education
Keep your child engaged in classroom activities. When parents expect their children with disabilities to continue their education beyond high school, the children tend to receive better grades than their peers whose parents do not have these expectations. In addition to the basic skills your child learns in the classroom, it is important that the child also learns how and when to tell others about any accommodations he or she may need.

Encourage Work-Based Learning Experiences
Schools and community-based organizations may offer internships, job-shadowing, and mentoring opportunities that focus on employment. While postsecondary education is important, it is also important to remember that it is not the only gateway to well-paying jobs. Vocational education classes can provide an alternate route for exposing young people with disabilities to careers and preparing them for work.
Create Leadership Opportunities
Encourage your child to connect with mentoring activities designed to establish strong relationships with other adults and peers. Encourage your child to become a mentor to younger youth. Participating in sports, student government, chorus, or volunteer groups can also build leadership skills. There are also a few leadership organizations specifically focused on youth with disabilities:
   — Kids as Self-Advocates (http://www.fvkasa.org/)
   — The National Youth Leadership Network (www.nyln.org)
   — The National Consortium on Leadership & Disability for Youth

Set Goals
Teach your child how to set goals and work towards achieving them. Start small and work toward larger goals. With an older child, goal setting might relate to entering a chosen field.

Develop Social Skills
Friendships play a key part in youth development. Through the day-to-day activities that accompany making and maintaining friendships, you will be assisting your child in developing the ability to interact and get along with others, another essential skill employers look for and value in an employee.

Listen to the ideas of experts—teachers, medical staff or community providers. Know in the end, however, that you are the one who knows your child best. Share experts’ input with your child, and, particularly as your child gets older, involve your child in any decision-making that affects him or her.

Additional resources for parents of children with disabilities:
   — Office of Disability Employment Policy (http://www.dol.gov/odep)
   — Office of Disability Employment Policy Guideposts to Success: (www.dol.gov/odep/categories/youth)
   — DisabilityInfo.gov (http://www.disabilityinfo.gov/)
   — The Job Accommodations Network (JAN)(http://www.jan.wvu.edu/)
   — PACER Center: (www.pacer.org)
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?  
   Yes  No
   Is it the kind of job you like? □ □
   Are the hours and days okay? □ □
   Do you get job support you need? □ □
   Does the pay cover your bills? □ □
   Do you get benefits? □ □

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

   When you think about your job (check the one that shows how you feel most of the time):  
   ___ 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?

10. What kinds of jobs or careers interest you?

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

   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.
Getting from Where I Am to Where I Want to Be!
Looking Ahead

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?
Getting from Where I Am to Where I Want to Be!

Looking Ahead

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?
<table>
<thead>
<tr>
<th>Moving towards your desired future, what do you need, want, or hope to happen in the next 1-3 years?</th>
<th>By what date?</th>
<th>What Kinds of Support Will You Need?</th>
<th>Who can do what?</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can . . .</td>
<td>Family, friends can help me by . . .</td>
<td>Agencies or programs can help me by . . .</td>
<td>I need additional help from . . .</td>
</tr>
</tbody>
</table>

How will we know if your plan has worked?
**Introduction**

The national percentage of people of working age with disabilities who are employed continues to hover around 37%, compared with 80% for their peers without disabilities (U.S. Census Bureau, 2005). However, according to the Harris Poll (2000), 67% of people with disabilities who are not currently working would like to be (Dixon, Kurse, & Van Horn, 2003). In the late 1990s, a Presidential Task Force began work on improving the employment rate for adults with disabilities, a national priority that was further supported by the New Freedom Initiative of 2001, creating a bipartisan effort. Despite these initiatives, the rate of employment for people with disabilities has not increased.

“One agency is not going to be able to change the numbers of people with disabilities who are unemployed. Collaboration is necessary if we want to see a difference.”

—Gregg Ames, Mass Rehabilitation Commission

While many people are involved in the effort to improve this employment picture, much of the responsibility for helping people with disabilities secure employment falls on the shoulders of job developers. Typically, job developers act as the bridge between employment services, job seekers, and businesses seeking qualified employees. Good job developers need knowledge, persistence, creativity, and a superior ability to build relationships.

A successful job developer knows how to collaborate with others. Toward that end, one strategy increasing in popularity involves networking with fellow placement professionals working at other provider agencies or for the state. Referred to as an employment networking group, this model offers job developers the opportunity to significantly increase their networking base and thus their own efficiency.

**Why join or start an employment networking group?**

At times, job development can be a difficult and lonely job. Working with job seekers who have multiple barriers to employment, reaching out to employers, and making quality job matches are challenging tasks. Because frequent disappointments and frustrations are a reality, you need patience, flexibility, and a thick skin. What’s more, job development is often done by a single individual. While some agencies have several employment specialists, other, smaller organizations might only have one person assigned this responsibility. It can be helpful to know other job developers with whom you can talk, vent, and collaborate on placement projects. Joining or forming an employment networking group provides just such an opportunity. In employment networking groups, professionals can come together to discuss labor market issues, share leads and ideas, and collaborate on securing employment for their job seekers.

Many employment specialists, however, are reluctant at first to join networking groups. In a field that relies on placement numbers for funding, competition is strong. Job developers often worry that collaboration could lead to the loss of their best-kept secrets, namely, their employers and job leads. However, job developers are finding that the benefits of networking far outweigh the risks. As Barbara Parmet from The Career Place, in Woburn, Mass., so aptly stated, “More hands on deck means less work for everyone.”

Joining an employment networking group has a number of benefits for job developers. Professionals who spend considerable time out in the community on their own find the opportunity to interact with their peers invaluable. Networking group meetings allow for group problem-solving in challenging situations, broadening of networks, and the building of relationships with others in similar professional roles. Job developers with varied levels of experience can participate in brainstorming and problem-solving discussions. Those who have been in the field for a while bring stronger contacts and experience, while newer job developers bring enthusiasm and a fresh perspective. It can be interesting to hear other viewpoints and learn how other agencies operate. Lastly, making connections with other agencies can be helpful in identifying your own agency’s strengths and weaknesses.
GUIDING PRINCIPLES OF PEER NETWORKING GROUPS

BUILDING TRUST

- It is important to acknowledge competition within your networking group and to revisit the topic from time to time. By talking about people’s fears, concerns, and ideas up front, your group can set clear guidelines for sharing job leads and/or employer contacts. Trust is essential within networking groups, and discussing the issue of competition openly can help to build that trust.

FAIR PLAY

- Some members may be more willing to share leads, contacts, and ideas than others, but the issue of unequal contribution has a way of righting itself throughout the life of the group. In one particular networking group, those who did not share ideas or leads gradually found themselves receiving less information from other members and eventually left the group. You may decide that not everyone is required to bring leads and contacts to every meeting, but that it is essential that everyone participate in idea sharing and brainstorming. In this way, members with fewer contacts can still feel comfortable participating, and those contributing more contacts can feel otherwise compensated.

TOLERANCE

- Not every agency or job developer has the same philosophy about who can and should work. Job readiness can be a controversial topic. Some job developers have the flexibility to look for volunteer positions; others are only able to count paid placements. Where do your group’s participants stand on integrated community work versus sub-contracted work? Are they looking for group placements or individuals jobs? Transitional employment or permanent positions? Some initial introductions on the part of your group’s participants, including the type of agencies they represent and placements they make, will allow members to have a better understanding of one another. Having the exact same values is sometimes less important than fostering an atmosphere of tolerance for different placement philosophies.

PROFESSIONALISM

- Professional standards should be defined from the beginning. Some questions for the group to ponder and discuss: Do all members practice similar business etiquette? Are there different approaches to and feelings about disclosure of disability information? Are all members interacting with and representing people with disabilities in a positive and empowering way?

- And keep in mind your networking group will hopefully gain visibility in the field as you plan activities or market to employers. Consider how can you ensure that your group develops a good reputation in your local community and how your affiliation with the group will reflect on you.

SUSTAINABILITY

- A networking group requires commitment and energy if it is going to succeed over time. Groups need to be structured in a way that will accommodate staff turnover. Sometimes, demands in the job development field limit a person’s activities beyond the typical scope of his or her job description. One practice that may prove useful is clearly defining and recording the leadership responsibilities in your group so that those practices are available to anyone new taking over a leadership role.

- The reality is that the makeup of any group will likely change over time. The big question is how to sustain momentum despite inevitable changes. At start-up, it may be useful to designate one individual or agency as the one responsible for sending out emails and reminders, and for performing other basic group functions, until a strong member base is established.

BEST PRACTICES

In successful networking groups:

- There is an atmosphere of cooperation and trust
- All members contribute to the coordination and momentum of the group
- Meetings are regularly scheduled and productive, and they meet the expectations of the group

STRATEGIES FOR SUCCESS

- EASE INTO SHARING LEADS. If the first time the group meets, everyone is asked to share job leads and employer contacts, group members may feel uneasy about their involvement. Instead, engage in less competitive start-up activities, such as discussing goals.

- DEVELOP PROTOCOLS FOR SHARING JOB LEADS. One group created a form on which members could fill in a job description, the name of the employer, whether or not the employer should be approached directly, and if the person bringing the lead wanted to be involved. Once group members get to know one another better, they can decide how free they want to be with contacts.
Knowing if you can contact the employer directly or if you need to go through the job developer is important. For some positions, a job developer might even do a prescreening interview prior to sending a résumé.

**CREATE A CORE LEADERSHIP TEAM.** Successful groups identify a core leadership team as essential to group longevity. Without one in place, many groups fizzle out. A leadership team can carry out administrative tasks associated with the group, such as organizing meeting details, maintaining member lists, and using input from the group to bring requested topics to the table. These and other tasks, such as hosting, providing refreshments, sending out meeting reminders, and taking and distributing minutes can be shared among members, but someone needs to be in charge to make sure it all gets done.

**SET UP A CONSISTENT MEETING SCHEDULE.** Early on, you should establish where, when, and how frequently your group will meet. Whether you meet monthly or quarterly, it is essential that you choose a consistent day and time, such as the last Friday of every month at 2 p.m. or the first Monday of the quarter at 10 a.m. Groups should also decide if the meetings will always be held at the same location, or whether the locations will vary. Depending on the community, members must consider such factors as accessibility, ease of commute, access to public transportation, and parking. One advantage of varying the meeting location is the shared responsibility of hosting. Some disadvantages are that not all agencies have adequate meeting space and a change in venue sometimes means confusion among members.

**CREATE AN ONLINE COMMUNITY.** Whatever the nature of the communication, groups need to develop a mechanism for sharing information between meetings. Some groups have created an email distribution list, a listserv, or an online message board. These tools can be used to support both the operation of the group itself as well as sharing information about job leads, new employers in an area, upcoming relevant training or professional development opportunities, job fairs, or job postings from member agencies.

**DIVERSIFY.** Successful networking groups encourage a wide variety of employment specialists to join them. Greater diversity among populations served decreases the sense of competition and can result in a greater likelihood that members will pass on leads they cannot fill. Mentoring relationships can also develop. When ideas and knowledge are the focus, competition over contacts is greatly reduced, and participation is seen as a benefit, not a risk.

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**Group Activities**

- Tour one another’s agencies. Members are able to see how other agencies do business and make an assessment of their own program by comparison.
- Facilitate vocationally oriented, beginner American Sign Language (ASL) classes to assist job developers, area VR staff, and employers in communicating with people using ASL in the workplace.
- Hold in-service trainings on topics that members commonly struggle with. Guest speakers could include disability specialists from a local community college, human resources professionals, job seekers, benefits specialists, and other nonprofit agencies, such as food share or clothing-assistance programs that could help job seekers with other areas of their lives.
- Plan employer events and job fairs together. Non-competitive activities give group members an opportunity to get to know and develop confidence in one another.
- Tackle processes that members struggle with, such as online job applications and other troublesome pre-employment screens.

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**Conclusion**

In the end, the goal of every job developer is to secure placements, not to run networking meetings. But forming or joining an employment networking group is a practice that has helped many to do their jobs better. Ultimately, what gets people jobs is links to businesses and contacts with those in a position to hire. Networking groups can help make those connections easier to form and maintain. The members of a group can serve as resources, support, and partners in planning events. How much or how little to undertake is up to a group’s individual members. So check out the networking groups in your area or consider starting one of your own. You never know where it could lead.

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“I really expected more of a sense of competition, but when you’re working together on something like a job fair or an employer forum, it becomes less about what you can do for your agency and more about what you can all accomplish together for the job seekers.”

—BARBARA PARMET, THE CAREER PLACE

“"The more often we can say to a business looking for an employee, “We can find you the right person,” the more valuable we will be to that business. Even if that person does not come from our caseload, we will be developing a relationship with the business.”

—DOUGLAS WHITNEY, VABIR Burlington
Toolkit

To maintain a networking group, you'll need

- A leadership team
- An agenda or meeting format
- A consistent location and schedule for meetings
- Listserv or email distribution lists
- Affiliations with employers or business advisory councils
- Protocols for sharing job leads and employer contacts
- A system for rotating administrative duties:
  - Secure or schedule a place to meet
  - Send a reminder/attendance confirmation prior to meetings
  - Provide refreshments
  - Have a typed agenda (solicit items from the group & distribute it with the meeting reminder)
  - Take minutes & distribute them to all members
  - Record tasks and persons responsible, and send reminders
  - Recruit new members

To start a group:

- Begin by contacting other community rehabilitation programs in your area. There may be a group you didn't know about or people interested in joining one.
- Reach out to VR, MR/DD, and MH agencies, and to other referral sources, to see if you can get their support. If there is interest but no staff time available, see if they can contribute other resources.
- Hold an open meeting to gauge the level of interest and commitment. Don't worry about being small at first. People are often reluctant to try new things until they see evidence of success.
- Be patient and persistent. Groups of this nature need some time to take off.

Acknowledgements

This publication was funded by a grant from the Rehabilitation Services Administration of the U.S. Department of Education (grant# H264BO50009). The opinions contained in this publication are those of the grantees and do not necessarily reflect those of the U.S. Department of Education.

Special thanks to Cecilia Gandolfo, Cindy Thomas, Danielle Dreilinger, Melissa Cook, Colleen Condon, Hugh Bradshaw, and Barbara Parmet for their input and editorial assistance.

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This publication will be made available in alternate formats upon request.

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- find other publications on this topic
- sign up for ICI’s email announcement list
### Key Provisions on Transition

**IDEA 1997 compared to H.R. 1350 (IDEA 2004)**


<table>
<thead>
<tr>
<th>Individuals with Disabilities Education Act of 1997</th>
<th>H.R. 1350: Individuals with Disabilities Education Improvement Act of 2004</th>
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</thead>
<tbody>
<tr>
<td><strong>Part A: GENERAL PROVISIONS</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Section 601: SHORT TITLE; TABLE OF CONTENTS; FINDINGS; PURPOSES</strong></td>
<td><strong>Section 601: SHORT TITLE; TABLE OF CONTENTS; FINDINGS; PURPOSES</strong></td>
</tr>
<tr>
<td>(d) PURPOSES. The purposes of this title are—</td>
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<tr>
<td>(1)(A) to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living</td>
<td>(1)(A) to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living</td>
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<tr>
<td><strong>Section 602: DEFINITIONS</strong></td>
<td><strong>Section 602: DEFINITIONS</strong></td>
</tr>
<tr>
<td>(30) TRANSITION SERVICES. The term “transition services” means a coordinated set of activities for a student with disability that—</td>
<td>(34) TRANSITION SERVICES: The term “transition services” means a coordinated set of activities for a child with a disability that—</td>
</tr>
<tr>
<td>(A) is designed within an outcome-oriented process, which promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;</td>
<td>(A) is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;</td>
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<tr>
<td>(B) is based upon the individual student’s needs, taking into account the student’s preferences and interests; and</td>
<td>(B) is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests; and</td>
</tr>
<tr>
<td>(C) includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation.</td>
<td>(C) includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation.</td>
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</table>
### Part B: ASSISTANCE FOR EDUCATION OF ALL CHILDREN WITH DISABILITIES

<table>
<thead>
<tr>
<th>Section 614, INDIVIDUALIZED EDUCATION PROGRAMS</th>
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<tbody>
<tr>
<td>(c) ADDITIONAL REQUIREMENTS FOR EVALUATION AND REEVALUATIONS</td>
<td>(c) ADDITIONAL REQUIREMENTS FOR EVALUATION AND REEVALUATIONS</td>
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</tbody>
</table>
| (5) EVALUATIONS BEFORE CHANGE IN ELIGIBILITY—A local educational agency shall evaluate a child with a disability in accordance with this section before determining that the child is no longer a child with a disability. | (5) EVALUATIONS BEFORE CHANGE IN ELIGIBILITY—  
(A) IN GENERAL – Except as provided in subparagraph (B), a local educational agency shall evaluate a child with a disability in accordance with this section before determining that the child is no longer a child with a disability.  
(B) EXCEPTION—  
(i) IN GENERAL – The evaluation described in subparagraph (A) shall not be required before the termination of a child’s eligibility under this part due to graduation from secondary school with a regular diploma, or due to exceeding the age eligibility for a free appropriate public education under State law.  
(ii) SUMMARY OF PERFORMANCE – For a child whose eligibility under this part terminates under circumstances described in clause (i), a local education agency shall provide the child with a summary of the child’s academic achievement and functional performance, which shall include recommendations on how to assist the child in meeting the child’s postsecondary goals. |

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<tr>
<th>Section 614, INDIVIDUALIZED EDUCATION PROGRAMS</th>
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<td>(A) INDIVIDUALIZED EDUCATION PROGRAM</td>
<td>(A) INDIVIDUALIZED EDUCATION PROGRAM</td>
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<tr>
<td>(vii)(I) beginning at age 14, and updated annually, a statement of the transition service needs of the child under the applicable components of the</td>
<td>(VIII) beginning not later that the first IEP to be in effect when the child is 16, and updated annually thereafter—</td>
</tr>
<tr>
<td>Individuals with Disabilities Education Act of 1997</td>
<td>H.R. 1350: Individuals with Disabilities Education Improvement Act of 2004</td>
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<tr>
<td>child’s IEP that focuses on the child’s courses of study (such as participation in advanced-placement courses or a vocational education program);</td>
<td>(aa) appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills;</td>
</tr>
<tr>
<td>(II) beginning at age 16 (or younger, if determined appropriate by the IEP Team), a statement of needed transition services for the child, including, when appropriate, a statement of the interagency responsibilities or any needed linkages; and</td>
<td>(bb) the transition services (including courses of study) needed to assist the child in reaching those goals; and</td>
</tr>
<tr>
<td>(III) beginning at least one year before the child reaches the age of majority under State law, a statement that the child has been informed of his or her rights under this title, if any, that will transfer to the child on reaching the age of majority under section 615(m); and</td>
<td>(cc) beginning not later than 1 year before the child reaches the age of majority under State law, a statement that the child has been informed of the child’s rights under this title, if any, that will transfer to the child on reaching the age of majority under section 615(m).</td>
</tr>
<tr>
<td>(viii) a statement of—</td>
<td>(ii) RULE OF CONSTRUCTION — nothing in this section shall be construed to require —</td>
</tr>
<tr>
<td>(I) how the child’s progress toward the annual goals described in clause (ii) will be measured; and</td>
<td>(I) that additional information be included in a child’s IEP beyond what is explicitly required in this section; and</td>
</tr>
<tr>
<td>(II) how the child’s parents will be regularly informed (by such means as periodic report cards), at least as often as parents are informed of their nondisabled children’s progress of—</td>
<td>(II) the IEP Team to include information under 1 component of a child’s IEP that is already contained under another component of such IEP.</td>
</tr>
<tr>
<td>(aa) their child’s progress toward the annual goals described in clause (ii); and</td>
<td>[Note: The following text appears in Part B, Section 614 (d)(1)(A)(i), as part of the definition of what an IEP includes.]</td>
</tr>
<tr>
<td>(bb) the extent to which that progress is sufficient to enable the child to achieve the goals by the end of the year.</td>
<td>(II) a statement of measurable annual goals, including academic and functional goals, designed to—</td>
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<td></td>
<td>(aa) meet the child’s needs that result from the child’s disability to enable the child to be involved in and make progress in the general education curriculum; and</td>
</tr>
<tr>
<td></td>
<td>(bb) meet each of the child’s other educational needs that result from the child’s disability;</td>
</tr>
<tr>
<td></td>
<td>(III) a description of how the child’s progress toward meeting the annual goals described in subclause (II) will be measured and when periodic reports on the progress the child is making toward meeting the annual goals (such as through the use of quarterly or other periodic reports, concurrent with the issuance of report card) will be provided;</td>
</tr>
</tbody>
</table>
## DEVELOPMENT OF IEP

(A) IN GENERAL – In developing each child’s IEP, the IEP Team, subject to subparagraph (C), shall consider –

(i) the strengths of the child and the concerns of the parents for enhancing the education of their child; and

(ii) the results of the initial evaluation or most recent evaluation of the child.

## DEVELOPMENT OF IEP

(A) IN GENERAL – In developing each child’s IEP, the IEP Team, subject to subparagraph (C), shall consider –

(i) the strengths of the child;

(ii) the concerns of the parents for enhancing the education of their child;

(iii) the results of the initial evaluation or most recent evaluation of the child; and

(iv) the academic, developmental, and functional needs of the child.

## CHILDREN WITH DISABILITIES IN ADULT PRISONS

(A) IN GENERAL – The following requirements do not apply to children with disabilities who are convicted as adults under State law and incarcerated in adult prisons:

(i) The requirements contained in section 612(a)(17) and paragraph (1)(A)(v) of this subsection (relating to participation of children with disabilities in general assessments.)

(ii) The requirements of subclauses (I) and (II) of paragraph (1)(A)(vii) of this subsection (relating to transition planning and transition services), do not apply with respect to such children whose eligibility under this part will end, because of their age, before they will be released from prison.

## CHILDREN WITH DISABILITIES IN ADULT PRISONS

(A) IN GENERAL – The following requirements shall not apply to children with disabilities who are convicted as adults under State law and incarcerated in adult prisons:

(i) The requirements contained in section 612(a)(16) and paragraph(1)(A)(i)(VI) (relating to participation of children with disabilities in general assessments).

(ii) The requirements of items (aa) and (bb) of paragraph (1)(A)(i)(VIII) (relating to transition planning and transition services), do not apply with respect to such children whose eligibility under this part will end, because of such children’s age, before such children will be released from prison.

## RESOURCES

CEC provides a summary of the law, their recommendations, and a link to the text of the law.

**National Association of State Directors of Special Education (NASDSE)**  [http://www.nasdse.org/](http://www.nasdse.org/)
NASDSE has a side-by-side comparison of IDEA ’97 and the new law available for purchase.

Wrightslaw provides information on changes in the law, as well as some brief explanatory comments.

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Self-Determination: Is a Rose by Any Other Name Still a Rose?

Ann P. Turnbull and Rud Turnbull
University of Kansas

We invite you to read this Exchange focusing on the need to have more coherence and consistency in terminology/descriptions and in anticipated outcomes related to self-determination funding. We also invite you to contribute to a national dialogue to seek the coherence and consistency for which the article advocates. You can join the online discussion by visiting the Beach Center website (www.beachcenter.org) and looking on the home page for a link to the discussion board or you may link to the discussion board through TASH.org. Please join in!

Q1

Does self-determination refer to a curriculum that teaches students with disabilities to be self-directed problem solvers, a technique for redirecting funding streams so that adults with disabilities can control the dollars allocated for their supports and services, or a philosophy grounded in democratic values and constitutional principles of autonomy and liberty? Or is it two or even all three of these? And, what terms should professionals use to inform policy leaders, practitioners, self-advocates, and families so that they will advance the self-determination cause?

One of the first times the term “self-determination” was introduced to the special education field, was the 1989 National Conference on Self-Determination sponsored by the National Institute for Disability and Rehabilitative Research. Prior to this conference, a number of researchers began to investigate the effects of choice making and self-directed learning strategies on the performance of students with severe disabilities (see Agran & Martin, 1987; Guess, Benson, & Siegel-Causey, 1985; Mithaug, Martin, & Agran, 1987; Mithaug & Hanawalt, 1978; Ward, 1988). (Note: At that time the terms “self-control” or “self-management” were used.) Shortly after that historic conference, and based on the developing body of research findings on the positive effects of self-management and self-directed learning strategies, the Office of Special Education Programs funded model programs and curriculum-development projects to promote self-determination of youths with disabilities during their secondary education (Ward, 1996; Wehmeyer, Bersani, & Gagne, 2000). Those early programs were well-documented in the literature (Wehmeyer & Sands, 1998) and laid a strong foundation for subsequent research, demonstration projects, and instructional/curriculum models. Although different definitions have emerged through the work of various research teams, the most frequently accepted definition of self-determination in the field of special education relates is: “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference” (Wehmeyer, 1996, p. 24).

At roughly the same that self-determination models related to self-direction and problem-solving continued to expand within the field of special education, adults with disabilities began to demand greater control over their lives. Specifically, they sought to have the right to use Medicaid Home and Community-Based Services (HCBS) funds in ways that responded to their choices and needs as they themselves defined those choices and needs. In making these demands, they insisted that HCBS funds to which they are entitled were theirs to direct because they are the entitled beneficiaries – they “own” the funds – and that they, not service provider agencies, should have the right to say how the funds should be used. Moreover, they were displaying their dissatisfaction with living lives controlled by others. Their frontal challenge to the service-provider enterprise is summarized in the TASH newsletter, TASH Connections (March/April, 2005) which includes an excellent overview of policy, practices, and success stories related to this version of self-determination.

The Robert Wood Johnson Foundation funded the first demonstration project on self-determination (the term here refers to self-determination funding) at Monadnock Developmental Services in New Hampshire. This model focused on the development of individual budgets for adults with disabilities that were developed and implemented through the process of person-centered planning (Conroy, Fullerton, Brown, & Garrow, 2002).

This paper focuses on the emerging literature related to self-determination funding which holds that individuals with disabilities should have greater control over the money allocated to serve them than they have had in the past, and that service-provider agencies have now. Our purpose is to review the literature on self-determination funding to analyze terminology/
descriptions and anticipated outcomes. We have two concerns that have spurred us to write this article. The first is that as students with disabilities who have had a self-determination curriculum as part of their special education curriculum move toward transition to adulthood, they are going to encounter a whole different use of the term (i.e., self-determination) as they consider funding options. Secondly, there are a wide variety of terms regarding self-determination finding that are used interchangeably, and that can unintentionally confuse stakeholders, including individuals with disabilities, families, service providers, and policymakers. For example, some of the different terms used to refer to self-determination funding include self-direction, consumer control, individual budget, and/or individualized funding (and various derivatives of each of these terms and others). In this article we present the broad range of terms/definitions and anticipated outcomes related to self-determination funding; and we invite you to participate in a web-based discussion to express your own perspectives about what you believe the preferred terminology should be.

Table 1 contains our analysis of terminology/ descriptions and anticipated outcomes of self-determination funding models as set out in 11 recent (1996–2005) documents (e.g., articles, chapters) about self-determination funding. These are all of the published articles and chapters we were able to locate that specifically address self-determination funding. (Please note that this review relates to self-determination funding, and not the substantial literature that has been published since the 1980s on self-determination related to being self-directed problem solvers.) We included direct quotes of terminology/descriptions and anticipated outcomes where possible. If the terminology/descriptions and anticipated outcomes could not be succinctly encapsulated into a single quote or two, we extracted the major concepts and highlighted those. In some cases, we needed to infer from the author’s writing what he or she was intending the outcome to be since this was not explicitly stated. We highlighted key terms in italics and ordered the entries chronologically, starting in 1996 with the Robert Woods Johnson (RWJ) Foundation call for proposals for self-determination projects and continuing through the most recent 2005 publications.

As we read the 11 documents, paying particular attention to terminology/descriptions and anticipated outcomes, it became obvious that no two of these documents define key terms in exactly the same way. For example, Nerney (2005) defines self-determination primarily from a values perspective:

Self-determination for citizens with disabilities is about freedom. Freedom to decide how one wants to live his or her life. It’s also about organizing needed support with the person’s support network – friends, family, those who care. Self-determination means having authority over resources and taking responsibility for decisions and action. True champions of self-determination honor the important leadership of persons with disabilities in changing our systems of support. Confirmation of the self-advocacy movement is a major principle of self-determination. We must not forget whose life is being lived” (p. 3).

Alternatively, Fortune and colleagues (2005) use the term person-centered system architecture as contrasted to the term self-determination. Furthermore, they use a functional definition rather than a values definition, but in the following passage they are generally referring to the same thing that Nerney refers to above:

Person-centered system architecture “…(1) attaches funding in the form of an individual budget to each individual; (2) gives individuals, their families, and their allies the authority to select the services and supports that reflect the person’s priorities; (3) affirms uninhibited free selection of service providers; and (4) employs open (rather than slot-based) contracting to foster a market place that encourages the free entry of providers” (pp. 241–242).

Comparing and contrasting the actual terms and their descriptions highlights the potential confusion for stakeholders in encountering such discrepant nomenclature. An analysis of the entries in the left-hand column of Table 1 pertaining to terminology/description reveals that the three terms used most frequently are self-determination, individualized funding, and individual budget. Several of the more recent publications (Moseley, 2005; Moseley, Gettings, & Cooper, 2005; Stancliffe & Lakin, 2005) briefly define self-determination or self-direction but then give primary attention to the individual budget.

Our review of the anticipated outcomes (in the right-hand column in Table 1) indicates substantial consistency over time. The anticipated outcome of self-determination/individualized funding/individual budgets primarily relates to individual control (i.e., autonomy). Indeed, five of the publications explicitly identified control as the anticipated outcome. The remaining publications described outcomes in terms of related concepts such as empowerment and decision-making. Thus, there appears to be uniformity with respect to the anticipated outcome of individualized funding/individual budgets, and that outcome is the autonomy/liberty to control one’s own life.

We believe that enhancing consistency and coherence in terminology/descriptions and in the specification of anticipated outcomes is important for a couple of reasons. There is a major need to communicate as clearly as possible about the revolutionary and even transforming potential in policy and practice that redirects how public funds can (and should) be used to
Table 1
Terminology/Descriptions and Anticipated Outcomes

<table>
<thead>
<tr>
<th>Terminology/Descriptions</th>
<th>Anticipated Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The Robert Woods Johnson Foundation (1996) and Shumway (1999)</td>
<td>“Self-determination is an important next step allowing persons and their families and friends, in conjunction with professionals, to be the decision-makers concerning the supports that are needed and how they best can be provided” (Robert Woods Johnson Foundation, 1996, p. 2).</td>
</tr>
<tr>
<td>• Self-determination is based on the four principles of freedom, support, authority, and responsibility.</td>
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<tr>
<td>• “...the elements of self-determination rests on the ongoing trend toward the following:</td>
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<tr>
<td>■ “People with disabilities and their families having a personally controlled, individual budget and the ability to determine how an individual budget will be spent...”</td>
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<td>■ “Supports provided in the community...”</td>
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<td>■ “Profound changes in public policy that would require new planning, operating, and financing structures...” (Shumway, 1999, p. 31).</td>
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</tr>
<tr>
<td>2. Dowson &amp; Salisbury (1999)</td>
<td>“It [individualized funding] gives people the freedom to develop their lives, using allocated public funds in the way that they consider best. It provides a means to ensure that plans and services will not be imposed upon them by community service providers and public officials. It provides for a process of negotiation between the individual and the holder of public funds. It also obliges service providers to treat the users as value customers and encourages the emergence of innovative services to meet their requirements” (p. 4).</td>
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<tr>
<td>• “If [individualized funding]...is public funding that is allocated to the individual, based on his/her unique strengths and needs, and placed under the control of the individual to enable them to live in community as a full citizen” (p. 4).</td>
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<tr>
<td>3. Aichroth et al. (2002)</td>
<td>“Such a perspective...allow[s] label people to make their own construction of who they are in the world, and ways in which they seek to have power and control over their lives” (p. 24).</td>
</tr>
<tr>
<td>• “…self-determination has been portrayed as...the value attributed to the autonomy of individuals [which] implies a social responsibility for cultural institutions to ensure that choice and control are available to all, not just some” (p. 17).</td>
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<tr>
<td>• “Self-directed services are defined in this way: ‘...the individual, with appropriate help from the circle of support, will define what is needed, how it is provided, and from whom the service will be purchased...the person receiving support is not the direct employer-of-record’ (p. 23).</td>
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<tr>
<td>• “In the self-managed mode, the person becomes the employer-of-record for providers...in essence, they manage the money” (p. 23).</td>
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<tr>
<td>4. Lord &amp; Hutchinson (2003)</td>
<td>“Individualized funding allows people to choose where they will live, how, and who will provide support. Many individualized funding programs promote a wholistic view of quality of life, looking at employment supports, community living, leisure pursuits, and relationship building” (Roeher Institute, 1997, p. 72).</td>
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<tr>
<td>• “…individualized funding refers to the allocation of support dollars directly to the person, in contrast to a service agency” (p. 72).</td>
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<td>5. Smith (2003)</td>
<td>“Individualized funding approaches have substantial benefit for people with disabilities in areas of personal empowerment, cost effectiveness, and reducing dependence on social services” (p. 294).</td>
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<tr>
<td>• “Individualized funding and support brokerage, alternatives to more traditional approaches to funding and support planning, are at the foundation of this understanding of self-determination and the cutting edge of the new way of thinking about supports for people with disabilities” (p. 294).</td>
<td></td>
</tr>
<tr>
<td>6. Fortune et al. (2005)</td>
<td>“…Individuals and families would have greater decision-making authority in the service planning process” (p. 258).</td>
</tr>
<tr>
<td>• Person-centered system architecture “…(1) attaches funding in the form of an individual budget to each individual; (2) gives individuals, their families, and their allies the authority to select the services and supports that reflect the person’s priorities; (3) affirms uninhibited free selection of service providers; and (4) employs open (rather than slot-based) contracting to foster a market place that encourages the free entry of providers” (pp. 241–242).</td>
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</table>
enhance individual control. The best case can be made in advocating for policy, developing model programs, and preparing youth with disabilities and their families for this type of adult support if there is a common nomenclature. It is noteworthy that the two lines of work on self-determination – the education and the fiscal-control lines – have been carried out in a parallel fashion over the last decade, but that only two articles to date have sought to merge best practices from both lines of work (Turnbull & Turnbull, 2000; Turnbull &
Turnbull, 2001). We believe that there is mutual benefit for both lines of research on self-determination to incorporate key findings from the other line. For example, demonstration projects that are redirecting public funds to individuals with disabilities can benefit from incorporating the knowledge and skill development processes that have been documented as evidence-based practices in enhancing self-directed problem-solving. Alternatively, a way to enhance the utility and potential quality of life outcomes of self-determination skills training at the secondary level would be to prepare students (and their families) in knowledge and skill related to accessing, implementing, and monitoring individual budgets.

Terminology related to self-determination funding needs to be considered in light of the terminology to which many children and youth with disabilities and their families are introduced throughout their elementary and secondary special education program. Terminology in the lexicon of adult services should be consistent with terminology in the lexicon of schools, because the words and phrases create expectations for curriculum, behaviors (by professionals, individuals/students, and others, including their families), and outcomes (for individuals and for service systems).

We encourage you to contribute to a national dialogue to increase the coherence and consistency in terminology/descriptions and anticipated outcomes related to self-determination funding; we will work towards terms that are clear, succinct, and reflective of the values that underlie them. The Beach Center, in collaboration with AAMR and The Arc-U.S., is hosting a discussion in an online format over the next several months on the following questions:

- What are the defining characteristics of self-determination funding?
- What are the preferred outcomes of self-determination funding?
- What is the preferred terminology for self-determination funding?

To join the online discussion, please visit the Beach Center website (www.beachcenter.org), and look on the home page for the link to the discussion board, or you may link to this site through the TASH website (www.TASH.org). We will archive the results and have them available both on the Beach Center and TASH websites.

In closing we ask: Is self-determination by any other name still self-determination?

References


Conroy, Fullerton, Brown, & Garrow, 2002


AUTHOR QUERIES

AUTHOR PLEASE ANSWER ALL QUERIES

Q1 = Please provide keywords.

Q2 = For the Conroy et al., 2002, bibliographic entry, please provide the authors’ initials and publication data.

Q3 = Please provide publication data for Roeher Institute, 1997, which appeared in Table 1, and include the entry in the bibliographic list.

Q4 = For the Nerney, 2005, bibliographic entry, please provide the volume number of the newsletter and the pages in which the article appeared.

END OF AUTHOR QUERIES