DOCUMENT RESUME

ED 363 985 EC 302 539

AUTHOR	Amado, Angela Novak; And Others
TITLE	Friends. A Manual for Connecting Persons with Disabilities and Community Members.
INSTITUTION	Human Services Research and Development Center, St. Paul, MN.
SPONS AGENCY	Minnesota Governor's Planning Council on Developmental Disabilities, St. Paul.
PUB DATE	90
NOTE	83p.
AVAILABLE FROM	Minnesota Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Building, 658 Cedar St., St. Paul, MN 55155.
PUB TYPE	Reports - Descriptive (141) -- Guides - Non-Classroom Use (055)
EDRS PRICE	MF01/PC04 Plus Postage.
DESCRIPTORS	Adults; Agencies; *Developmental Disabilities; *Friendship; Individual Development; Interpersonal Competence; *Interpersonal Relationship; Normalization (Handicapped); Personal Autonomy; Program Development; *Social Integration
IDENTIFIERS	*Minnesota

ABSTRACT

This manual describes the "Friends" project, a year-long effort in Minnesota to develop methods for the staff of residential service agencies to support people with developmental disabilities in establishing friendships with nondisabled people in their communities. Six agencies around the state selected a total of 23 individuals (ages 11 to 71) in a variety of residential settings to participate. A focus group was formed to support each individual's efforts to build community connections. The major portion of the manual presents a variety of strategies used in the project. Planning strategies focus on discovering the person's interests and capacities, creating a vision, and deciding on first steps. Connecting strategies include: look for opportunities for relationships, strengthen existing relationships, model the meeting of new people, and know the community. Strategies for introducing people include planning for success and knowing how much support is necessary. Among strategies for supporting and nurturing the relationship are demonstrating how it is done, continuing to encourage, solving problems, and watching out for problem areas. Finally, agency support for relationship building includes seeing staff as community connectors, extending agency structures to support friendships, and utilizing volunteers. (Contains 10 resources.) (DB)

A Manual for Connecting Persons with Disabilities and Community Members

Human Services Research and Development Center
1989-90 Friends Project

funded by the
Minnesota Governor's Planning Council
on Developmental Disabilities

Friends

A Manual for Connecting Persons with Disabilities and Community Members

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The development of this manual was funded in part through grant number 17673 under provisions of the Developmental Disabilities Act of 1987 (P.L. 100-146). Content of this document does not necessarily reflect the position or policy of the Governor's Planning Council on Developmental Disabilities nor that of the State Planning Agency.

Additional copies of this publication may be obtained from the Minnesota Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155, 612-296-4018.

The recommended citation of this publication is: Amado, A.N., Conklin, F., & Wells, J. (1990) *Friends: A Manual for Connecting Persons with Disabilities and Community Members.* St. Paul, Minnesota: Human Services Research and Development Center.

Cover Artwork by Jeph Lyon and Pat Lyon
Photographs by Houston County Group Homes Staff
Photographic Layout by Greg Lyon

Acknowledgements

We must profoundly thank all the persons who participated in the 1989-90 Friends Project. Twenty-three individuals with disabilities generously allowed us into their lives and relationships, and let us poke around and learn about how they would like friendship to be. Others who participated included families, who graciously allowed us to participate with their families and in their homes. Also thanks to the staff from day programs and schools, and several county case managers.

Ron Kaliszewski of the Minnesota Governor's Planning Council on Developmental Disabilities has been the "godfather" of this project, and we most gratefully appreciate his unremitting support. In addition, Colleen Wieck, Eric Rudrud, and Sharon Patten, through the Council, contributed to many of the ideas presented here.

Jane Wells provided the format and layout work for the manual (with more than a little help from her Macintosh), and Linda Albert did much of the typing. Thanks for an extraordinary job.

Lastly, this project would not have been possible without the participation of the staff of the following agencies. From our very first invitation to participate, through to the last group meeting, there has been no question of every single person's commitment to quality, joy, and friendship for people they serve. Through the ups and downs, successes and failed attempts, the staff never stopped in their commitment, continuing to generate new ideas and try new things. Also a special thanks to the administrators who generously committed their staff time for a year, in order to make a real difference in the critical area of relationships for the people served.

These administrators have agreed to act as resources for other agencies. They are available for questions or information about the issues involved in having staff support community relationships and friendships.

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Contents

Michelle and Chris

Michelle is 17 and lives in a 13-bed group home with people who are mostly older than she is. She speaks very little, mainly one word statements like "mama," "no no," and "baby." It was often difficult to get her up in the morning, and to get her onto the school bus. She would often sit in front of her cereal bowl, and not initiate eating, or asking or reaching for the milk. Staff worked on goals for a long time to try and have her be more "motivated," and to speak more.

During the Friends project, staff worked on having Michelle have more friends her own age. The school aide from her classroom participated with staff form the group home in coming up with ideas. She offered to put a notice in the school bulletin to ask for students who would like to become friends with a special education student. Two girls, Melissa and Chris, responded.

They came out to the home and visited and met Michelle. The first time they brought a crafts activity with them, and the staff let them know that really they didn't expect the girls to do structured things, but just hang out, have fun, and be friends.

With her programs already going on and with new anticipation of going to school, Michelle started getting up much more easily, reaching for her milk and finishing her cereal. One morning when it was time to get on the school bus, the staff were running around trying to find her—then they realized she was already out on the bus, waiting to go!

The girls come over after school on Friday afternoon. Staff drive them home after the visit. The staff have supported Michelle in being a "hostess" for her friends. They make sure she answers the door when they come. They help her bake cookies the night before. They also try to "stay out of the way" during the visit. During the summertime, the girls planned a picnic for the three of them. When there is no school on a Friday, they come over to visit Michelle anyway.

The three girls do teenage stuff together. They look at Michelle's pictures, listen to music, shoot baskets, play computer games, etc. They spent one afternoon putting on makeup and fixing their hair. A couple of days after this visit, a staff person walked by the bathroom and saw Michelle primping herself. She was saying emphatically to herself in the mirror, "You're cute!" They have never heard that much from her before.

When the girls were asked about what they were getting out of being Michelle's friend, Melissa said, "Now I have something to look forward to on Friday afternoons."

Introduction

Most of us count our family and friends among our life's richest treasures. The people we care about and who care about us are the ones to whom we turn to celebrate our accomplishments and share our losses. As we grow, the variety of relationships we have also grows. As adults, most of us know hundreds of people, in a rich network of our families, work, neighborhood, associations, churches, and clubs. In each new relationship we learn about ourselves and our world, we figure out where we fit into the scheme of things, where we belong.

Although individuals with disabilities are living in their communities and participating in community activities, they often do not have the opportunities to build the kinds of relationships that the rest of us take for granted. Too often persons with disabilities have no real best friend, or their relationships are limited to their immediate family, human service staff, and other people with disabilities.

Many individuals are also separated or distant from their families, so that all of their relationships are dependent on the service system. Many people with disabilities are isolated from regular community people, and have no experience of community. Sometimes this isolation is a result of the individual having been forced to leave their home community to live in an institution or to receive services not available close to home. Sometimes it's simply a matter of having lived a very segregated life—going to school, working and living only with other people with disabilities.

Whatever the cause, a life without close, supportive family and friends can be very lonely. That loneliness can be as serious a threat to emotional and physical health as any diagnosed disease. In addition, a true sense of one's self and self-esteem can be lost when paid people come in and out of one's life. Knowing who it is that cares about you, and who to trust, can become confusing. A sense of uncertainty often results.

Relationships are probably the most important aspect of our lives, and yet the human service system has given very little attention to this fundamental human need. A person with disabilities has the right all of us have, to be in relationship with people who like us and want to be with us, just for ourselves, and to have people who care about us, to whom we can turn and on whom we depend.

We have become quite sophisticated about identifying deficits in intellectual functioning, communication, daily living skills, and vocational skills. We have made great strides in designing training techniques and equipment to help people in these important areas. However, most of us would agree that having fun with our friends is far more important to us than whether we make our bed or balance our checkbook. Yet, for people with disabilities, we have given a great deal more attention to bed-making and checkbook-balancing than to having friends. *We are helping people be more competent, but they are still alone.*

We believe that it is not only people with disabilities who are hurt by being segregated from non-disabled people in their communities. There is also a loss to the community. Typical citizens miss the opportunity to have a network of friends

that includes people with disabilities, and miss the richness of relationship that a person with disabilities provides.

In the last few years, a great many efforts to encourage relationships between children with and without disabilities have been initiated in schools across the country and in other countries. However, outside of school systems, efforts regarding community friendships have been less systematic. This manual is the result of one systematic, planned, intentional effort for human services agencies.

A Different Role for Staff

Part of what is implied in this manual is essentially a different role for staff of human services agencies. Because of the limited number of relationships in the lives of most persons with disabilities, staff can be the people who assist persons in having a lot more people in their life.

It is possible that a significant, if not primary role, for staff can be that of *community connector.* Staff can be people whose job it is to introduce people with disabilities to others, and who support their relationships with people who are not part of the service system. That is a vastly different role than teaching people what they don't know, or providing for basic needs of shelter, food, and daily needs, all of which are important and not to be ignored. It is also a very different role than "training social skills."

Being cared about by others who really like you *is* one of the basic needs of human beings. So is having a sense of self-esteem through knowing that you're valued and cared about by others who are also valued. Staff can take on the meeting of these needs as one of the most important parts of their job.

Addressing this need does not have to mean just one more thing for an agency or service provider to be doing, or be required to do. Rather, addressing this need does mean doing things differently than they are being done. It does mean a different, rather than an additional, role for staff.

Background of the Friends Project

"Friends" was a one-year grant project, sponsored in 1989-90 by the Human Services Research and Development Center of St. Paul, Minnesota, and funded by the Minnesota Governor's Planning Council on Developmental Disabilities. Its purpose was to learn about and develop methods for the staff of residential service agencies to support people with disabilities in establishing friendships and relationships with non-disabled people in their communities, and to assist people with disabilities in being more a part of their communities. It was based on the premise that, given the importance of relationships, the job of human services staff should be to build community connections and assist persons with disabilities in having more friends. The

project investigated what was involved in having residential service staff support community friendships. This manual is based on the work done by the Friends Project participants and focus groups.

Participants

Six agencies participated, all of whom provide residential services (support in daily living) to persons with developmental disabilities. Each agency selected two to six individuals to participate. A total of twenty-three individuals were selected by the agencies, which provide services in different parts of Minnesota, in both rural and urban/suburban environments. The individuals had disabilities ranging from mild to severe. Some had physical as well as mental disabilities. They ranged in age from 11 to 71. These twenty-three individuals lived in a variety of settings: group homes, foster homes, their parents' homes, and independent apartments. Homes ranged in size from a one-person apartment to a 16-person group home. The amount of support provided by each agency ranged from a few hours a week to 24-hour care.

Focus Groups

In starting out the project, a "focus group" was established for each of these twenty-three individuals. Each group was made up of people who cared about the person and who wanted to help the individual become better connected in his or her community. Groups varied in size from two to seven members. All included at least one residential staff person, and some included family, a case manager, day program staff, or a teacher. The groups (including the individuals) worked over the course of the year, brainstorming, trying various strategies to help the focus individuals meet new people, assessing their progress and trying again. Although similar in some ways to "Circles of Friends," these particular groups were more structured and were focused on one particular issue: building community connections.

A Totally Individualized Focus

The emphasis in each of the group's work was on the individual with disabilities, and the strategies that were generated were those that fit the individual's personality, strengths, interests and preferences. The ultimate goal was to widen the person's circle of relationships with non-disabled people. The activities, meetings, and efforts were totally individualized, and depended both on the focus person and the character of the group members themselves.

About this Manual and About Friendship

This manual is for anyone who is interested in supporting a person with disabilities to widen his or her circle of relationships and develop deeper friendships. It describes the processes we used in the Friends Project, strategies and methods which we learned were effective or non-effective, observations based on our experiences, and real-life examples. Although we used a particular design in our project, it's not necessary to repeat that design. You don't need groups, or circles, or projects to be successful. You do need to care, and to think.

Some readers may wish to use this as a step-by-step manual to community participation. The manual does provide concrete suggestions about relationship building that we hope will be useful to individuals with disabilities, their families, friends and human service professionals. However, we don't intend that these steps be turned into "programs" or "recipes." Community and friends are about spontaneity, celebration, and genuine affection. We do have to work hard, and there is planning to do, but the bottom line is caring about people and wanting them to have the joys of real friendship. The key is what works with the person you care about, and creativity rather than prescription.

Although we worked with residential service agencies, almost all the information can be used by anyone committed to working on friendship and community participation: day training and habilitation programs, schools, families, case managers, etc. Also, the people with whom we worked all had developmental disabilities. Some also had physical disabilities or other impairments, such as traumatic brain injury or mental illness. Much of what is contained here will be useful with persons with other types of disabilities. We also recognize, however, that there are other and distinct issues with every individual, and that not everything will apply. The use of this manual will need to be thoughtful and considerate of each person's situation.

We also recognize that some of our examples and issues are either specific to Minnesota or perhaps are bigger issues in Minnesota than in other states and countries. Again, be creative in your own situation and if you don't have the same problems we do, just ignore us!

An Explanation

We believe all people belong together. We believe all of us have strengths and weaknesses. We apologize for having to use the term "persons with disabilities" to make this text understandable. Certainly many of us without that label have very severe impairments of our own, as does our language.

Before You Begin

One of the reasons why often so little has been done in the way of promoting relationships is that it is sometimes a very difficult thing to do. It requires not only an understanding of why relationships are important, but it also often requires us to restructure our thinking about the people we serve—what is most important in their lives, what will make the most difference. Faced with an already long list of program objectives and responsibilities, we often hesitate to "take on" one more responsibility.

Our experience with Friends has convinced us that:

- Relationships are so important to the well-being of people with disabilities that we cannot afford *not* to pay attention to them;
- Supporting friendships does not have to mean doing *more*—it can mean doing *differently*;
- Supporting relationships is something that can be incorporated into the day-to-day support we provide;
- Discovering ways to help people get better connected is not always as hard as it seems, can even be fun, and is rewarding to us as well as to the individual with disabilities.

People who participated in the Friends project told us: "This work on friends really brought us back to what we're here for . . . it was re-invigorating, a breath of fresh air . . . it reminded us we're in this for the people . . . it brought back idealism."

"The investment of time just to brainstorm and network was really all it took to initiate the friend relationship—a pretty cheap investment."

"I got a new view of [my son]. Unfortunately with special children, one tends to focus 'out there' on aims, expectations, goals, etc. This project got us looking at who [my son] is, what he likes, dislikes, how he responds, etc.—NOW! It was invigorating! And comforting! and a happy exercise. I guess, since then I've viewed [my son] more wholly . . . I also think there's an opportunity . . . to see beneath his symptoms, he's a person just like the rest of us."

Before you begin, these are some general principles we discovered are *critical* to the support of friendships:

Care

It's best to make these efforts for people you really care about. If you don't genuinely like and appreciate someone, it's hard to talk to others about being their friend. Usually the deeper the connection, the better the chance for success. However, this isn't a 100% time rule. By participating in this process, some staff had the opportunity to discover how much more they could like and appreciate someone.

Be a Friend Yourself — LIVE IT

Perhaps the most valuable contribution one can make to real friendship for persons with disabilities is to be a friend yourself. It's difficult to support others in being friends when you don't know the day-to-day in's and out's yourself. Being personally committed, having a deep connection, struggling through the problems, experiencing the joys — all make a difference in being able to promote such relationships to others.

Maximize Opportunities for Connections to Happen

We cannot *make* people be friends with each other. Looking at our own friendships, we know that we meet and know many people, but few are our closest friends. We also know that many of our friendships have taken a long time to develop.

What we *can* do is maximize the opportunities for people with disabilities to get to know others, and maximize the opportunities for others to get to know these individuals. And, we must make these opportunities happen on as individualized a basis as possible. John must be known as John, not as "one of those people who live in that home." When we're maximizing the numbers and depth of potential acquaintances and friends, maximizing the opportunities and continuing to support those opportunities over time, the "click" of real friendship will have the best chance to happen.

Plan

Discovery consists of seeing what everybody has seen and thinking what nobody has thought.

—Albert Szent-Györgyi

You got to have a dream
If you don't have a dream
How you gonna have a dream come true?

—Rodgers and Hammerstein

Think, Plan, Dream

There are many ways to start. You don't need a project. An agency can designate several individuals, and plan a big approach. One staff person can decide to start making efforts for one person with whom they work. A parent can enlist friends and others to get started.

It does take a one-by-one way of looking at people. It makes a difference to start with a person that someone really cares about, and make sure that that caring person plays a major role. If the person lives with a member of his or her family, it is important to have the family's support. If this is the first time anyone in the agency is trying something like this, it helps if the situation has some "stability"—that there is at least one person involved who has known the person for a long time, and the person's life situation is not expected to undergo major changes in the near future.

However, in our Friends work, we also encountered individuals for whom staff turnover, change of agencies serving the person, family turmoil, or other disruptive circumstances, made efforts to widen and deepen the individual's relationship networks very difficult. Unfortunately, the people whose lives are the most disrupted are usually the ones who are most in need of a network of stable relationships with people who will be there over time and despite the disruptions.

The most important thing is simply to start *somewhere*. No matter where you start, everyone will learn and that learning can then expand to others.

Discovering the Person's Interests, Gifts, and Capacities

Sometimes the people with the thickest files are the people we know the least. The person is known as their problems or needs, as a receiver of services and programs, but not as a human being. The *real person* is often lost.

To get a clear picture of the real person, we need to understand what the person's life has been like from his or her perspective ("in his or her shoes"). By discovering what the individual likes and doesn't like, what makes the person happy or frustrated, and by identifying what the individual has to contribute to someone else, we can find clues to the kinds of strategies that are most likely to work in connecting the person to others. Each of the Friends focus groups spent time getting to know about the focus person by talking with him or her (when possible) and with each other about the questions listed in this section.

This method is not an "assessment." It requires looking at the individual in a different light, a way in which the strengths of the person show more vividly than the weaknesses. It does not have to take much time, but it should be done with care. This process of discovery depends on the individual's participation to whatever degree possible, as well as the involvement of someone (or several people) who genuinely cares about and likes the person.

It is not necessary to work with a group, but gathering input from other people and having a chance to share ideas and insights can be immensely helpful. Also, helping people develop relationships will almost certainly be a lot of work, and the more people who are involved and committed to the effort, the better.

These methods and this format for getting to know the person have been drawn from the Framework for Accomplishment Personal Profile model (O'Brien and O'Brien) and the Personal Futures Planning model (Mount), and are used here with permission. Additional information about this process is included in the List of Resources at the end of the manual.

1. What Have the Person's Life Experiences Been Like?

A person's history can tell us a lot about why the person is the way he or she is. Knowing the circumstances of the person's life can help us to better see that person as a human being, and can provide clues about what the person's most important needs are. Look for major themes rather than all the details.

Questions to Ask:

- What have been the important events and circumstances?
- Where has the person lived, worked, gone to school?
- How has the person's life been different from a "typical" non-disabled person of the same age? different from other members of his or her family?
- How would you feel today if this is what your life history had been?

Dot has lived in over a dozen different places over the past 25 years. She left her family's home to live with a foster family, then a child-care institution, several more foster homes, another large institutional facility, another foster home, and more recently several different apartments. She has been moved from one town to another, often hours apart.

Her contact with her family has been sporadic and sometimes antagonistic. Her school experience was disrupted by the frequent moves. She has received a variety of services from numerous different agencies, depending on where she was living.

Dot does not have a sense of a permanence or of a future. When she has a bad day at work, she is ready to quit her job. When she meets someone she really likes, she clings to that person out of the fear that this person, too, will "disappear." She is often depressed.

Greg grew up in a town in northern Minnesota, where he had lived in a very distinct neighborhood. Greg knew everybody in the neighborhood, and loved to do odd jobs for people and get paid for them. A man who paid him minimum wage for painting his fence said, "Just because he's handicapped doesn't mean he shouldn't be paid like anybody else." For another man, Greg did spring and summer yard work and watched his oldest child. When other kids asked about working for him, the man said, "This is Greg's job. Greg's worked for me for many years."

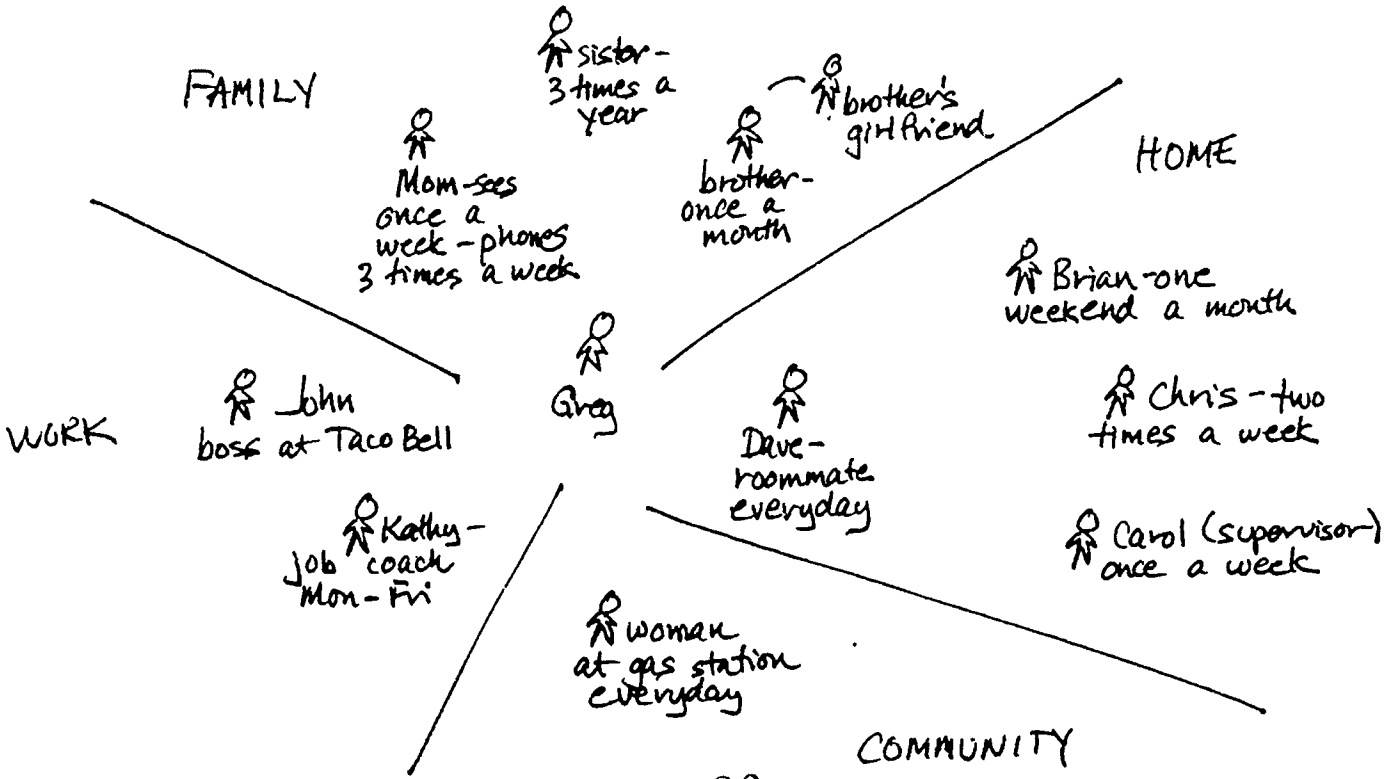
Around age 17 he started having serious seizures and problems at home. Greg soon moved to a series of group homes, spent 3 weeks in a hospital, and lived a year at a state institution. Now he is living with a roommate in a suburb of the Twin Cities; it is a "bedroom community" with very little sense of neighborhood.

2. Who Are the People in This Individual's Life? What Kinds of Roles Does the Person Play in Those Relationships?

A good way to gather information about the individual's relationships is to make a relationships "map" like the one below. To make the map, you might want to use a big piece of paper taped to the wall and draw with water-based felt-tip markers. Have the individual help as much as possible.

Start by putting the person in the middle, and then draw the closest relationships in the "inner circle." Add anyone the person considers a friend or someone important . Ask the individual about other people. Add them either closer or farther away, depending on the importance of the relationship to the person.

Use your imagination to devise symbols or ways to indicate the roles people play and the quality of these relationships. You might use different colors for paid staff, family, other people with disabilities, etc. You might draw heavy solid lines connecting the individual to people with whom he or she feels a strong connection, or use a dotted line for less important relationships.



Questions to Ask:

- Who are the people who are most important to the individual?
- Who else does he or she see on a fairly regular basis? (Family, neighbors, people at work or school, church, other places the individual goes, people he or she sees in the evening or on weekends.)
- Is there anyone with whom the person feels close that he or she hasn't seen for a while and would like to have contact with again?
- Which people are paid to be there?
- Who are other people with disabilities in the person's life?
- How often does the person see each of the people on the map? talk to them on the phone? write or receive letters from them?
- When they see each other, how do they spend their time together? do they spend time just with each other or in a group?
- Who initiates the contact?

It may be necessary to talk to family or others in order to complete the picture of important relationships, and to get a sense of how family members or friends see their relationships with the individual.

Once the map is made, look for patterns in the person's relationships. How many people are on the map? Are most of the names those of other people with disabilities or paid staff? Does the individual feel close to his or her family? Does the family have frequent contact? Are the people the individual feels closest to the ones he or she sees the least? Think about what the map would look like for a non-disabled person of the same age. What relationships seem to be missing? The patterns that emerge can guide your decisions about priorities and where to start in your efforts.

Relationships maps are discussed in more detail in *It's Never Too Early, It's Never Too Late.* (See List of Resources, p. 79.)

Dot said she had "lots of friends" and really didn't need any more, although her staff saw her as a very lonely young woman, with no close relationships and no friends her own age. Dot didn't put her family on her relationships map. She did include about 15 staff from the various places where she had lived, as well as "just friends" she had "known for a long time." Almost all of these people lived in other towns or even other states.

Out of around thirty people Dot called "friends," there were only three non-staff people that she had seen within the last two years. There was no one on Dot's map whom she saw regularly, except for staff. Dot's relationships map painted a poignant picture of a young woman who has lost contact with the people about whom she said she cared most.

3. *Where Does This Person Spend Time? In What Activities Does the Person Participate?*

The activities in which the person already participates provide a starting point for identifying where the person might make connections with non-disabled people. It is important not only to list the activities and places, but also to what extent the person participates in the activity and who is involved.

Questions to Ask:

- How often does the person participate in each activity?
- Who does he or she do it with? in a group? alone? with staff?
- How likely is it that the individual would have an opportunity to meet and get to know non-disabled people in each of these activities or places?
- Which of the activities does he or she enjoy most?

Take a moment to consider the information you've gathered on the relationships map and activities and places list. Do any patterns emerge? Does the individual go lots of places but only with other people with disabilities? Are the activities segregated (that is, are community settings used only at times when non-disabled people aren't there)? Could there be genuine opportunities for getting to know non-disabled people built into the types of activities the person already enjoys?

Laurie is in her late twenties and is a dedicated sports fan. She is an active participant in the activities organized by the community adaptive recreation service and is always ready to go to a game—football, softball, hockey, whoever is playing. She would love to meet a member of the Vikings or Twins.

Laurie spends most of her time in human service arrangements. She lives in a group home with five other women and works at the sheltered workshop. She goes to Mass each week—usually on Saturday evenings so that she won't miss sports on TV on Sunday mornings.

Laurie's group decided to explore having Laurie become involved in sports and fitness activities at the same time and in the same places as other members of the community. Laurie decided she would like to learn to use the equipment at the local community center so she could work out with other people rather than doing exercises by herself at her group home.

4. What Works and What Doesn't Work for This Person?

Each of us has our own set of conditions under which we are at our best, and conditions which we find particularly frustrating or stressful. A "morning person" might be bright and cheery at 6 A.M., while a "night person" is at her best after the sun sets. Some people need to plan everything they do; others take whatever comes up in stride and thrive on spontaneity.

When we live or work with someone, we usually come to understand at least some of what works and what doesn't work for them. Understanding the whole person in this way helps us determine which strategies may be most effective and what kinds of supports and safeguards will be necessary.

One way to think about what works and what doesn't work for a person is to make a chart like the one below. Some questions to ask:

What Works:

- How does the individual like to be treated?
- What kinds of people does he or she seem most comfortable with? respond to best?

What Doesn't Work:

- What kinds of situations or events frustrate or upset her? what kind of people do they respond to worst?
- What situations get the person "in trouble"?

WHAT WORKS	WHAT DOESN'T WORK
coffee-treats-snacks listening to polka music newspapers and magazines going out to eat church helping in kitchen vacuum-cleaning beer and enchiladas folding papers getting in the mail pushing shopping carts naps-relaxing sanding blocks shaking hands being in the community painting people doing silly things	being made to do something he doesn't want to do doctor, dentist, neurologist appointments environments where vision is important uneven surfaces unfamiliar places loud noises crowds waiting for someone to take him to the bathroom mornings being rushed being tired being touched putting pajamas on

5. What are the Person's Interests, Gifts, and Abilities?

We often meet new people through shared interests, like softball, volleyball, sewing, art, music, or hobbies. A person's interests will often provide the best clues to possible places and groups with which they can be connected.

If a person has a particular gift or strong abilities, that will also provide clues to the best strategies for making connections. Someone with a good sense of humor may do well in new social situations. Someone who likes to work hard might enjoy helping set up bingo at the V.F.W. hall. This list can help identify people who would share their interests, places and groups where the person would be appreciated, individuals who would appreciate getting to knowing them, and others who would benefit from their capacities.

Questions to ask include:

- What are the person's interests?
- What are their strongest gifts and capacities?
- What sort of service does the person have experience offering?
- What contributions does the person make to other people's lives?
- Which of the person's skills and attributes are needed and wanted by others?

CAPACITIES, GIFTS, AND INTERESTS
nice makeup dresses nice pretty smile great sense of humor talks nice pretty smart, knows what's going on good writing needlepoint collects: Santa Clauses, rock and roll books, posters, record collections, silk flowers bowling walks, parks friendly-invites people over clothes-shopping wins radio contests

6. What Does This Person Have To Contribute To Others?

Because we are used to assessing what the person *cannot* do, it may be difficult to see what he or she could *contribute* to someone else (especially if the person has a reputation for being a "problem"). And when we are used to thinking of an individual as a *receiver* of assistance or services (a "client"), we have to switch gears to think about what the person has to *give*.

This step in the process of getting to know the individual from a new perspective can help overcome any uncertainty about whether anyone would really want to get to know the individual. It can help decide where to look for other people who would value the individual's unique characteristics. There may be some overlap with the previous section.

Questions to Ask:

- What does the individual do well?
- What is there about him that people like or might like?
- What does he or she have to offer that others would see as a contribution?

One way of getting at the uniqueness and capacities of the person is to make a list of words or phrases that best describe the individual. Doing this with the person as much as possible, or with a family member or someone who cares about the person, will help keep the list on track. Focus on the positive characteristics--don't let this become just one more list of what's *wrong* with the person.

Patrick's group was having a hard time with the question "What does Patrick do well?" It was easier to think about what there was about Patrick that would make it hard for someone to get to know him. They tried making a list of words and phrases that describe Patrick. Here is the list:

handsome
snazzy dresser
quiet
shy
funny
good sense of humor
sensitive
intuitive about people's feelings
affectionate
dedicated to people he cares about
stubborn
manipulative
volatile moods
predictable and unpredictable
artistic

When the group took a look at this list, they agreed—who wouldn't want a friend who was sensitive, dedicated and affectionate, handsome, and fun, even if sometimes he was stubborn and moody?

7. What Assistance Does the Person Need?

It's important to think specifically about the kinds and amount of assistance that would be required if the person were to spend time with another person in a typical community setting.

The supports necessary to help someone who is quite independent meet non-disabled people and participate in community activities will probably be very different than those necessary for someone who needs physical assistance or supervision throughout the day. Sometimes we simply don't know what kind of assistance the person might need in a new situation. Thinking through *exactly* what is necessary and how it might be provided in specific situations helps insure that both the individual and community persons will be comfortable and safe, and that the new experience will be a success.

Questions to Ask:

- How much assistance does the person need? (physical assistance, medication, supervision, personal care, understanding communication, being interested in someone else, not overeating, etc.)
- Under what circumstances does the person need help?
- Who provides this assistance now?
- Could someone from the community provide the necessary assistance?
- How could someone be trained or supported to provide the necessary assistance?
- What are the implications for the person's participation in various community activities?

Dot receives only minimal assistance. For the most part, she takes care of herself. She does not require supervision. She could participate in a variety of community activities independently, but might need someone to provide transportation.

Because Patrick has seizures, he needs someone available to help him all the time. He also needs someone to give him his medication. In order to participate in regular activities, at least one person who is with him needs to understand how to manage his seizures. New people could be trained to manage them.

Creating a Vision

Each focus group in the project needed to have a *vision* of what the individual wanted and what they wanted for the person in terms of a network of relationships. Creating that vision was necessary before each group could decide *how* to go about creating opportunities for the person to meet non-disabled people. Sometimes there was a lack of agreement about what was most important for the individual. Some individuals said they didn't need any new friends, while others in their groups believed that the lack of relationships was a key issue. In some groups there was some question about just how idealistic to be in creating the vision. Some visions were very modest— wanting just one friend for the individual. Other visions were larger—wanting the person to enjoy a full and active community life with lots of friends and family.

In order to visualize the ideal relationship future, it is necessary to set aside thoughts about what seems possible or probable, and instead do some "wishful thinking." Don't worry if the ideal seems so unrealistic that you don't see how you could ever reach it. Sometimes what seems impossible at first is actually within the realm of possibility. However, if you are working with an individual who might not understand that this is "wishful thinking," it is important to be careful not to mislead the person with your enthusiasm only to set him or her up for disappointment.

Questions to Ask:

- What kind(s) of relationships does the person want?
- What is the most ideal situation, in terms of relationships, that we can imagine for the person?
- Is there anything about existing relationships that we or the person would like to see change?
- Who are the people who could benefit from being in a relationship with this person?

April is a woman whose goal was to find a boyfriend. However, although she is very forward about meeting men, conversations almost never get beyond the first two sentences. Her constant conversation about boyfriends also seemed to indicate a desire to be really close to someone, and wanting to be liked just the way she is. Her group and April wanted her to have a few close friends—people who would spend time with her, who really liked her, who would call her up to do things.

Deciding on the First Steps

Once the vision is created, it's time to decide how and where to start. Sometimes there are problems in the individual's situation that need immediate attention. It may be necessary to sort out what is most important for the particular individual *now* in order to know where to start working toward the ideal relationship future. Or, the possibilities and opportunities may be very clear and straightforward and everyone is excited to get started immediately.

After completing all the steps listed above, a lot of ideas and patterns emerge. The group members, or single staff or family person, can then generate a list of ideas.

Questions to Ask:

- Given these interests, what's worth looking into?
- Do I know anyone who shares similar interests?
- What groups or associations are worth exploring?
- Who can I ask about this . . . ?

The first steps to take will come from being clear about what you *can* do as first steps. It's time for action when an action is identified in a clear step and someone says "I can do that." The next section presents some general principles to consider in doing the real work of connecting.

Linda left her family home to live in an institution when she was 4 years old. She doesn't speak, uses a wheelchair, and needs assistance to get around. After years of institutional placements, she now lives in a large group home.

Linda's group had already decided that the ideal was for Linda to have a friend who could spend time with her, get to know her, and eventually be able to take her out for rides, to eat, or home for a holiday. However, there was another issue for Linda that they wanted to address. Linda's parents had had very little contact with her for years, although they lived less than two hours away. There were other family members who had kept in touch with the group home, but only infrequently, and no one knew how to contact them. The group decided what was most important for Linda now was to be closer to someone in her own family, and made that their first order of business.

Lily is 11 years old and lives at home. She attends a regular third grade class in her local school. She speaks some, uses some signs, is affectionate and physical, but needs constant supervision. While Lily has an extensive family, almost all of her time outside of school is spent with adults. The group decided that the first priority was to find ways for her to spend time with children her own age in the neighborhood, and to have some friends her own age.

Connect

No man is an island, no man stands alone . . .
We need one another, so I will defend
Each man as my brother,
Each man as my friend.

—Joan Whitney & Alex Kramer

People who need people
Are the luckiest people in the world.

—Jule Styne & Bob Merrill

Connecting Strategies

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. They are from *Ties and Connections* (see List of Resources, p. 79):

- **Friendship:** having friends, relationships, including a 'best friend'. Mostly these will be what 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.

There is no formula for choosing which activities and strategies to try for any given individual. Such efforts can start anywhere — small businesses, public places, associations and clubs, churches, staff, friends, parks. The list below is an example of the types of clubs, interest groups, and organizations found in just one community: (from John McKnight, "Regenerating Community")

Artistic Organizations:	choral, theatrical, writing
Business Organizations:	Chamber of Commerce, neighborhood business associations, trade groups
Charitable Groups:	Red Cross, Cancer Society, United Way
Church Groups:	service, prayer, maintenance , stewardship, acolytes, men's, women's, youth, seniors
Civic Events:	July 4th, art fair, Halloween
Collectors' Groups:	stamp collectors, flower dryers, antiques
Community Support Groups:	"friends" of the library, nursing home, hospital
Elderly Groups:	Senior citizens
Ethnic Associations:	Sons of Norway, Black Heritage Club, Hibernians
Health and Fitness Groups:	bicycling, jogging, exercise
Interest Groups:	poodle owners, old car owners
Local Government:	town, township, electoral units, fire department, emergency units
Local Media:	radio, newspaper, local access cable TV
Men's Group:	cultural, political, social, educational, vocational
Self-Help Groups:	Alcoholics Anonymous, Epilepsy self-help, La Leche League
Neighborhood or Block Clubs:	crime watch, beautification, Christmas decorations
Outdoor Groups:	garden clubs, Audubon Society, conservation clubs
Political Organizations:	Democrats, Republicans, caucuses
School Groups:	printing club, PTA, child care
Service Clubs:	Zonta, Kiwanis, Rotary, American Association of University Women
Social Cause Groups:	peace, rights, advocacy, service
Sports Leagues:	bowling, swimming, baseball, fishing, volleyball
Study Groups:	literary clubs, bible study groups
Veterans Groups:	American Legion, Amvets, Veterans of Foreign Wars, their auxiliaries
Women's Groups:	cultural, political, social, educational, vocational
Youth Groups:	4H, Future Farmers, Scouts, YMCA

Based on our work with Friends groups, we discovered some general principles that can guide the work of beginning to make connections.

Focus on Opportunities for Relationships Rather Than on Activities

Think about community participation in terms of the relationships the person might develop, rather than the places he or she might go. While activities can provide the setting for meeting people, there is a danger in assuming that going to a movie or shopping or bowling is "the answer." Some activities hold more opportunity for meeting and getting to know people than others. A group outing to the mall is not likely to produce an opportunity to get to know people. Neither will simply having one staff accompany one person with a disability. While malls are great for "people watching," they are less effective for "people meeting."

However, one individual accompanied by a staff person, if necessary, could go to a neighborhood cafe on a frequent basis. If he or she repeatedly went at the same time that the "regulars" were there for their coffee break, there is a greater likelihood of results. The results may not be immediate friendships to last a lifetime, but instead a familiarity that may lead to relationship.

> *Ollie is in his early 70's. Ollie does not communicate by talking; he does make sounds that those who know him well can understand. Once a person spends some time with Ollie, it is easier to know if he is frustrated, if he is enjoying himself, or if he is bored.*
>
> *Ollie enjoys listening to music, people-watching, and drinking coffee. The agency made arrangements so that one staff person would take Ollie out one day a week to "hang out" at a local coffee shop. The group believes that as more people in the community come to know Ollie, he will be seen as a potential friend rather than just "one of the men from the group home."*

> *Jay is a real sports enthusiast, and his group used that enthusiasm to explore opportunities for him to meet regular people. First, they looked into his being an assistant coach for a local T-ball team. Second, his minister was very interested in him. He invited Jay to play ball with the church's softball team in their league; the team was a group of people that got together mainly because they enjoyed playing.*

"Community activities" can mean taking the group home van out for a ride with seven or eight residents and stopping at McDonald's, or it can mean one staff person taking an individual to help at the church pancake breakfast. The first instance is not likely to create an opportunity to really get to know any community citizens—working at the church breakfast would. It's important to be creative. Use the resources you already have.

"It Never Hurts to Ask"

The only way to start finding out what you don't know or have is to ask. If you're unsure about community resources, investigate. Call anyone you may know, look things up in the phone book, ask others who they know.

The only way to discover if someone would be willing to meet someone, or do something with someone, is to ask. Sometimes we're reluctant to ask others to do things. We typically expect that people will say "no." However, over and over again in the Friends project, staff were amazed at what happened *when they simply asked.* They thought others would be reluctant, or need more information. Over and over again, people simply said "yes." And not only "yes," but "yes, no problem" or "sure, have her come over today."

Art has a real interest in history. A few miles outside of town the historical society has maintained a country general store that is open in the summer. The group thought Art would enjoy volunteering at the store, and Art agreed to give it a try.

The staff person who volunteered to call the woman in charge of coordinating volunteers made a long list of reasons why Art should be a volunteer. She was expecting some hesitation if not resistance. When she made the call, the woman in charge said "yes" before the staff had a chance to give her even one good reason.

Vicki's group wanted to find ways to bolster her sense of self esteem. She had expressed an interest in having a boyfriend, but didn't like any of the men from the sheltered workshop. When the annual dance was coming up, one of the staff members in Vicki's group had the idea to talk to the very handsome and suave exchange student from Argentina who was staying with her family.

The staff person really didn't think he would agree to go to the dance with Vicki, but she asked him anyway. He said, "Sure," and he and Vicki went and had a great time. Vicki was the envy of all the women at the dance—she had one of the cutest dates. The staff person said she herself had learned that "It never hurts to ask."

Encourage Everybody

Sometimes people are reluctant to try things. We all have some fear of a new situation. Often people who are initially hesitant will be willing to try something with very little encouragement. Some people take more encouragement, or more time to feel comfortable.

Sometimes, after trying something and it has not gone well, it becomes even harder to try the next time. However, the most important thing after falling off a horse is to get right back up on it.

We found that it was important to maintain an encouraging attitude. People learned a lot when they were encouraged to believe: "Yes, I *can* do it. It *is* possible." This was true for:

- the person with a disability
- the parent of someone with a disability
- the community person
- community organizations
- staff members
- agencies
- case managers

Almost every single person in the project, over the course of several months, became reluctant or discouraged at one time or another. Sometimes encouragement was not enough in itself, and more plans needed to be made. But in the end, when people did finally try after they had initially been reluctant, unexpectedly positive events almost always resulted. You can never underestimate really believing in yourself and others.

If you become discouraged, seek out someone who will give you a different light on the issue and help you see what is possible.

> *April had been on a diet for years. Her staff had kept encouraging her to exercise regularly, or join a health club. She kept saying No, No. Everybody knew she was one of those people who hates to exercise. One of her big interests, however, was meeting men. So her group kept encouraging her at every meeting to at least try going to the health club. They enthusiastically spoke about how attractive the men were who attended, and what a good place it was to meet people. Finally, April agreed to at least try it.*

> *Patrick's group had decided they wanted to find some other teenage boys to hang out with him. Marge, the staff person, knew a young man at her church she thought might be interested. She began the conversation with him one Sunday, "I know somebody you might want to meet." Then she "kept after him" a few Sundays in a row. He finally agreed to come and meet Patrick, but said he'd be more comfortable if his friend, another teenager, could come along.*

"Community" May Have More to Do with Belonging than Zip Code

In our own lives, there is not one "community" which exists "out there"—like a thing we can highlight on a map. Some of us don't live in a community that has a particular character. We may live in an area where we don't have a sense of community from the physical region. Our "community" might not be our town or neighborhood, or our geographic voting area.

We might rather define community as the people, places and associations to which we are connected. Our communities are defined by the people and associations we have and where we *do* have a sense of belonging, of being a part. For some of us, it may be our church, a social club, the group of people we work with, our softball team, or it may be our neighborhood.

People with disabilities often lack these community connections. For the person with few or no connections, we need to think about where to begin to build these types of connections and this sense of belonging.

For most of us, our relationships and associations change over time. Our friendships and our sense of belonging come from different people and places than they did ten or five years ago, or even one year ago. Establishing and maintaining relationships is an ongoing challenge for all of us, but especially for those individuals who have disabilities. In our work to support people with disabilities in being related and connected, we'll probably never be able to say that we have "met the objective 100%"— that the job is completely done. As people come and go in their lives, each individual will likely continue to need assistance in maintaining relationships.

> *Kay moved into a new house in a new neighborhood. There was a church just one block away in which she could get involved. The person who was her roommate belonged to a church that was farther away in a different neighborhood. However, it was his family church. He had attended there since he was a little boy, and both his parents had worked for the church for years. They knew everybody there and so did the staff person. It might be a much better church in which to involve Kay, since he already had a deep experience of belonging and relationships. She could be much more naturally included.*

Keep Your Eyes Open for Opportunities

Once you start thinking about possibilities, you might be surprised at the opportunities that present themselves—a neighbor who shares the individual's interest in vegetable gardening, a church bulletin announcement recruiting volunteers for the fund-raising bazaar, a friend of a friend who shares the individual's interest in local history. It's important to keep looking and to keep asking.

> *Vicki's group had talked a good deal about finding a woman close to Vicki's age who could get to know her and spend some time with her. Someone in another focus group had mentioned the name of a woman who had recently moved into town. When the staff person in Vicki's group heard the name, she said "Oh, I know her. I went to school with her. I never thought about it, but she might be a good friend for Vicki. I'll ask her." She did, and the woman has become Vicki's friend. They talk on the phone, go for walks and shopping together, and Vicki is getting to know her whole family.*

Strengthen and Rekindle Existing Relationships

One place to look for opportunities for belonging and connectedness is in the already-existing relationships on the person's relationships map. Pay attention to the relationships that seem the most important to the individual.

Family

Even if the individual's family has not been very close, there may be a member who would welcome the chance to become more involved. Some families have been discouraged from maintaining contact by physical distance or "professional distance"—when the service system has made them feel like they are not needed or can't do as good a job as the professional staff can. Some family members may feel guilty or hurt as a result of their experience raising or sending away a child with disabilities. While we can't undo the past, we can . . .

- make sure there is a record of family members, their addresses, phone numbers, birthdays, anniversaries, etc.;
- help the individual to maintain or reestablish contact with family members;
- contact family directly in order to maintain relationships on behalf of individuals who cannot do so themselves;
- look for ways that the individual can be an active and contributing member of his or her family—sending cards (and gifts) for birthdays and holidays, keeping in touch by letter or phone, sending photos and keeping an album with family pictures, or inviting family members to visit.

When Linda's group began to look for ways to reconnect her with her family, the first thing they decided to do was to send Christmas cards with Linda's photo enclosed. A staff person called Linda's parents and asked for the names and addresses of relatives so that she could send cards. Linda received several cards and letters in return.

Her great aunt, who lives in the same town, came to visit Linda; they had not seen each other for some time. On Christmas Day, Linda's parents and brothers came for a visit—their first visit in over four years.

The contact with her sister and grandmother which began with the Christmas cards has continued. Linda now has a bulging album with her photos and cards that reminds her that she belongs to a family. Linda also received a letter from her younger sister saying that although she never really had a chance to know Linda, "It's good to know she has a sister" and she "thinks a lot about what it would have been like if we'd been able to grow up together." The staff who read the letter to her were amazed at Linda's depth of recognition and tearful response to the moving letter.

The group decided to have Linda visit her family home, which she had never done. They called up the parents, unsure of what to expect. But the family agreed to work with the staff so that Linda could come home for a visit.

Marvin lives by himself in a small house; in the beginning, his focus group included just two staff members. The group soon realized that it would be helpful to include some of Marvin's family members, most of whom lived in a community less than 20 miles away.

At the next focus group meeting, Marvin's mother told the group that he had always been very close to his sister. Since Marvin had moved to this community, they rarely had a chance to get together. The focus group decided to have the next meeting in the community where his mother and sister lived so that they could be a part of his group. Throughout the project, staff tried to arrange other opportunities for Marvin to spend time with his sister.

Michelle had been in a couple of foster homes before she came to the group home. The group home staff knew that Michelle had a big family, but they had only had contact with a brother and Michelle's grandmother.

When Michelle was to be confirmed, the group home staff asked these family members if they would like to have a confirmation party. They offered to have the party at the group home and asked the family to help with the planning. Twenty-six members of Michelle's family came. For most of them, it was the first time they had visited Michelle's new home and the first time they had been together at an event in honor of Michelle.

Of course there will be some family members or others who don't share the individual's feelings of closeness and won't want to be involved. Some people don't want to stir up the past, especially if it has been painful. However, others might find comfort in reestablishing their relationship with an estranged family member.

Other Old Friends

The same strategies that encourage and support family involvement can be used to strengthen or rekindle relationships with others. There are often old friends or neighbors, and former staff people who now might enjoy spending time with the person as "just a friend."

Vicki had told her Friends group about a couple of former teachers she really liked. When Vicki decided to have a birthday party, she invited them. Neither was able to attend the party, but, not too long after that party, one of them called to invite Vicki to an open house for another teacher who had moved away and was coming back for a visit. Vicki was really thrilled to be included in this "welcome home."

Model: How We Ourselves Meet New People

Most of us meet new people in a variety of ways—in our neighborhoods, through our work or our children, in church, civic organizations or leisure activities. We make friends with people we're around a lot. Sociologists have shown that proximity or physical closeness is the number one factor affecting who we make friends with. We are more likely to develop a close friendship with our next-door neighbor or someone we work with every day than with someone we only bump into occasionally. In addition, our friendships often develop slowly over long periods of time.

Most people who are settled in life don't consciously undertake serious friend-making activities. However, there are a few times in life when we do consciously set out to make new friends: starting college, moving to a new town, or after losing a spouse, for example. At those times, it's typical to look in the places where there are people who share our interests. We might look in the Yellow Pages under "Clubs and Organizations," watch the local newspaper for announcements about events and activities of interest to us, or look up the class schedule for the local adult education program.

Sometimes, we consciously decide to look into a new activity we've never tried before. We might ask people we do know if they know anyone who belongs to a book club or likes to ride in bike races or go bird-watching. When moving to a new town, we're often much more assertive about meeting our neighbors, and we pay more attention to the local news to find out "who's who."

When we're trying to help people with disabilities meet new people, it helps to identify our own strategies, what's worked for us in the past. We can ask ourselves what we did, or how we would do it if we had to figure it out for ourselves. The simplest question is, "If this were *me*, what would I do?"

Art loves history and books; he especially likes history books. He told the group that he would like to volunteer at the library. The group decided the best way to begin was to just ask.

One of the focus group members agreed to stop in at the library and talk to the head librarian. He thought it was a great idea, and asked if Art could come by to meet the other staff that afternoon. By the next evening, Art was a volunteer at the library—and the entire process took just a little over 24 hours.

Vicki was very interested in sewing. The staff person who worked with her chatted with other staff about people they might know who were also interested in sewing who might really like Vicki. She kept asking people until somebody suggested Muffy, who sounded like exactly the right person.

Knowing the Community

In connecting people, it also helps to know the community—what organizations exist, who belongs to them, where there is to go, and what there is to do. It helps to identify the community leaders—the "movers and shakers" with their fingers on the pulse of community activity. Sometimes, there are community members who are not necessarily leaders, but who are the people who know everybody and who know what everybody is doing. These people can not only be information resources, but also effective allies in our efforts.

Most people with disabilities are not active in civic and social circles in their community, and often, the people who work with them are not either. It can be a confusing and frustrating experience to sort through all the available community opportunities to find the "right one." It helps to . . .

- gather information (from the local Chamber of Commerce, the newspaper, etc.) about community groups and activities;
- find people who know the community well—people who have lived there for a long time, know a lot of people, and are active in local organizations;
- get involved in a community group or activity yourself.

In our work with "Friends," we found that in the rural areas, it was easier to find the community leaders; someone always knew someone who "belonged to that church" or "lived in that neighborhood." The social and civic structures seemed to be better-defined and easier to access. The communities were smaller and had well-defined places where community people gathered—where the "action" was. Everyone in these towns, including the staff, *knew* these places.

In some of the larger, urban communities, there may have been more connecting opportunities, but there was much less sense of a well-defined community. In some suburbs, there was almost no sense of place, or of people knowing each other. It was more difficult to identify the "community" leaders and establish personal contacts. But it *was* possible—it just took more asking.

> *Bill is a teenager who had been severely injured in an accident. Although he had traumatic brain injury, he retained most of his teenage interests, including music and girls. He told his group he would really like to meet people by finding a band to hang out with. Of course, he was also particular about what kind of band—it had to be heavy metal.*
>
> *Because he lived in a suburban area with no music clubs of its own, it was not easy at first to locate a heavy metal band nearby. A member of his group contacted a music store in the next town. She asked the owner if he might help a young man connect with a band. The music store owner said, sure come in anytime and we'll talk. Bill's staff person took him over to the store. The owner was friendly and helpful, and gave Bill the names of three heavy metal bands he knew in the area. He said if they didn't work out, come back and talk to him again.*

Find and Use Bridge-Builders

"Bridge-builders" are the people with a wide range of connections in the community who can help introduce people with disabilities to non-disabled community members. It helps to have someone like this as an ally—supportive of the idea that people with disabilities belong in the community. If you do not already have someone like this, you might want to consider making it a priority to find these people and enroll them onto your side.

Bridge-builders have the advantage of being seen as regular community people—not human service workers. Because they are community leaders (whether formal or informal), their support for the inclusion of people with disabilities in social and civic activities can be very effective. Bridge-builders can be very visible community members—someone active in local government, the postmaster, a teller at the bank, the manager of the grocery store. They also may be not so visible—a mother or father who's active in the PTA, 4-H, or Scouts, the organizer of the summer softball league, etc. A good way to find these people is to ask around: "Who do you know who knows lots of people in town?"

Henry's group hoped to find an older man close to Henry's age from his church who would be willing to get to know him, sit with him at church, visit with him at the after-service coffee hour, and maybe even give him a ride to church each Sunday. The staff contacted a woman who had served on the agency's Board of Directors and who was also an active member of the church to explain their idea. The woman then met with the minister and asked him to help her find someone who would like to get to know Henry.

Introduce

A friend may well be reckoned the masterpiece of nature.

—Ralph Waldo Emerson

It is only with the heart that one can see rightly;
what is essential is invisible to the eye.

—The Little Prince, Antoine de Saint Exupéry

Introducing People

If you've ever introduced one friend to another or to a group of friends, you probably wondered beforehand if they were going to like each other. If one of the friends is a bit unusual (has a prominent tattoo or looks just like Barbra Streisand), you probably wanted to say something to put the other friend at ease when they met. ("He doesn't mind tattoo jokes—he collects them" or "Whatever you do, don't mention that she looks like Barbra Streisand—she *hates* Barbra Streisand!")

When you want to introduce a person with disabilities to someone who might not have had too much experience with people with disabilities, or to a group of people, you will want to make everyone as comfortable as possible. The time, place and circumstances of the meeting could make a difference. What you tell each person can also make a difference. It may help to think of it as setting up a "blind date" in which you want to do everything you can to make sure that both people "hit it off" with each other from the start.

Plan for Success

Think through beforehand: what will make the meeting successful for the person with disabilities as well as the community person? It makes a difference to do everything we can to insure that the experiences an individual with disabilities has in the community are successful—for the individual and for the community. That means anticipating as clearly as possible what will be most likely to ensure a positive experience for all concerned, what the potential problems might be, and preparing adequately by building the right supports and safeguards into any situation. These supports might include having staff accompany the individual in the community along with the non-disabled person, or "training" the community person to assist the individual or to manage potential problems. Insuring success might also include preparing the individual for the new experience.

For some people who are very sociable, outgoing and at ease in new situations, introducing a new friend does not require much groundwork. For others who are painfully shy, or anxious, it could take some time and support before they feel comfortable with someone new. We need to think through who the "audience" (community) is, and what will have them be most receptive. A class of high school sophomores will require a different approach than the regulars at the neighborhood tavern.

> *Wanda is a woman who does not warm up to new people quickly. She is nervous around strangers, and worries about whether someone she meets will be nice to her. She doesn't like to ride in a car with someone unless she's sure that the person is a careful driver. She is most comfortable when she can take her time getting to know someone.*
>
> *In Wanda's situation, it worked to have a trusted staff person go along the first couple of times she went out with a new acquaintance until she decided she liked and trusted that person enough to go without staff.*

Jay likes everyone. He is independent enough to get around his town on his own and meets new people easily. Jay wanted to take an exercise class. When his group talked with him about the class, he seemed comfortable getting himself there on his bike and was prepared to go on his own. He had attended other classes in the same building, knew how to find the room where the class met, and knew how to dress and what to take along. After the first class, Jay said he didn't want to go again. He didn't say why, except that it was "too hard."

This might have been an instance in which it would have been helpful for someone to talk with the instructor ahead of time or go to the first class with Jay. He could have had the chance to meet the instructor beforehand and let her know that he had never taken this kind of class before. Of course, this would have to have been done without embarrassing Jay, and maybe the class would still have been so hard that he wouldn't have enjoyed it. Perhaps the others in the class were unkind; maybe the instructor would have been willing to help the others welcome Jay.

Mark is 20 years old and attends classes at the local high school. His group wanted to find some students his own age who might be interested in getting to know him better and becoming a friend. The group decided to write a letter and worked with one of the high school teachers to get the letter distributed. When there was no response, group members looked at the situation and decided that a typed letter was probably not the best way to approach teenage boys.

Presenting a Very Important Person

Reputations are powerful forces for every person in every population. Reputations of people with disabilities are often built on single incidents or on descriptions of what the individual can't do, what needs "fixing," or what's "different." Once an individual gains a reputation for being strange or offensive (demanding, aggressive, etc.), a vicious cycle begins. People expect the "deviant" behavior, respond to the person with aversion or rejection, and the individual never has the opportunity to overcome the reputation.

When introducing an individual with disabilities to a community member, there is a delicate balance to be struck. We need to provide enough information about the person so that the community member knows what to expect or can respond to the individual's needs. We must also avoid giving information that's not really useful and might damage the individual's image and future relationships. The need to respect people's reputations is so crucial that it deserves careful attention.

When it comes to image, people with disabilities already have one strike against them. It is far too easy for a person who is already seen as "different" to gain a reputation that keeps others away, especially when the difference is already or easily apparent.

Anyone can be introduced in a way that is both realistic and that emphasizes his or her best qualities. Of course, we need to provide adequate information to someone who is going to spend time with an individual to insure everyone's comfort and safety. It helps to have new people get to know each other around familiar faces before they spend time alone. If someone is going to be responsible for an individual who needs medication, has seizures or a physical condition that could require assistance, the person needs to know exactly what to do to manage a potential situation. This would also be true regarding individuals who might do something to injure themselves or someone else.

However, we need to guard against being overprotective or exaggerating the potential danger, especially when we're introducing a person for the first time. For example, we don't need to explain that a man had started a fire playing with matches when he was five, even though the incident is in his case history and has become part of his reputation. We don't need to tell everyone that he is known to be aggressive and has other behavior problems. Rather, we would first describe the things about him that we think the other person would like. (He has a great sense of humor, he wants to learn to cook, and he's a big sports fan.) Then, if we thought there was a chance he might get upset while with that person, we would let the person know that he has recently been striking out at whoever is within reach when he gets frustrated. We would let the person know what to do, or assure them someone will always be there the first few times. We would also set up the conditions as much as possible to eliminate frustration.

There are things we can do to let others know that we value people. People may be impressed that the individual knows someone willing to make the effort to introduce him or her to others. Sometimes, quantity helps. If three staff or family members attend an event with a person with disabilities, it makes a powerful impression—here is someone who has a lot of friends who like to spend time with the individual, and this person is worth knowing.

> *Michelle is 17. She is labeled moderately to severely retarded, and uses only a few words. Although she can take care of most of her personal needs, she needs prompting to complete tasks like brushing her teeth or taking a bath. She is terrified of dogs, cats and other small animals.*
>
> *When a staff person introduced Michelle to two non-disabled girls who came to visit at the group home, the only information she provided about Michelle was that she likes music, has some favorite tapes, loves to put on make-up, and made cookies for their visit. She also made sure that Michelle showed the girls her communication book which had pictures of her family, teachers, friends, favorite foods, etc. She decided that she would also tell them about the fear of animals if they decided to go for a walk.*

Patrick, who is 19 years old, has seizures. Sometimes he makes strange hand movements and he has a number of other unusual habits. A couple of other teenage boys were going to meet him and go bowling. His group debated a long time on what to tell the boys. Should they tell them "nothing" and just see how well they liked Patrick? Or should they tell them "everything" Patrick might possibly do that might seem bizarre?

The person who introduced them finally decided the other boys should know that it was possible that Patrick would have a seizure, and what the seizure might be like, and that they should be assured that the staff person would be there to manage things. The first time Patrick flicked his fingers in the air, she told the boys what that meant—that Patrick was having a good time.

Tony became a member of a local service organization. However, the group already had a number of members with disabilities. One of the first events they had after Tony joined was a steak-fry and horseshoe night. If you were a member, you got a free steak if you brought a guest as a potential member. Tony brought three guests: his staff person, his former staff person, and another member of his Friends group. All of his guests were young women. Tony and his guests received a lot of attention from the other members.

How Do We Know How Much Support is Necessary?

The best guide to what kind and amount of support is needed in each situation is the individual and the community person or group involved. If the person with disabilities is not able to communicate what they need to feel comfortable, if they have limited experience in social situations, or if they may loudly demand attention or food, then it's up to us to anticipate how the individual might respond in a given situation. We need to figure out how others might react to him or her and plan for the best level of support (neither too much nor too little).

We also need to anticipate the needs of the community person or group. Some people are very out-going, capable of handling a wide variety of individuals and situations, or even already have a great deal of experience with persons with disabilities. Others are more timid or hesitant, and may need more support from staff, especially in the first few meetings.

Planning the amount and type of support to provide is not always an easy task. No matter how hard we try to plan for success, there is still a risk that things won't work out as we planned. *This is not cause for giving up. It is an opportunity to learn what didn't work and try again.*

While we want to emphasize the importance of thinking through each strategy for potential problems, our tendency may be to anticipate problems based on the individual's behavior in a service setting. Research has shown that

sometimes "institutional" behaviors are not good predictors of behavior in community settings with non-disabled community members. When an individual has the opportunity to participate in interesting activities with regular people, the "institutional" behaviors often disappear. When we give individuals the chance to be at their best, more often than not, their abilities surpass our expectations.

We have also been surprised at the genuine caring and regard shown by many community members. Rather than thinking we need to train them to be more like us, to handle certain behaviors the "right way," we *can* often trust them just the way they are. They are often quite capable of figuring things out for themselves. Whatever they do naturally in their activities and communications is often just fine, and is just what is wanted and needed.

Introducing . . .

Individuals can be introduced to others on a one-to-one basis or to a group.

Making One-To-One Connections

A method that worked extremely well in the Friends project was the use of one-to-one introductions. Staff identified people's interests and generated possible connections. They looked for people they might know who shared these interests. They thought of places they might look for people who might like to get to know people.

Once they identified people and places, they asked. When they found people who were interested in getting to know people as friends, they introduced them. They worked through the areas presented here—what was best to say before the initial meeting, how to best ensure success, etc.

> *Linda's group wanted to find someone who could come and visit her regularly and perhaps take her out away from the group home. Marie, one of the staff who was a member of her Friends group, decided to ask the women at her church who were the presidents of all the women's circles. She attended one of their meetings and explained her request. They described Marie's request in the minutes of their meeting. Eleanor, a member of the church, saw these minutes and decided she might be interested in meeting Linda. Marie arranged for her to come and meet Linda at the group home.*

> *Michelle's group wanted to find some friends her own age for her. Nothing was happening at her school regarding integration. However, her class aide was a member of her Friends group. The aide put a notice in the school bulletin asking for students who might want to become friends with a special education student. The group got four replies to the notice. Two students wanted to be paid. But the other two girls who responded did want to meet Michelle. They came over to the group home, met and liked Michelle, and planned to come regularly to visit her.*

Introducing an Individual to a Group

Becoming a member of a group often adds to a greater sense of real community participation and a greater sense of belonging. Introducing an individual with disabilities to a group of people requires the same kind of forethought as introducing someone to just one person. Sometimes the best way to do this is to identify a member of the group, such as the instructor or president, who can be the first connection. This person can then include the individual in the group and act as a bridge-builder to other group members. If the group is formally organized, like a club or service organization, an approach to the group as a whole might work.

> *April has lots of energy and loves to get out and meet people. Her group decided to investigate a local community service organization that sponsors frequent social get-togethers as well as participating in community events. April asked that someone from her Friends group "check it out" for her before she decided to go to a meeting.*
>
> *One member of April's group, Barbara, attended a meeting to get a feel for the group. At the meeting, Barbara explained she was there because a friend of hers was considering joining and she had come to the meeting to check it out. The group was very impressed that April had friends like Barbara. Barbara told them that her friend had a mild disability, was really a lot of fun, and enjoyed meeting people. The group was very enthusiastic about meeting her.*
>
> *After hearing about the meeting, April decided she would like to see for herself, so she went to the next meeting with Barbara and Carol, a woman who works with her. After the meeting, group members spontaneously came up to introduce themselves. April had a chance to meet a number of the members, hear about the group's activities, and decided to join. Everyone was very gracious and welcoming toward her.*
>
> *The group has something going on almost every week, and a couple of staff people have accompanied April to events. The scheduled activities are so appealing (a pig roast, a yacht trip, a steamboat ride) that it became fun for staff to "argue" about who was going to accompany April. Her participation was more than just "community outings" that were part of the job staff had to do. Instead, her group membership meant fun events that the staff could also look forward to going to. Carol is thinking about joining herself because it is such a fun group.*

Continuing Support

Let me tell you the secret that led me to my goal.
My strength lies solely in my tenacity.

—Louis Pasteur

No problem is so big or so complicated that it can't be run away from.

—Linus (Charles M. Schultz)

Beyond Acquaintance: Supporting and Nurturing Relationship and Real Friendship

Having opportunities to meet people is an important first step to developing meaningful, supportive relationships. However, it is just the first step. People need time together to get to know each other better and to share experiences. From there, friendships develop.

There is no recipe for turning a casual acquaintance into a true friendship. As we think about our own relationships, most of our acquaintances don't become close friends. When they do, when two people really do "click" as friends, there almost seems to be an element of "magic" involved. In working on friendships for persons with disabilities, we can't deliver or program magic. What we *can* do, however, is have people meet as many people as possible. We can support the connections growing. And, we can promote as many and every occasion for magic as possible.

Being a Friend (Or: It Takes Two....)

Few relationships can grow strong without reciprocity—the give and take in our associations. People with disabilities are often "excused" from contributing because of their disability. Too often, we unconsciously overlook the possibility that a person with disabilities has something to contribute. Helping individuals learn to reciprocate, how to *be a friend*, may be the most important support we can provide.

Reciprocity means giving, receiving, sharing, cooperating and communicating. Most children begin learning about how to be a friend very early. Often children with disabilities don't learn as easily as other children do, even though they may have the same opportunities. Parents or others might overprotect them, anticipate their needs, and solve their problems. These children may find it very difficult to relate to others in two-way relationships. They may expect to have their own needs met without much thought to the other person's needs and may demand more attention than the other person is willing or able to give. Over time, people with disabilities may come to the conclusion that they have nothing of value to offer and can only act as the receiver of help and attention.

The best way to learn about being a friend is by being one. Learning "social skills" without having any social relationships is like reading the bicycle "Rules of the Road" without ever getting on a bike. Just as you can't learn how to ride a bike without actually getting on one, no one can learn how to get along with other people without having relationships. Social skills training programs are likely to keep people forever reading the book without *ever* getting on the bike. Meeting and spending time with people in the community is the best way to learn how to act in social situations. Regular community people are the best "teachers"—not service professionals or social skills training programs. Parents, teachers and service workers *can* help the individual learn about being a friend by modeling and talking about how to be a friend, and by encouraging the individual to reciprocate in his or her relationships with them and with others.

If the person with disabilities is limited in his or her ability to reciprocate, someone else may have to carry out acts of friendship on his or her behalf. This doesn't mean that the person can't be a friend—it just changes the appearance of the friendship. It might mean that a staff person keeps track of family birthdays, and sends cards on the individual's behalf. It might mean that a parent continues to tell his child's friend how much that friendship means, even if the child can't say so themselves.

The most satisfying relationships are two-way. People with disabilities, even very significant disabilities, can *be* friends as well as *have* them. Because they are givers as well as receivers in such relationships, individuals with disabilities can gain a sense of self-worth that they don't get from one-way relationships.

Learning to be a friend can take time, and there is some risk to developing close friendships. There is no way to learn to ride a bike without falling, and there is no way to experience friendship without making mistakes, and sometimes getting hurt.

When two non-disabled classmates were coming to the group home to visit Michelle for the first time, staff made a point of talking to Michelle about her friends' visit. They helped her make cookies, straighten up her room, prompted her to answer the door when the girls arrived, and to show them to her room. They continued to talk about the new friends, what Michelle might like to do with them, etc., throughout the following week, in anticipation of their next visit.

Linda does not communicate with words and she can't write, but her focus group decided that she should send Christmas cards to her family. One staff person offered to sign the cards and address the envelopes. At Easter, they sent cards again and the staff person wrote notes on each one—what she thought Linda would say if she could write.

Why bother sending cards when the family knows that Linda can't write? When she doesn't know she's sending them? In Linda's case, the Christmas and Easter cards brought a barrage of contact from family that had been out of touch for a long time. To her family, the cards made Linda seem more like a regular family member. She became someone who contributed to the family. Her sister wrote, "When I got your card today it made me feel real good . . . little things like receiving a letter from you brightens my day."

Vicki is someone who is often quite demanding of other people's attention. Her focus group realized that she had mostly "one-way" relationships, and wanted to find ways that Vicki could do things for others, especially her family.

Vicki felt very close to her family, but it seemed they did not share her sense of closeness. They seldom invited her home for a visit and sometimes celebrated holidays without her. Vicki talked about how she missed her family and wanted to see them. Someone suggested to her that she invite her family over for dinner and cook it herself. She had never done this before. She did, and the dinner was a great success.

Since Vicki liked to sew, the staff person who helped her with the dinner helped her purchase a sewing machine. Together they have completed several projects. Vicki made a pillow which she gave to her mother, and some bibs for her sister's new baby. Vicki is proud of her work.

Vicki was also introduced to a friend who shared her interest in sewing. This friend suggested she enter another pillow which she had made in the County Fair craft competition. However, Vicki could not take it up to the Fair on Entry Day because of her work schedule. Her friend offered to take it for her.

Demonstrating How It's Done

One of the most effective ways to support people in relationships is to demonstrate for others how it's done. Others will relate to persons with disabilities based on the example we set. We can demonstrate very powerfully to others how to successfully:

- engage people in conversation
- get somebody to stop doing something irritating
- have someone smile
- react when someone raises his or her voice, etc.

People will learn how to act by watching us. If we speak in a patronizing tone, they will learn to do the same. If we do everything for someone, others will learn the person is dependent. If we constantly treat someone as a "client," others will treat them as someone who is "different" rather than a member of the community.

Greg loved music, especially country-western. Kathy, who worked with him, had a friend Neal who was a professional musician and who taught guitar. She called Neal and asked if he would be interested in meeting Greg. The three of them set a time to get together and take a walk on a Sunday afternoon. Kathy introduced Greg and Neal, walked with them, and they all chatted together. Kathy helped Neal understand what Greg was saying. Neal agreed to get together again and go to a concert together, and Greg wanted to come to one of Neal's concerts.

Don't Stop Encouraging

Even after people have met friends, or joined groups, more experiences of discouragement or disappointment can occur. Other new experiences also must be faced. Often, people continue to need to be encouraged. Not just the person with disabilities, but also the community friends or groups, may need assistance in exploring new territory.

Tony is somewhat hesitant to try new things, and usually when asked if he'd be interested in something new he says, "I have to think about that." When it was suggested he become a member of a local service organization, he did think about it for a few weeks and considered whether it was worth the money. He did finally decide to join.

Once he had paid his dues and taken the pledge before the whole group, new opportunities to try new things arose. At a club steak-fry, he was asked if he wanted to play horseshoes. He initially said, "No," then "Maybe," and then a few minutes later, "All right, I'll play."

One of the major fund-raising events this group sponsors is selling drinks at a local medieval fair. When asked if he wanted to do this, Tony said no. But his group just continued to tell him that it would be nice for him to help out. Tony attended a group meeting held the week before the event started. He could tell from the amount of time spend on discussing the fair, that is was a big deal for this group. He realized that it was important for the event to be successful and they did need help. By the end of the meeting, he had agreed to help out and asked to sign up for a shift.

Walking around and talking after the meeting, he told people he was going to help out at the fair but he expressed concern about doing a good job. One of the members told him to not worry, just sign up for the booth that he was in charge of and he'd show him just what to do—it was easy.

Solving Problems

When persons with disabilities start to meet others and become part of their communities, problems will arise. Many people don't know how to deal with or are uncomfortable with some of the differences presented by the individuals with whom we work.

The only way to overcome these problems is for both parties to face them and work out their own solutions. Staff can, of course, often be of great assistance. But community persons and individuals with disabilities also can be quite creative, when given the room to come up with their own solutions.

Things can go wrong, and maybe do more often than not. Trying something new is always risky; change is always uncomfortable. There is power, however, when the problems we are challenged to solve are problems concerning what's really most important to people. There is excitement when the problems concern real relationships and aren't the same old problems of rules and systems. Working in an area that was really important, that really mattered to people, provided much of the greatest satisfaction for staff participating in the project.

There were some new things that April was reluctant to try. One was joining a local service organization. She asked the members of her Friends group to check it out for her first, and they did. She finally went to a meeting and decided to join. Staff agreed to assist her in going to events the first few times until both she and the group were familiar and comfortable with each other.

She started out her membership by going to a couple of events with the organization, including a riverfront festival and another festival in which she helped out at their booth. However, a major issue arose. April considered the club members "her" friends, and she did not want any staff to accompany her. She wanted to go to club parties on her schedule, not on the schedule of when staff could take her and bring her back. She started to refuse to go to events.

A member of her Friends group that was not a staff member offered to take her to an evening social event, and it took a lot of encouraging just to have her go. The staff is still working on how to best support her membership until group members can support her on their own.

Are We There Yet?

Each of our communities is different today than it was a year ago. People have moved in and out of our lives. Our own friendships and relationships continue to take time and work. Having an individual enrolled in one community education class, an integrated recreation program, meeting one person, or joining one organization, is not enough.

After people join, or meet, or attend, new problems and challenges arise. Once people are introduced and like each other, the job's still not over. After a few times of being together, other problems can arise. After someone has joined an organization, they may become reluctant to keep going. A new friend may become upset after some "bad" behavior. With someone whose behavior is difficult to understand, the new acquaintances may not know if they're important or not to the person. Being successfully connected and maintaining friendships is never something that will be totally complete, finished, achieved.

For all of us, being connected to others is ever-changing. For people we work with, establishing and maintaining friendships will continue to be a challenge. Even after friendships become strong, we can support additional ones. The need for work will continue.

Things to Watch Out For

There are ways we can support individuals in their relationships that can help pave the way for friendship to happen. There are also some common obstacles that we can help people get over.

General Lack of Experience with Relationships

Many individuals with disabilities have little or no experience relating to non-disabled people other than families or staff. Due to a lack of experience, people have not had many opportunities to learn social rules and practices in natural settings. Learning social skills in a class at school or at the adult day program can help, but it's not the same as being in relationships and learning as you go. Individuals may need continuing help to learn how to be with people outside of the service system. People may need our help to learn to contribute and what it means to be a friend. Community people may need suggestions about how they can help the individuals understand what is expected in certain situations.

Often people with more severe handicaps have the least experience with relationships. Sometimes their appearance or actions are very distracting or sometimes even disturbing. Persons with more significant disabilities may be the most difficult to connect and support. Efforts may need to be more creative and intense. Again, these individuals may be the most in need of relationships with people who care.

> *Ollie lived at home with his family in a small town with a strong Norwegian heritage until he was 40 years old. Then he lived in a state hospital for 31 years. He has been living in a small group home for a little over a year. Because Ollie does not talk, it takes time to get to know him well and to understand the ways in which he communicates. Members of the group felt that Ollie's limitations would affect the likelihood of others wanting to get to know him. Because Ollie has limited ways to express his frustration and occasionally will act defiantly, group members were concerned that others would not understand Ollie's expressions of frustration or confusion.*
>
> *One method staff have pursued is having Ollie go with one staff person to a local coffee shop at the same time every week when other "regulars" his age are there. The staff person also took Ollie to a local bar, and they were quite proud of him going right up to the bartender, giving his money, and indicating he wanted a beer.*

Limited Interests

The more interests a person has, the more activities he or she is likely to enjoy, and the more he or she is likely to have in common with other people. For some individuals with disabilities, limited experience in the community has left them with very few areas of interest. Sometimes, because the range of a person's activities has been so narrow, or his or her life experiences so limited, one interest may have become almost an obsession or a "fetish".

Sometimes this singular interest might be seen as strange or inappropriate by most non-disabled people. Most of us know individuals with disabilities who talk almost exclusively about one thing (a girlfriend or boyfriend, a favorite rock star or athletic team, etc.).

When an individual has one prevailing interest, that *might* be the place to start in finding ways for him or her to share time with non-disabled community members. However, another avenue is also possible: giving the individual opportunities to explore a wider range of activities in order to help him or her have a more interesting life. (Apart from the topic of having friendships, assisting individuals with disabilities in building more interesting lives is a worthwhile objective!)

> *Henry has spent most of his life in large institutions. He loves trains. He has a train whistle record which he plays for anyone who will listen. When he talks about trains, he makes train sounds. His group was in a quandary trying to decide if it would be a good idea to pursue some activity related to trains, or if it would be best to try to interest Henry in something else.*
>
> *The group decided that as long as Henry had this powerful interest, it would make sense to find out how other train-lovers shared their interest in the hope of finding someone who could get to know Henry. At the same time, this new friend could explore other activities that might capture Henry's interest. With a wider variety of interests, Henry could have more opportunities to get to know people, and perhaps trains would become less important in his life as his interest in other areas grew.*

Confusion about What a Friend Is

People with disabilities are sometimes confused about what a "friend" is. There can be many reasons for this confusion. For example, staff often show people the same kind of regard and caring as a friend. Sometimes staff are the *only* people who care about an individual. While paid staff can be friends, usually their contact with the individual changes or ends when they are no longer paid staff. When staff are seen as friends, the person may get confused about the nature of friendship. (Are friends around only when they're "scheduled"? When a staff person leaves for another job, does that mean he or she doesn't like me anymore? Can friends "quit"? Do friends only like me when I do what I'm supposed to?)

Another source of confusion is that sometimes when an individual with disabilities meets someone who is friendly, the individual sees the person as a "friend for life." Many individuals walk around claiming certain people as their "friend," even though they just met the person once.

A real friendship is based on people spending time with each other because they want to and they enjoy being with each other. Individuals who have never experienced a real friendship may need some help understanding what they can expect from a friend.

Sometimes persons with more mild levels of disability may express the most confusion. Their awareness is often acute that staff are paid to be with them. They may long the most for real friends—people who just want to be with them for themselves. Any indication of rejection by regular community people is felt deeply.

At the same time, for these individuals, specific staff efforts to help individuals meet and become friends with regular community citizens may seem like interference. Why should staff be helping? People want to find friends on their own and to have their own friends. Sometimes they don't even want staff to meet the people they consider friends—they want to keep their worlds separate. In these cases, efforts to provide genuine and needed support must be non-intrusive and non-interfering.

> *Kay has lived in many different foster homes, and been in and out of institutions. Her relationship map indicated nobody in her life except staff and family. At her first focus group meeting, Kay was sure that she didn't need any new friends. She kept saying "I don't need any friends. I have Dan and Nancy." These were her two staff. Soon after the first meeting, Nancy moved out of state. By the end of the year, Dan had changed jobs.*
>
> *Kay spent a few months getting to know Fran, who became her friend. They played tennis, did other things together, and Kay spent the night at Fran's house. After a few months, Kay one day said to Fran, "I do want to have more friends. Let's start working on it."*

Alienating Potential Friends

Sometimes an individual has very few people to count on, or even only one. Those people can become "everything," and the demands the individual places on those relationships can be overwhelming. The individual may want or expect too much of the person's time or attention and may end up alienating potential friends. That one person has to serve as the equivalent of what 20-30 friends and acquaintances provide to a typical person.

Some individuals have experienced so much rejection in their lives that they have learned *not* to get too close to anyone, or have developed behaviors that insure that no one will get too close to them. In "self-defense," they might reject potential friends before they are rejected again.

Kay has experienced a great deal of rejection in her life. She was removed from her family's home and bounced from institution to foster placement and back. She has a reputation for testing people she meets with offensive language. It sometimes seems like she is trying to push people away. Instead of assuming that Kay's behaviors were an indication that she didn't want to meet new people, her Friends group wondered if this was Kay's way of protecting herself from being rejected.

Fran got to know Kay over the course of the project. She soon discovered that Kay usually started using offensive language when their time together approached its end. If Fran took that opportunity to talk about what they would do next time, the bad language decreased. The more Kay came to trust that there would be a "next time," the less necessary it was to protect herself by pushing her new friend away.

Within a few months, Kay was readily meeting other people. When staff took her out with their friends, the friends thought she was very funny and really enjoyed being with her. The staff, her parents, and even Kay herself say she isn't the same person she was a year ago. Kay says, "I'm doing great."

The Possibility of Rejection

It's not always possible to protect the individual from rejection by people they will meet in the community. Some non-disabled people are not sure how to let a person with disabilities know when enough is enough, and may simply withdraw altogether. (They "disappear in the night.") We might need to be in communication with the community friend regularly and early on when we know someone may be difficult to be friends with. We can be sensitive to signs that things aren't going well in a relationship, and do what we can to help work things out. We can't change the way people are, but we can let community people know that it is all right to set limits and conditions. We can also help the community person and the individual with disabilities work out and understand those limits and conditions.

> *Dot met a woman who lives in her apartment building. The woman was friendly, and Dot liked her immediately. Dot began hanging around in the hallway outside her apartment, waiting for her to come home from work and for the chance to talk to her. When the new friend would explain that she had something to do or needed time by herself, Dot would write her notes and slide them under her door.*
>
> *When the woman started becoming annoyed with all the attention, she contacted one of Dot's staff, who set up a meeting at which Dot and the friend worked out some ground rules: Dot would not wait in the hall for her friend to come home from work or leave notes under her door. Certain times were established when it was O.K. for Dot to visit if she called first, etc. The staff helped Dot stick to the ground rules.*

Protecting the Individual from Abuse

We may also have to help the person with disabilities see when he or she is being treated badly or being taken advantage of. There is some risk in any new relationship. The relationship might end. The new friend might take advantage of the person with disabilities. We can:

- be selective about the people we introduce to the individual;
- support the individual in any new relationship by talking about the new friend and paying attention to signs of discomfort;
- trust the individual's judgment;
- try to be fair in our judgments about the individual's friend(s)—get the facts;
- make sure the individual has opportunities to meet a variety of people, so that one person is not the "only option."

Assisting Others

Always waiting untold in the souls of the armies of common people, is stuff better than anything that can possibly appear in the leadership of the same.

—Walt Whitman

Imagine all the people living life in peace . . .
Imagine all the people sharing all the world.

—John Lennon

Assisting Others in Meeting and Becoming Friends with Persons with Disabilities

The range of attitudes, experiences, and beliefs of community citizens toward individuals with disabilities is extremely wide and is as individualistic as people themselves. More individuals with disabilities are living, working and attending school in the community. As a result, people's experiences are changing. Typical citizens seem to have a greater awareness of persons with disabilities; this awareness is creating a greater interest in individuals with disabilities. Often it seems that the service system itself is much more of a problem than "the community." People who have become friends with individuals with disabilities report the experience as rewarding, fun, and enjoyable—just like any friendship.

The first and probably most effective way to educate people and to change the nature of our communities is direct inclusion. It is only when non-disabled people have a chance to *really get to know* someone with disabilities that everyone will learn the day-to-day, "nuts and bolts" experience of relating.

Traditional efforts to "educate the community" or "increase awareness" have included talks to local organizations about people with disabilities. Another common activity is the "walk a mile in his shoes" approach such as having students pretend to be disabled by using a wheelchair for a day. There might be times when these efforts are useful; however, they are not likely to give non-disabled persons the opportunity to meet and get to know an individual who can teach, first-hand, that people with disabilities are just people and have an enormous amount to contribute.

The Basic Strategy

In our work with Friends, assisting community members was a critical part of the connecting process. Some of the strategies we used with specific individuals are described in the examples in this manual. Many of the strategies for meeting individuals followed these basic steps:

- Meet the community person, such as the local music store owner, the librarian, or the minister.
- Explain that you know someone who is interested in music or history or church activities, and is interested in meeting other people who share this interest.
- Ask for and obtain the community person's agreement to help;
- Then introduce the person with disabilities to the person who shares the interest.

For introducing a person to a group, we followed these steps:

- Go to a meeting of a community group or organization to check it out and talk to the members before they meet an individual with disabilities.
- Support the individual and the community members in whatever way is necessary to help insure positive experiences for everyone concerned.

Introduce People One-to-One

We found that people were very open to being introduced to individuals with disabilities when they were asked personally and individually. Ask people you know. Ask people you know who else they know.

People Are Waiting to be Asked

You have nothing to lose in asking. The worst that can happen is that someone says no. You may be very pleasantly surprised.

Ask People Who Have an Understanding of Community

It helps to think through the right people to ask. Some people are more open to meeting new people than others. Some individuals may be much more willing and open to the idea of meeting a person with disabilities than others. They may have an instinctive sense of "community," whether they know that they understand it or not. Look for "like-minded" people.

It also helps to connect people through like-minded groups and organizations. These are groups and organizations that already have some sense of and commitment to community. We found churches to be very open—not only the ministers, but also church groups and individual members of the congregations. A number of community service organizations readily considered the opportunity of new members.

Being a Model

Community members will often find it easier to get to know and feel comfortable with persons with disabilities if staff or others familiar with the person come along, at least initially. The staff can assist in:

- understanding the speech of someone who is difficult to understand
- interpreting the communications of someone who has no speech
- meeting other group members
- successfully managing out-of-the ordinary behaviors
- letting the community members know what to expect
- making sure the person is getting what they need
- helping toward the future independence of the relationship

At these times, often the most powerful "teaching" method is for people to observe whatever the staff does. If the staff person talks to the community member about the person with disabilities in front of their face, as if they could not hear or weren't there, the community member will learn that it is all right to treat people as if they were invisible. On the other hand, if the staff person conscientiously includes the person in the conversation, community members will feel more confident doing the same. They will learn that speaking directly to people is natural and expected.

Of course, people will always discover their own ways to relate to each other. Some will be quite beyond anything the staff expected or know. However, it is always crucial to remember that "we teach by example."

Watch Out For . . .

Many human service practices have segregated people with disabilities and emphasized their differences. When services focus on a person's *dis*-abilities and need for professional care, it is difficult for typical citizens to understand how they could be a friend. These practices have contributed to misconceptions that create obstacles when we try to build relationships between non-disabled community members and people with disabilities. We've made people seem "special," different, and needing our professional knowledge and skills. Even when we emphasize that they are special in a *good* way, the individuals still stand out as "different" from the rest of the community.

"Special" Activities and Programs

Most well-organized communities provide special programs for people with disabilities. Many individuals enjoy these programs, and without them would not have the opportunities the programs provide. However, when segregated programs are the only way a community includes people with disabilities, individuals are being denied access to the real community and real opportunities for relationships with each other.

Even in some organizations that have welcomed individuals with disabilities, those individuals can be unconsciously grouped and treated as different. A sense of "us" and "them" can develop, rather than a sense of "all of us together." This tendency is one of the drawbacks to integrating a number of individuals into one community organization. Even a small number of people with disabilities can be too many for an organization to assimilate and treat as regular members. The individuals with disabilities are at least physically included, but it becomes too difficult for each person to contribute and to be known for him/herself. They become "one of them."

The "Noble Volunteer"

Another way that some community people sometimes relate to individuals with disabilities is out of an unconscious sense of pity or charity. This behavior can take very subtle forms, communicating messages such as, "oh, you poor thing . . . " or "I'm a good person for spending time with you." Being sympathetic to another human being or sharing with someone who is less fortunate is one of the ways people can show that they care, and services for people with disabilities have relied heavily upon volunteers and charitable giving for their very survival. However, we must recognize that when someone acts out of pity, or out of a desire to do a good deed, the role of "giver" can create too much distance for a genuine friendship to develop.

This is not to say that services should abandon the use of volunteers or community fund-raising. It *is* to say that we must be careful not to substitute volunteers for friends. Even though people are invited to be friends or even *want* to be friends, their initial behavior might be tinged with a subtle attitude of pity or charity. We have particularly noticed a tendency toward this kind of attitude when the person has more severe disabilities—when he or she has a physical disability, uses a wheelchair, or can't talk.

People can be assisted, however, in more fully knowing and appreciating the individual with disabilities. They can get past the initial reactions to become real friends. (For more information about the role of volunteers see page 74.)

> *When Eleanor was recruited to visit Linda at the group home and get to know her, the members of her focus group were very much aware of the issues about volunteer roles. Because Linda has significant physical disabilities, anyone who would spend time with her would need to know about her needs, and the group recognized the need for some orientation. However, the staff also recognized that in order to support Eleanor and Linda becoming friends, they had to minimize the formality of the situation. No time schedules were required and there was no paper work for Eleanor to report her volunteer time. Staff referred to Eleanor as Linda's friend, not Linda's volunteer.*
>
> *Eleanor was also a volunteer with R.S.V.P. (Retired Seniors Volunteer Program), who are very strict with accurate recording of volunteer hours. After Eleanor had been visiting Linda for several months, the local R.S.V.P. coordinator heard that Eleanor was "volunteering" at the group home. She called up Eleanor and asked her why she wasn't reporting her hours. Eleanor replied, "I'm not a volunteer, I'm a friend."*

The Novelty

Sometimes when someone starts "hanging out" with a person with disabilities, it's very interesting at first. The person and his or her characteristics or quirks are a novelty. It's important to support the community person in really appreciating the individual as a whole person, and also assist the person with disabilities in contributing to the relationship.

When the Individual Isn't "Disabled Enough"

Sometimes community people have the hardest time warming up to the individuals who have mild disabilities. These individuals do not fit the image of the dependent, needy recipient of good will. Non-disabled people may need extra support in their relationships with individuals who are vocal, independent, assertive, sometimes obnoxious or controlling.

In some cases of relationships with individuals who are "more like us" it is easy to have it *look* like the person is included, when they're really not. Many times it is easier to be an acquaintance rather than a real friend.

Common Misconceptions About Communities

Community people are not the only ones with misconceptions. Human service professionals have some erroneous ideas about their communities, too. It's easy to let these "myths" discourage us from trying to get individuals connected in the community—to not try, or to give up when it gets a little hard.

Underestimating the Community

"That might work in St. Paul, but it'll never work here!"
"They don't want our clients around."
"They think all people with mental retardation are 'crazy'."
"They wouldn't know how to deal with her manipulative behaviors."

MYTH: "Communities won't welcome people with disabilities."

It is not true that most communities won't welcome people with disabilities. In fact, in most communities, it was easier than we anticipated to find individuals and organizations with a genuine interest in getting to know people with disabilities.

A service organization in a rural/suburban community was approached by a group that coordinated recreational activities for persons with disabilities. The group asked the service organization if they had members that would be willing to meet individuals with disabilities and become friends with them. The two groups would work together to match people up. Even though the service organization was not large, fifteen men offered to meet people and explore becoming friends.

When April joined a local service organization, they enthusiastically welcomed her. At the first event she attended, the vice-president came up to the friend who had accompanied her, and asked her directly, "Is there anything we need to know about April?" She was sincerely interested.

For years April had been talking non-stop about two things: men and complaining about spending money. At this event, April started complaining to the vice-president about money, saying "I don't like to pay." Jean, the vice-president, straightforwardly replied, "I don't either. But sometimes, we all have to." April stopped talking about it.

When April started talking to the vice-president about men, Jean very naturally asked her about her preferences. She answered April's questions about different men in the group and told her whom she wouldn't like. April asked Jean to find her someone, but Jean said "No, I can introduce you, but you're going to have to find them yourself."

When Jean introduced April to any man in the group, they handled her direct questions in a natural way. No, they were already married or they already had a girlfriend. No, they wouldn't like to go out, but they would keep their eye out for someone who might like her.

MYTH: " 'Regular' People wouldn't know how to handle her without a lot of instruction."

Often community people don't see the behaviors we see as "inappropriate" or "manipulative." Sometimes, the individual behaves differently in a community setting with a typical person. Sometimes the behaviors are there, but aren't as much of a problem for community people as we expect them to be. Sometimes the community people don't even see the behavior as "a problem."

Vicki had a reputation for inappropriate behavior in her relationships with co-workers at the sheltered workshop. In fact, that was one of the reasons she was considered "not ready" for community employment. It was also one of the problems staff identified as an obstacle to making friends with regular community people. However, when Helen, a staff person, took Vicki home with her for an evening with her college-age daughter and one of her friends, Helen was very surprised. Vicki acted "just like one of the girls."

Underestimating the Need for Support

Sometimes we expect too much from the community. Because of our belief in the community's capacity for including people with disabilities, we might hesitate to interfere with the individual's independence, even when he or she might need our support. It is important to think through and provide the support that will best assure success without interfering with the capacities of either the person with disabilities or the typical citizen.

When Jay said he was interested in helping coach a T-Ball team, one of the people in his Friends group contacted the program director and got the name of a coach who needed an assistant. The coach was hard to reach by phone, except at night, so the first plan was to leave a message for him to call Jay about the job. Staff realized, however, that because of Jay's speech problem, the coach might not be able to understand what he said. They also realized that Jay might not be able to understand the information from the coach. It was decided to arrange for Jay's roommate to help him call the coach and be the "interpreter."

Service Practices that Foster Community Understanding and Acceptance

The following is a checklist of service practices that can help foster the genuine understanding and acceptance of people with disabilities that opens the door for friendships. Some of the items have been discussed elsewhere in this manual, but they are collected here.

Introduce . . .

- Treat each person as an individual, and introduce people on an individual basis.
- Avoid using jargon and initials (CP, MR, DD, SIB, TBI, etc.)
- Emphasize the characteristics the individual has in common with all people—we're all human beings.
- Don't share information that points up the individual's weaknesses or problems unless it is necessary in that situation. Don't "gossip" about what's wrong or different about him or her. When this information must be shared, do it as positively as possible.
- Don't exaggerate the individual's need for professional help.
- Think carefully about the situations you choose to introduce individuals to the community, and be sure you are providing enough support for the experience to be successful for all parties.

Connect . . .

- Teach by example.
- Treat the individual with the respect you would give anyone of the same age, in public and in private situations, and help him or her find ways to spend time with other people of the same age.
- Support individuals with disabilities to meet and get to know non-disabled people in regular community activities.
- Give individuals the chance to do what they can, and find ways to help individuals make a genuine contribution to others in the community.
- When a group or organization is receptive to including *one* person with disabilities, don't flood them with all the others. Think through individual approaches for *each* person.

Ongoing support . . .

- Know that problems will arise. Trust people to solve them.
- Be creative, providing the necessary help as unobtrusively as possible.
- If someone may be difficult to understand or challenging to continue to like, be in communication to provide any understanding possible.
- Support members of the community by helping them learn what they need to know to be comfortable with the individual.

Agency Support

Power undirected by high purpose spells calamity; and high purpose by itself is utterly useless if the power to put it into effect is lacking.

—Theodore Roosevelt

Here is Edward Bear, coming downstairs now, bump, bump, bump, on the back of his head, behind Christopher Robin. It is, as far as he knows, the only way of coming downstairs, but sometimes he feels there really is another way, if only he could stop bumping for a moment and think of it.

—A.A. Milne

Agency Support for Relationship Building

This section is for people involved in all kinds of agencies that serve people with disabilities: direct care staff, administrators, board members, advocates, case managers, etc. It is for people who want to develop or increase support for relationship-building as a service priority. While it is possible for one person to "go it alone," it is much easier if agencies are committed to helping individuals get better connected and are willing to commit certain service structures to assisting those connections.

The six agencies that participated in the 1989-90 Friends Project did so as a reflection of these commitments. Because of their generosity, we learned a good deal about what that kind of commitment means in the day-to-day operations of an agency. We also learned about some of the roadblocks agencies face. It often seems that the barriers "the system" puts up are bigger than any of those in "the community."

An agency's responsibilities to a "client" are dictated to a great extent by regulations, governmental units such as counties or regions, case managers, and sometimes parents. These powerful entities may not always support efforts to help people develop and maintain relationships and friendships. Or they may support the concept in general but often have built-in roadblocks to specific efforts. Some barriers are unintentional or unconscious, with little awareness of how real friendships are affected. For example, we saw how regulations about volunteers can unconsciously be a barrier to developing friendships.

Agencies are expected to do a great deal for individuals they serve, even if they are providing only a few hours of help each week. They are expected to provide services within the constraints of volumes of regulations, financial limitations and reporting requirements. It often seems that there is too much to do and too little in the way of money and staff with which to do it. Agencies and the people who work in them are, understandably, often reluctant to take on "one more thing."

Assisting people in relationships and community belonging may seem just one more item on an already-overworked staff person's "to-do" list. However, friendships are too important in real lives of real people to be treated this way. We propose a different perspective.

Working on What's Most Important In Life

Usually it's not possible to do *everything*. Perhaps it's most important to work on what's most important in life.

One way to look at an agency's responsibility for an individual is to look at the list of needs, goals and objectives on the person's "Individual Service Plan" or "Individual Program Plan." These plans usually represent a type of contract between an agency and a county, or other accountable entity. The goals and objectives represent what the agency promises to do. It is possible that the formal plan might address what the person needs most in his or her life. However, often

the plan represents a list of what is wrong with the individual and needs "fixing." Frequently the goals represent new skills that are missing and should be learned. Often goals and objectives for a person have been derived from a list of specific problems or skill standards, and miss the "big picture" of the person's whole life. Individuals with disabilities themselves report that friendship and their relationships with others are the areas of highest priority in their lives.

As we mentioned in the section on "Discovering Interests, Gifts, and Capacities" (see pages 10-18), the first step in relationship building is understanding how important relationships are in everyone's life and what it would mean to the individual with disabilities to have friends. Over and over, we have seen that when an individual starts to have more relationships with community citizens and begins to realize that regular people care about him or her, the things that were "problems" start to disappear.

Having a valued role and being included by "regular people" seem to address some of the most basic needs of each human being. When those needs are met, the individual can become "a new person." They no longer have to demand attention, or be withdrawn. Friendships provide a "gestalt," a whole, from which to see someone—a bigger perspective than a specific behavioral objective. When things start to happen in the big picture, the smaller objective can be automatically drawn along or can even disappear as an issue.

Arthur is 40 years old and lives in his own home with two other men. He loves books and history, and has a fascination with cemeteries and death. He was described by the staff as hesitant to try new things. They said, "We have to go slow with Arthur." Arthur also tended to be a "yes-man," willing to comply with whatever staff asked or expected him to do. Staff had been working on the goal of Arthur being more "assertive" for quite some time.

Because Arthur loved books and the library, his Friends group had the idea that volunteering at the library would be a good way to connect Arthur with other people. One of the people in his group knew the head librarian because their daughters were in a school activity together and both had the same first name. She offered to ask him if Arthur could volunteer. She called him in the morning, halfway expecting to have to make a lot of arrangements and do some convincing, but the librarian said, "Sure, have him come over this afternoon."

The first time that Arthur came home from the library he told his staff, "The books were really dusty. They really needed me."

The library staff had given him a name-tag on his first day. Staff were amazed to find out that when they had spelled his name wrong, Arthur by himself told them it was wrong and requested a new one. He proudly wore his library name-tag to the sheltered workshop and told people, "I have a new job. I work at the library now."

Staff were willing to go with Arthur for as long as necessary, but after just two visits Arthur told them that they didn't need to come along anymore—he could walk by himself and handle it himself. One staff said, "But Arthur, what about walking home? It will be dark out." Arthur firmly told her, "But Sandy, there are street lights."

Arthur also tried other things for the first time. He agreed to stay for the coffee hour between church services and went to the adult Bible class. One Sunday, he sat way up in the front so that he could attend communion. Art said he was "proud of himself for trying."

Arthur went shopping for a desk for his room and asked staff to help him keep a journal. He wanted to write about his life because now he "was doing so many interesting things."

Staff as Community Connectors, Not Just Skill-Trainers

In the introduction to this manual, we spoke of a "different role" for staff (see page 2). Training skills, fixing problems, or preparing people for more independence and/or more integration are all important. However, we propose a different role. Given that relationships and being cared about are some of the most important needs all people have, staff *can* play a bigger role in that arena. Staff can develop roles as community connectors.

That role will often require some agency commitments and structures to support it. Certain of those structures are discussed in this section. The first priority, however, is for the agency itself to be clear on its commitment in this area.

Enlisting the Powers that Be

Helping the person make and keep relationships is a legitimate and crucial responsibility of a service agency. Sometimes, the "powers that be" need to be convinced.

If the support of case managers, agency decision-makers, a parent, or anyone, needs to be enlisted, one way to do that is to involve them in the process of getting to know an individual described in the section "Discovering A Person's Interests, Gifts, and Capacities" (pp.10-18). This process can often open people's minds about what is really important for the individual they "get to know," even if they think they already know all about them! Taking a careful look at what's missing in an individual's life in terms of relationships and friendships often forces us to realize that a lot of "what's wrong" is there because the individual has no friends, no people who care and like them just for themselves. This realization can help foster the kind of support the agency may need to use its resources to serve the individual in a different way.

Another way to enlist support is to share success stories. The examples in this manual and some of the other resources listed at the end of this manual can provide such stories. However, the most convincing evidence is found in stories about people already known to the agency. Even small successes can provide support for increasing efforts at relationship building.

Other strategies can include:

- sharing written articles for the convincing process
- attendance at specific sessions at state or national conferences
- recommendations for in-service training
- enlisting the support of powerful allies who share this commitment (parents, case managers, board members, community members, etc.)

and other means to communicate the real importance of friendship and community.

One agency serves many people who live fairly independently and receive only a few hours of support a week. Most of the staff time is used to check on people, check that their apartments are clean, beds are made, and checkbooks are balanced. The agency realized that one of the things they can do is to advocate with the county for a different use of staff time—to decrease the amount of time spent on cleanliness and increase the amount of time spent on connecting and supporting relationships.

Not Doing "More," But Doing Differently

Because almost every agency faces the challenges of a tight budget, staff shortages and time constraints, it is not reasonable to assume that an agency can really do "more." One of the things we learned from the agencies participating in Friends was that sometimes it is possible to do what looks like "more" with the same resources. It is often possible for an agency to rearrange the use of the resources it does have. The primary avenue for this rearrangement is to examine the way staff time is spent now, and then to discover or design ways to have staff spend their time differently—assisting individuals to meet and get to know others, and to go places where the likelihood of connecting is maximized.

These efforts do take time. Sometimes there needs to be a conscious agency commitment to allocating the time directly for this priority. Some examples of the ways the Friends agencies found to do this include:

- Find ways to create opportunities to meet people within the context of what is already being done. Instead of taking someone to a segregated swimming class at the "Y" take the individual to the community pool during adult swim time.

- Instead of using staff time twice a week to take several individuals out into the community, take just one individual at a time. Even though each individual might then have less time in community settings, each opportunity can be tailored to the person's own interests, and is likely to provide better opportunities for meeting other people. (Of course, planning is usually required to make this possible and staff time with the individuals remaining behind needs to be planned.)

- Re-examine priorities. It might be possible to use more of the staff person's time to get people to places where they have a chance to be with non-disabled community members (an adult education class, a Jaycees meeting), rather than solely teaching independent living skills in service settings.

- Examine the activities the person with disabilities does do, and design ways those activities can be altered to meet more people. For example, if someone likes to sit in the park, how could he or she volunteer for the park system so that the person could meet more people?

Michelle has two friends who come to visit her at her group home every Friday afternoon after school. Although the school is near the group home, both girls' homes are about ten miles away from the town. Staff time is used to take them home after the three girls visit. Michelle goes along for the ride in the car, and to continue to visit with her friends on the drive.

Extending Agency Structures to Support Friendships

Once an agency is convinced about the importance of relationship building, it might have to revise some of its roles and structures. One possible different role for an agency is as an advocate for individuals' rights to opportunities to spend time with non-disabled people in regular community settings (Rules 34 and 42 in Minnesota). Agencies can advocate with counties and case managers to make relationship building a priority for the individuals they serve. Case managers can advocate with agencies and families.

Some agencies are experimenting with staff schedules and roles, trying to increase flexibility to accommodate support for participation in community activities that take place outside of regular staff hours. Staff orientation training can include more about friendships with community citizens. Activities that are now centered on "community integration" can transform into "community connecting." The following list of examples is from the agencies that participated in the project:

- Changing orientation training: "community integration" now means helping people have friends instead of doing community activities
- Program policies include specific "how-to's" to help people have friends
- Streamlining reporting and paperwork requirements to free up staff time for relationship building
- Using staff from smaller homes to work with some of the people in the larger homes when they have some free time
- Flexibility in staff scheduling: someone can take an individual out even if it was not originally scheduled
- Encouraging staff to take individuals to their own community activities
- Using well-connected board members as a resource by asking them "who do you know that might like to meet so-and-so?"
- Using the staff who have been involved in the Friends project as resources for other staff to assist other individuals served
- Forming a support group with other people (such as case managers, day programs, school, recreational programs, and community people) to work on efforts together

Staff Development and Community-Building Skills

Helping individuals with disabilities get better connected in their communities would be much easier if the staff people who worked with them were themselves connected in 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 persons 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 is 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, and can inspire others to try. When one staff person discovers that "It never hurts to ask," and helps someone make a connection, others see that it *can* be done.

- Encourage staff to get involved in the 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, out-going, and to take more risks. With continuing encouragement, several staff during the course of the project became more willing to ask more people to become involved and to investigate more possibilities. The staff themselves became more a part of their own communities just by helping others to do so.

The Role of Volunteers

Some agencies have used volunteers as a way of involving people with disabilities with non-disabled community members. Volunteers can play valuable roles in human service agencies. However, if formal volunteers are substituted for more natural relationships, dependence on volunteers as a way to provide relationships can sometimes create problems.

Recruiting volunteers is one way to create opportunities for the development of lasting friendships between non-disabled people and individuals with disabilities. However, the "formal" status of a volunteer can sometimes get in the way of genuine friendship. The images of dependency sometimes unconsciously associated with volunteering can also get in the way. The volunteer may feel an obligation rather than just liking and wanting to be with the person. When volunteers are "paid" by being awarded hours of volunteer credit, are given credit for school, or are acknowledged for their "good deeds," the "helper-helpee" nature of the relationship is emphasized. Neither the volunteer nor the individual may feel like he or she is really a friend. Also, if the formal volunteering agreement ends, there is usually little continuing contact.

Agencies can address this problem by examining their practices that are designed to promote friendship and their existing volunteer recruitment practices. Agencies can also work to clarify volunteer roles, and eliminate or at least minimize formal roles for individuals who are simply friends.

> *April and her friend Angela had had a great day together, shopping for magazines and books, checking out clothes, and having lunch. Angela really enjoyed being with April. At the end of the day, she was letting April out of the car. Just before she got out, April turned to Angela and said in her usual loud, commanding voice, "WILL YOU BE MY VOLUNTEER?" Angela was a little stunned, but she said, "Well, what's a volunteer?" April said, "You know, somebody who takes you out once a week and does stuff with you." Angela replied, "Well, I won't be your volunteer, but I will be your friend."*

What About Liability? (The Risk of Being Related)

Agencies have a responsibility to protect and safeguard the well-being of the individuals in their care. On the other hand, individuals with disabilities have the right to as much independence, choice, and self-expression as possible, as well as the right to interact with non-disabled people in community settings (as required by Rules 34 and 42 in Minnesota). Often, the balance between agency responsibility and individual rights is difficult to maintain, and requires creative problem-solving. For all of us, getting to know others involves some risk. Whether the relationship is casual or intimate, there is a possibility of being rejected, conned, misunderstood, taken advantage of, or not liked. People with disabilities face the same risks, and sometimes additional ones as well.

A providing agency must balance the risks of community life with the safeguards needed. A tightrope must be walked, with balance between what's overprotective and what's foolhardy, what's encouraging of community relationships and what's too "professional," "suppressive," and, yes, even what's *too* "safe." No matter how many guarantees an agency tries to put in place to minimize liability, things happen. Even in the most apparently safe and protected environments, things happen. Each individual has the right to the dignity of risk of meeting people, going places, and becoming involved with others. An agency has the responsibility to reasonably support and safeguard the individual, but not thwart the joys and letdowns of full participation.

Concerns about agency liability have dampened some agencies' enthusiasm for involving people other than paid, trained staff in the lives of individuals with disabilities. These concerns have also caused some agencies to spend their time training and certifying as volunteers people who would otherwise be considered just friends.

A Friend is Not a Volunteer

Minnesota regulations define a volunteer as someone who "under the direction of the license holder, provides services without pay to persons or to the residential program" (Rule 34), and "an individual who, under the direction of the license holder, provides direct services without pay to persons served by the license holder" (Rule 42). The regulations do not define a "friend." But clearly, a friend is not a volunteer. A friend is someone who wants to be with someone they like, just because they want to be with them, not to "provide services." Volunteers provide services. Friends provide friendship. Agencies must be clear that what individuals do with "just friends" is different than what they do with volunteers. The agency must also be clear about their responsibilities for developing and supporting relationships for each individual.

Consider the Issues Based on the Individual

For individuals who are fairly independent and spend time in the community without agency supervision, it may be fairly clear how to best support the individual's social relationships. For some of these individuals, staff may need to thoroughly address the potential risks of abuse (financial, sexual, etc.). Staff may also need to carefully consider how to best provide sufficient support for the person while encouraging relationships. For individuals who need more assistance, especially those for whom the agency has 24-hour responsibility, staff may need to think through different issues related to building relationships and address these issues in the formal planning for the individual. This planning could include: discussion of the best ways to support relationships, what information a community person needs to know, whether staff need to accompany the person and for how long, and how to ongoingly support the development of real friendship.

Friends Can't Be Programmed

Minnesota's Rule 34 requires agencies to "increase each person's opportunities to interact with non-disabled individuals who are not paid caregivers in settings used by non-disabled individuals." Rule 42 requires service providers to "increase each person's opportunities to interact with non-disabled individuals who are not paid caregivers." These and other regulatory requirements sometimes result in formalizing attempts and turning friendship efforts into programs. Agency commitments to the quality of people's lives beyond what the rules require may result in friendship goals and objectives in habilitation and program plans.

It is good to have specific plans known and agreed-upon, especially regarding efforts to have people meet each other. However, there is a danger of having efforts become too boxed-in and narrow-minded. Our intent is *not* to have friendship goals become just one more persistently unmet skill objective, such as "Charles will achieve 90% accuracy in toothbrushing sequence." It makes little sense to write a goal such as "Mary Jane will have one friend by December, 1991." Neither Mary Jane nor the friend are that predictable. Rather, *if* goals are set (and they don't have to be!), they should be aimed at staff actions for connecting and providing the support necessary for existing relationships. Examples of goals that may make sense include:

- If Gordie chooses, he will enroll in a community education class this fall. Staff will go along at least the first two times to introduce him to the teacher, other students, and see what else he needs.
- The program manager will investigate community opportunities based on Helen's interests in rock and roll, crocheting, nature, and dancing, and will identify at least two concrete opportunities to explore.
- Staff will support Marjorie in understanding the appropriate number of phone calls to make to her friend Jill.
- Staff will provide transportation so that Ed can get together with his friend Tom at least once a month.

In planning for each individual, staff, case managers, family members, and others involved need to figure out how best to help the individual meet and spend time with non-disabled community people, and how to make sure that both the individual's and community person's needs for comfort and assistance will be safeguarded in those interactions. It's important that connecting and supporting friendships be enjoyable for everyone involved. But no matter how well-intentioned or planned staff efforts are, the "magic" of two people connecting must be given room. Sometimes the best thing for staff or an agency to do is to *get out of the way*—to let people be, so they can figure out their own appreciation of each other, and be themselves.

Almost always, the best staff to work on relationships with others are those who care deeply about the person, are committed to their relationships with others, and can unabashedly be *for* them in representing them to the community. Connecting requires providing the best chances for success, and a commitment to working out the problems that do arise.

Decrease, Don't Increase, Distance

Much of what agencies have to do in the course of day-to-day operations results in creating distance between individuals with disabilities and non-disabled community people. Whether the distance is a result of traditional service practices or of government regulation, it is a barrier to relationships between the individuals we serve and others in the community. If we are to be successful in our efforts to help individuals with disabilities become more a part of their communities, we have to find ways to minimize the distancing effects of our operating practices.

The practices to examine are those which make people look "special" or "different" or as "needing special help," rather than just like people. Although people with disabilities often do require special assistance, that assistance can be provided in non-obtrusive ways that are as much like the ways other people do things as possible.

Examples of service practices that can create distance are:

- how people are referred to
- where they live
- how they are introduced
- in what vehicles they ride
- how they are spoken to
- what kind of work they do
- how they are included

The key factor is how people are supported in seeming like people we ourselves would like to get to know and be friends with. The agency responsibility is to promote those practices, and re-examine practices that do not bring people together.

Suggestions for Agency Practices

Based on our experiences with Friends, here are some suggestions for agencies to promote community relationships and friendships:

- examine the major priorities of life and redirect energy and resources to those priorities
- focus on capacities and gifts rather than correcting deficits
- be willing to experiment and maybe take some risks
- start large conversations with all the "powers that be" for the importance of friends and relationships
- prioritize the staff role of supporting friends and full community belonging—in job descriptions, staff training, staff evaluation
- redefine staff roles, incorporating the ideas of: community connector, social guide, escort, chaperone
- examine creative uses for staff time
- promote normal friendships rather than formal volunteer roles
- encourage staff creativity regarding their own connections, memberships, ideas, people they know
- trust the natural capacity of the community, and provide sufficient support for that capacity
- recognize that small changes can make a big difference
- recognize that overall change takes a long time

Things to watch out for:

- thinking that all this will cost more money or require more staff (our agencies found that this was not so)
- requiring community people to be volunteers rather than "just friends"
- turning friends into volunteers (special awards, formal training programs, etc.)
- using "liability" as a justification for not supporting individuals in having as integrated and independent a life as possible
- using "risk-taking" or "trusting the community" as a justification for carelessness or thoughtlessness
- trying to "over-program" and "formalize" friendship

List of Resources

Beeman, Pat, Ducharme, George, & Mount, Beth. (1989) *One candle power: Building bridges into community life with people with disabilities.* Available from Communitas, Inc., P.O. Box 74, Manchester, CT 06040, for a fee.

Center for Urban Affairs and Policy Research. (1988) *Getting connected: How to find out about groups and organizations in your neighborhood.* Evanston, IL: Northwestern University.

Mount, Beth, Beeman, Pat, & Ducharme, George. (1988) *What are we learning about bridge-building? A summary of a dialogue between people seeking to build community for people with disabilities.* Available from Communitas, Inc., P.O. Box 74, Manchester, CT 06040, for a fee.

Mount, Beth, Beeman, Pat, & Ducharme, George. (1988) *What are we learning about circles of support? A collection of tools, ideas and reflections on building and facilitating circles of support.* Available from Communitas, Inc., P.O. Box 74, Manchester, CT 06040, for a fee.

Mount, Beth & Zwernik, Kay. (1988) *It's never too early, it's never too late.* Available from Minnesota Governor's Planning Council, St. Paul, Minnesota.

Newton, J.S. (1989) *Social support manual.* Eugene, OR: Neighborhood Living Project, Specialized Training Program.

O'Brien, John and O'Brien, Connie. (1989) *Framework for accomplishment.* Atlanta, GA: Responsive Systems Associates.

O'Connell, M. (1988). *The gift of hospitality: Opening the doors of community life to people with disabilities.* Evanston, IL: Center for Urban Affairs and Policy Research, Northwestern University.

Ordinary Life Working Group. (1988) *Ties and connections.* London: King's Fund Centre.

Perske, Robert. (1988) *Circles of friends.* Nashville, TN: Abingdon Press.

Muffy and Vicki

Vicki lives in her own apartment and works at the sheltered workshop. She is pretty independent, but usually gets attention from people by doing negative things. For instance, she would call her landlord constantly to come and fix things in her apartment. When she scheduled a birthday party, she called her guests to tell them what to bring her as presents. At one point, a few days before the party, she was calling people every 15 minutes. Although she is one of the best workers at the sheltered workshop, she has a reputation for "inappropriate behavior" in her relationships with co-workers. That is one of the reasons the workshop considers her "not ready" for community employment. When the Friends group first started meeting, some members of her group despaired of finding people who would like her, because she had such a reputation of being annoying.

But with persistence and encouragement, some positive things started to occur. Her group started to work with her on what it was to *be* a friend. For instance, she made cookies and took them to her landlord. Although Vicki felt close to her family, they seldom invited her home for a visit. When her family did visit, they usually all went out to dinner. Her group suggested she invite her family over for dinner and cook it herself, which was something she had never done before. She invited them over and cooked, and the dinner was a great success. A staff person also helped her purchase a sewing machine. Vicki made a pillow to give to her mother, and some bibs for her sister's new baby.

One of her regular staff persons had an exchange student from Argentina staying with her. When there was a special dance coming up, the staff thought of asking Pablo to take Vicki, but didn't really think he would agree to go. However, she asked him anyway, and he said, "Sure, no problem." On the night of the dance, it was the first time the staff ever knew Vicki to wear a dress, and she also wore pantyhose for the first time. She went and had a great time. All the other girls wanted to dance with her handsome date.

One of Vicki's former teachers who had declined to come to her birthday party because of the persistent requests for presents, did call her up shortly after that. She invited her to come to an open house for another former teacher that was coming back to town for a visit. Vicki bought her former teacher a present, and was thrilled to bring it. (She normally would have complained about spending money.) After the party, the teacher wrote Vicki a thank-you note and told her that every time she looked at her present, a night light, she thought of Vicki and really appreciated the gift.

Her Friends group continued to look for someone her own age who might be willing to be her friend. Because Vicki was very interested in sewing, her staff person chatted with other staff about people they might know who were also interested in sewing. She kept asking until somebody suggested Muffy, who sounded like she might be just the right person. The staff called her up and asked. Muffy said she would not necessarily be interested in doing "scheduled" things with Vicki, but that if Vicki wanted to come over and hang out at her house while Muffy watched her children, that would be fine.

Vicki and Muffy live only a few blocks away from each other. They have become great friends. Vicki is thrilled to watch Muffy's children with her. The two of them talk on the phone, go for walks and shopping together, and sew together. Muffy helped Vicki enter one of her pillows in the County Fair craft competition. Muffy really likes Vicki, and thinks she is "really funny." Vicki is not at all annoying with Muffy, and really is a delightful person to be with.