PERSON TO PERSON

VOLUNTEER RECRUITMENT AND TRAINING GUIDEBOOK

Written by Jackie Sinykin & Sue Vineyard
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CONTENTS OF GUIDEBOOK

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The cooperation and trust developed for the project will be a contributing factor to its success.

April, 1989

Jackie Sinykin
Sue Vineyard

OPEN YOUR HEART

Cara Curtis

When my cousin Mindy was born, it was like a cloud had passed over the sun. The joy experienced at the birth of a child was short and bittersweet. Dr. McAlister cradled the baby in his arms. "It's a girl, Myrna," he said to my tired, yet overjoyed aunt.

Drawing the doctor's eyes like metal to a magnet was the child's face. He knew there was something different about Mindy, something special and mysterious.

After only a week, Myrna was very suspicious of Mindy's peculiar behavior. Perhaps it was lack of behavior; Mindy seemed to do absolutely nothing. She was much too quiet for a newborn baby.

My aunt took her to Dr. McAlister's office. He carefully examined the baby. His eyes dropped and his shoulders sagged. Myrna's eyes implored him to tell her the truth.

"Mrs. Fligg," said the doctor, "I don't quite know how to break this to you." Her eyes urged him to continue.

"Mindy has a chromosomal problem — an extra twenty-first chromosome. It's a genetic mutation usually occurring in women who are over 35. I'm sure you've heard the common names: Down's syndrome, mongoloidism.

"I can't tell you how awful I feel. Being only a country doctor, I haven't had much experience with this type of thing. I wish I could have told you sooner, to prepare you. I'm sorry."

Aunt Myrna silently gathered up her tiny child. Tears plummeted down her cheeks and fell on the face of Mindy. Myrna had longed for a child of her own for all her life. A girl was her dream. A girl with long hair to braid, to tell her about her old boyfriends, to relive her own life through Mindy. Her dream had shattered.

Life went on, as it tends to do. Our family felt deep sympathy with her. My dad, her brother, had especially known of her dream. We felt helpless, a thousand miles away from Des Moines in Pennsylvania.

Bravely, Aunt Myrna had another child. Kevin was the "perfect" child, healthy, happy, and normal. Perhaps, he made it even harder for my aunt to accept and understand Mindy.

Mindy and I are very close. It was hard for me to be more advanced in school since she was older than I. I could always understand her. I, too, was a child.

Now Mindy is still a child, in a grown-up body. She's learning cursive writing and to read the letters she receives at the home for retarded people in Marshalltown, Iowa. Friends and relatives feel sorry for my cousin. "Poor Mindy, who has to go through life with such a burden," they say.

Many times, I envy her.

Mindy sat in the grass beside the swingset in her backyard, talking to me. She told me about her new friends in Marshalltown.

Suddenly, a ladybug landed on Mindy's arm.

"Be quiet, Cara," she said. "If we just be quiet, we can watch my bug and he won't know we're here."

I sat there entranced with my friend and the red and black bug. They had some unspoken communication. We remained still for many minutes.

It was Mindy who broke the silence. "It's time to fly away now, buggie," she said. "Fly away and talk to someone else now."

She shook her arm and the bug took off in search of another person as kind as she. I doubt he found one.

Anyone else would shake the pesky bug right off of her arm. Only someone with true patience could find meaning in such little bits of life.

This incident, plus many others, have shaped the way I think about Mindy. She has more happiness to share and more love to give than anyone I know. Feeling sorry for her doesn't help her; listening helps.

Mindy can find joy in a smile or a ladybug. She is not troubled by the plights of the world. She knows nothing of hunger, war, or desperation. She sees the everyday things as beautiful, the common as extraordinary.

One might say that it is a pity that such a wonderful person should be trapped inside a cumbersome body with such a slow mind. Yet these are the things which make Mindy so easy to love if you just open up your heart and let her fill you with love. I did.

SPECIAL NOTE TO *PERSON-TO-PERSON* PROJECT COORDINATOR

The best trained volunteers may not be successful if adequate planning and communicating do not take place before any volunteer is brought into the project.

The professional players need to sit down together to fully understand the scope of the project. The one-to-one relationship and advocacy roles must be understood so that an adversarial attitude is not present. The common bond of working together for the mutual benefit of the people who have developmental disabilities is always primary and must be accepted by all players. Central to the entire process is to always keep the needs, rights, and best interests of the person with a developmental disability in mind. In this way, the role of the friend/advocate becomes less threatening.

Mutual expectations and understandings should be clearly communicated, negotiated, and even written into an inter-agency agreement. Items included should cover:

1. Confidentiality.
2. Times of access to facilities if there is an issue of convenience.
3. Complaint and compliment procedures for problem resolution.
4. Respective roles and responsibilities of direct-care staff, supervisory personnel, management, and volunteer.
5. Provisions for ongoing supervision, communication and evaluation.

Clarification with the professional team of the training procedures for the volunteer will help to build in confidence and trust. Stress the primary importance of the friendship relationship to help meet social and emotional needs, to facilitate the normalization principle, and to ensure a good quality of life for residents with developmental disabilities. If the professionals involved look upon the advocacy role in this light, it will hopefully be viewed in a positive way and will add to the probability of success for *PERSON TO PERSON*.

WANTED: Just one friend.

RECRUITMENT

As the coordinator of volunteer recruitment and training you may be called upon to use the information found on the following pages in one of two ways:

1. As a direct recruiter of volunteers.

2. As one who trains others to recruit.

The pages offered in this section offer a birds-eye view of recruitment, volunteer trends, motivation and marketing. They are augmented by the book *101 Tips For Volunteer Recruitment* by Sue Vineyard and Steve McCurley.

You will need to personalize the broadly sketched points made here so that they fit your particular needs, community and prospective volunteers.

Good luck!

RECRUITING VOLUNTEERS

INTRODUCTION

Recruiting one on one volunteers to work with adults with developmental disabilities through the *PERSON TO PERSON* program is a multi-faceted challenge.

Unlike recruiting volunteers for many of the jobs we offer through our agencies which are easily understood and anticipated, the kind of volunteer we're seeking will have to be a very special person with unique skills of patience, acceptance, creative thinking and empathy coupled with a depth of maturity and good judgement.

To accomplish our goal we need to understand recruitment (marketing) and persuasion and then be prepared to manage the assigned volunteers effectively so that they remain in their placement to see their new friend through the adjustment to community life.

To have all these skills or to pass them on to direct supervisors of such volunteers, we must look both to the ART and the SCIENCE of recruitment and management.

MARKETING

In the case of the science of recruitment, we are really tapping into the principles of marketing, or the "CARING TRADE OF VALUE FOR VALUE."

Marketing has three components:

1. Publics: identifiable segments of society either by name (Girl Scouts of America) or generic quality (senior citizens).

2. Markets: those publics that have what you want or need.

3. Exchange relationship: the trade of value for value.

When beginning your brainstorming on where you might find volunteers for this special assignment, think of all the publics that surround you in your community. The yellow pages of your phone book offer hundreds of businesses, agencies, schools, churches, associations, etc. Your Chamber of Commerce usually has a list of groups in your area, etc. etc. List these and try to think of people you know who have any

connection with them (as owners, workers, officers, members, leaders, etc.).

Circle those that you feel might have people who would be interested in becoming a one on one volunteer. Also list individuals that you or your fellow brainstormers know personally that might also be interested. Such a list becomes the start of identifying target markets.

Next list what benefits and support such a volunteer would receive in this position. Think in terms of motivations, assistance, satisfactions, etc.

PLANNING

When you have identified your value trade you can move on to planning your approach...who will be contacted by whom, when, and where.

In following this process you are actually tapping into the four step strategy that must be employed whenever you are trying to attain either support, funds, people or permission. That strategy is:

1. What do you have? (what values can you offer to others?)

2. What do you need? (specific assignment needs.)

3. Who's got it? (identifying publics and markets.)

4. How do you get it? (motivation, art of asking, persuasion.)

MOTIVATIONS

To assist you in identifying the values you might have to "trade" or offer potential volunteers, let's take a look at a few motivational theories that give you background information on people's needs and desires.

David McClelland offers us his "Motivational Classification Theory" which identifies three basic motivations found in all of us, with one usually dominating the other two. He points out that everyone wishes to be successful and have their energies flow toward that success, but that we can define success (and satisfaction) very differently.

The AFFILIATOR is a people person and defines success by relationships that have either been created or strengthened. Such a person for our purposes might be attracted to this job by the idea that they can make a new friend and become close to them. They might heavily concentrate on their

personal relationship and help the client develop other meaningful relationships with people they live or work with.

The ACHIEVER is a person that measures success by attainment of pre-set goals that are practical and achievable. Such a person might be attracted to the job of one on one volunteer because they can set goals with and for the person that can then be worked towards, and when achieved, celebrated. They would probably ask for a great deal of information about the clients skill level and then, with input from a case worker or equivalent, would set goals that can be readily measured. (i.e.: grocery shopping, menu planning, buying needed clothes, etc.) All of the emphasis on goals does not preclude their having a good personal relationship with the client, and in fact, the true achiever is the first to recognize that when a person feels safe and trusting in a solid friendship they are most likely to succeed in goal attainment.

The POWER person is one who very positively wants to impact and influence. Unfortunately, the word "power" in the English language can have a negative connotation as many people associate coercion with it, but it is the word's positive side that we try to tap! Such a positive power person might be interested in working one on one with a person who is developmentally disabled to try to teach them skill building, thereby influencing their entire lifetime by increased independence. Power people are frequently found in teaching or coaching roles in life because of their desire to influence and enable others to reach their highest potential. They too understand this is best attained through a good personal relationship.

NEEDS

In addition to McClelland's theory we have the old standby, Abraham Maslow who offers us his "Hierarchy of Needs" which categorizes five separate human needs of physiological (food, water, air, etc.), safety (free from harm etc.), social (relationships), esteem (being valued by associates) and self actualization (using gifts & talent to highest potential).

Maslow shares two key points as he focuses on human needs:

1. An unmet need motivates, a met need does not.

2. People go to their lowest level of need.

To tie this into recruitment, understand that if you identify a person with social needs, your best avenue to their agreement to be a one on one volunteer is probably by emphasizing the relationship they might enjoy with a client. If self actualization is their need, the chance to use their skills (teaching, communicating, etc.) might be the key that turns them on.

In working with the volunteers, Maslow's second key point needs to be kept in mind in case you see such a volunteer shift in time commitment, interest, etc. It may indicate a shift in their needs...i.e. a very self actualized volunteer may suddenly have a health problem that makes them think at a physiological or safety level, with little time or energy left to work with their client. Such a change is recognized by the volunteer's supervisor and a frank discussion couched in "How can I help?" terms is initiated by the supervisor to insure that the client's needs will still be met. It may be that a temporary assignment of another volunteer will be necessary.

EXPECTATIONS

The third motivational theory that has bearing on recruitment is Victor Vroom's "Theory of Expectancy," which simply states that people will feel let down and distrustful if reality does not live up to expectations. In other words, when recruiting NEVER PROMISE WHAT YOU CAN'T DELIVER! As you recruit, honestly sketch out the time commitment and requirements. As you talk in terms of a specific placement with a particular client, talk honestly about skill levels, needs, background, personality, etc. so that the volunteer has a clear picture of what their relationship might be. It would be better to have a potential volunteer, after hearing all the facts, decline the placement ahead of time rather than get into it by several months and withdraw. Such an action hurts everyone...the volunteer because they might feel they "failed"; the agency that must quickly find a new volunteer and most critically, the client who could feel rejection and abandonment.

All of the theories of the three men listed above need to be filed for reference in the back of the mind of the recruiter as tools to help identify what approach would be best received and heard by the potential volunteer. In other words, such theories become your clue to the "hot buttons" you might push in recruiting volunteers!

INTERVIEW

A thorough interview of potential volunteers should help you define their needs, wants, expectations and motivations as they explore working in the *PERSON TO PERSON* project.

Watch for motivations as simple as wanting to help, repaying a perceived indebtedness, putting faith into action, sharing unused skills of teaching, counseling or coaching. Also look at additional benefits to the volunteer that you might offer such as experience building, resume additions, socialization, filling time, job or school credit, career exploration, feeling needed, as a counterpoint to paid work, etc. etc.

PR

Do not be fooled by thinking that a lot of publicity or PR will be all you will need to do to recruit such volunteers. PR can augment your efforts but actual recruitment, to be effective and to create good "matches" between volunteer and client, must be one on one. Certainly, speak to groups that you think might harbor individuals suited to this assignment, but follow the group talk up with personal meetings with identified, interested individuals.

ASKING

Remember that in the art of asking you have four options: one on one; one to a group; via phone and via mail. The last is the least effective, the first the most. Actually the last three are simply screening devices that can peak people's interest and lead to individual interviews.

REMOVE "NOs"

Also remember when interviewing that YOU ARE NOT TRYING TO TALK ANYONE INTO SAYING "YES," BUT TRYING TO REMOVE THEIR REASONS FOR SAYING "NO." When you interview candidates, give them clearly stated information (never use quarter words when nickel ones will do!) on the job requirements and clients and answer their questions and concerns honestly. Keep in mind that it is better not to "hire" a volunteer than to have to "fire" them later on if a serious problem arises.

Don't be discouraged if you do not have immediate results in large numbers of volunteers...people will naturally have to think carefully and explore fully before entering into such a relationship. It may take them hearing about the program several times before they even tell you of any interest. Consider this a good sign, as you want people to enter into such a friend relationship carefully and with your having the time to examine the potential recruit's motivations, expectations and capabilities.

In offering here the "science" of recruitment, we have also discussed the "art" of it, which requires sensitivity, understanding, top listening skills, job knowledge and communication on the part of the recruiter.

CONCLUSION

Recruiting, placing and managing such special volunteers is not an easy chore, but the effort it demands will be well worth it as clients all across Minnesota benefit from the friend relationships created and subsequent skill building and independence.

MARKETING IN THE COMMUNITY

THE CHALLENGE

As more and more people with developmental disabilities come to live in the community, it is vital that the general population accept them for the individuals they are.

This acceptance, founded on good information, will also form the foundation for potential volunteers accepting your invitation to become part of the *PERSON TO PERSON* program.

You are urged to brainstorm with interested parties and representatives from the educational, business, media, health, religious and service communities to devise ways to positively alert and involve the population as they welcome these friends into their circles. These carefully chosen representatives then become a nucleus of advocates or spokespersons for the *PERSON TO PERSON* program.

CHOOSING POTENTIAL ADVOCATES

As you first plan such brainstorming, identify and personally contact leaders from each of the mentioned segments of your community. Explain the *PERSON TO PERSON* project. Emphasize the client's needs and how these, and the general needs of the community will be met when as many people as possible understand the project. Tell them you need their input as to how the community should be approached and educated.

Send a *PERSON TO PERSON* brochure to the leader along with a letter of invitation for a brainstorming meeting (set on an evening and at an easy to reach and well known location). Share the generalized agenda in the letter so they know what is and is NOT expected of them (they may think you really want them to be a *PERSON TO PERSON* volunteer).

Do your homework on who might best represent their population segment. You do not need to limit it to just one person per segment.

BRAINSTORMING MEETING

Keep the meeting relaxed and informal enough to stimulate creativity but structured enough so participants feel their time was not wasted or their energies non-directed.

1. Have people introduce themselves quickly by name and segment (religious, school, etc.).

2. Explain *PERSON TO PERSON* project briefly, Show short, appropriate video on people with developmental disabilities.

3. Show training and supervision materials to help them see that the recruitment, training and management of the volunteers is professional and well directed.

4. Ask them for suggestions as to how best to acquaint the public with the project and special challenges of the clients.

5. Look for opportunities to have the people present return to their own circle of influence (church, business, synagog, newspaper, club, etc.) and actively advocate for *PERSON TO PERSON*. Ask them to forward to you the names of any individuals who express interest in becoming a volunteer in the program.

6. Follow up the meeting with a thankyou letter to all participants. Recap any agreements on action decided on at the meeting. Keep these people informed on progress as time goes by...you may need to call on them for future assistance and want them to be "up" on efforts and feel a part of the program.

IDENTIFYING GROUPS YOU NEED TO IMPACT

Be careful to identify specific groups or individuals you need to impact as your clients and their volunteer friends venture into the community. Such groups might include Homeowners Associations, specific churches or synagogues, merchant's associations, etc.

After identification, decide who might be the most effective advocate for the client and program. This may be the volunteer themself in some instances, a case worker in others, etc.

MEDIA INVOLVEMENT

Try to set the stage of acceptance and interest in the *PERSON TO PERSON* project in your community by carefully crafted stories in newspapers and possibly even on radio or TV (cable TV is often interested in such projects).

Feature stories which offer successful examples of volunteer/client friendships and the client's integration into a community are most effective (they require written permission for release by the client's family or guardian, obviously).

SPEAKERS BUREAU

For this project and others that might involve individuals with developmental disabilities, it can be helpful to have a group of well informed and trained speakers who can talk to groups and get your story across. Carefully instruct them so that they report any individuals or groups wishing to become involved as volunteers.

ENLISTING HELP

There are several potential groups of people in your community that are already familiar with the challenges and needs of people with developmental disabilities. You may wish to enlist their support and suggestions in your effort to educate and sensitize the general public.

Such groups might include:

- Special Olympics
- Teachers of students with developmental disabilities
- Family support groups for people who are disabled
- Social and case worker groups
- Special education teachers groups
- Rehabilitation specialists
- Easter Seal Treatment Centers
- Schools for students with handicaps

SUMMARY

There are many different avenues that can lead to greater informed awareness and sensitivity to the needs, challenges and understanding of developmental disabilities. It will constantly be up to the individuals involved to find these avenues and pursue them so that the clients and volunteers are accepted, and hopefully, even welcomed into life's mainstream.

These same efforts will also serve as a base of positivity and awareness for potential volunteers to be recruited, placed and trained as *PERSON TO PERSON* friends and set the stage for long term relationships in every direction. Good luck!

REASONS PEOPLE MIGHT VOLUNTEER FOR *PERSON TO PERSON*

- They want to help
- Build skills
- Fill time
- To be part of a team
- To learn new information
- To make a difference
- To feel loved and needed
- Solve a problem in the community
- Gain experience (for job, school credit, etc.)
- Put faith into action
- To have fun!
- To have a relationship with a new friend
- To repay a perceived indebtedness
- As a challenge

QUALITIES/CHARACTERISTICS NEEDED IN ONE-ON-ONE VOLUNTEERS

- Patience
- Sensitivity
- Flexibility
- Initiative
- Sense of humor
- Very human
- Dependability
- Willing to learn
- Can accept "failure" & turn to positive learning
- Non-judgmental
- Creativity
- Willing to work on a team
- Common sense
- Self-confidence, personal stability, maturity
- Honors confidentiality
- Realistic
- Caring of self and others
- Good sense of boundaries
- Non-threatening attitude, no hidden agenda

TRENDS IN VOLUNTEERING*

- 45-50% of American adults volunteer regularly.
- Almost 50% of American teens volunteer regularly.
- 47% of volunteers are male.
- Working women (outside of home) are more likely to volunteer than homemakers.
- 47% have household incomes under $20,000.
- 17% have household incomes under $10,000.
- 28% live in towns with populations under 2,500.
- 52% have a high school education or less.
- Most people volunteer "because someone asked me."
- The average time given is 4.7 hours a week.
- 25 million adults give 5 hours or more a week to volunteering.
- Americans give 19.5 + billion hours a year.
- Americans give over $150 billion worth in volunteering.
- Volunteers are twice as likely to donate money to causes than "non-volunteers."
- Pro-volunteering people not volunteering now were asked why — "No one asked!"
- Volunteers demand: "Involve me in decisions that effect me!"
- By 2010 one-fourth of our population will be over the age of 65.

DISCUSSION QUESTIONS:

1. What do these trends say to the future of our organization for recruitment? Program planning? Funding?
2. What new options do the trends suggest for future volunteers?
3. Where might we locate future volunteers for our program?
4. What is the profile of our current volunteers? How will that change?

*Major statistical source: Independent Sector's Gallup Poll on Volunteering and Giving; Independent Sector, Washington, D.C. Annual updates.

MARKETING "MAGIC"

Marketing is the CARING TRADE OF VALUE FOR VALUE; a win-win that makes participants happy about their relationship. Marketing has 3 components:

PUBLIC: An identifiable segment of society that exists. Publics can be identified by proper name (Girl Scouts) or generic quality (girls between 10-12). There are supplier, agent, consuming and internal publics. Publics can have smaller publics inside of them (Church — choir, council, etc.)

MARKET: An identified public that you decide you wish to have a trade relationship with; they have what you need!

EXCHANGE RELATIONSHIP: The trade of value for value; you get what you need in exchange for providing to the giver something they value.

MARKETING ORIENTATION shows concern for needs of consumers; came about in the '50s after coming through two other types:

Production Orientation: Concern for production, systems etc.; little concern for consumer; gave basic items of need.

Sales Orientation: Tried to convince people their product was needed; aimed at disposable income; little concern for people's real need . . . tried to "hook" people!

FOUR VARIABLES IN MARKETING:

PRODUCT: What business are you in? How do you know it's needed? Who needs it? What do you offer volunteers, donors, supporters? Three things you can do about products: introduce new, modify old or drop them.

PRICE: What does it cost people to be involved with you? Time, energy, emotional drain, dollars, etc.

PROMOTION: How do you get your message across? How do you package your offerings?

PLACEMENT: Where do you recruit, fundraise, etc.? How do you reach people? Where are your jobs located?

FOUR STEPS OF MARKETING:

1. What do you HAVE?— Resource inventory file; contacts; publics; public perception; differentiation; competition; trends; history; analysis of your market, demands; energies; staff, etc.
2. What do you NEED? — Be specific: people, goods, dollars, services support, etc.; strategic planning; management, timeline, etc.
3. WHO HAS what you need? — Market identification; motivation, homework; the marketing plan; why people give; etc.
4. HOW do you GET what you need? — Strategizing: undifferentiated, differentiated, concentrated; life cycles; art of asking; removing "nos"; diagnosing objections; how people relate; hidden questions; asking techniques; what to avoid.

MARKETING IS — TARGETED, ETHICAL, CARING, FAIR, WELL PLANNED, MANAGED AND THOROUGH. IT BUILDS ON YOUR OWN NATURAL RESOURCES, IS SPECIFIC ABOUT NEEDS AND EXCHANGE RELATIONSHIPS. IT IS IN TUNE WITH REAL NEEDS, IS FLEXIBLE, DYNAMIC, HONEST AND REWARDING!!!

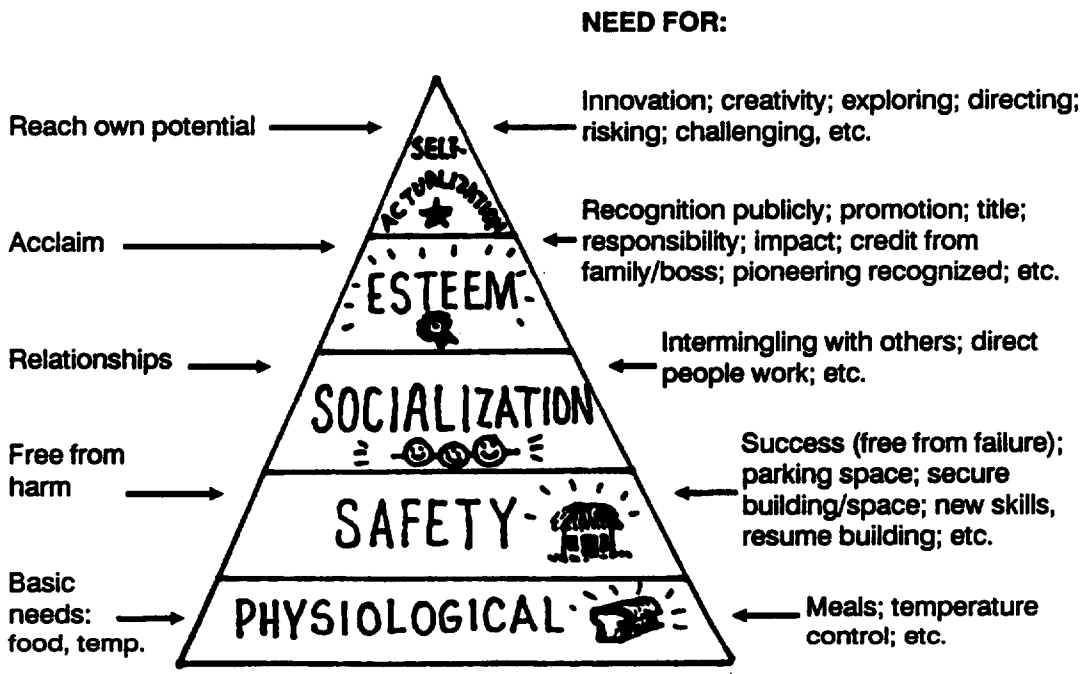
From *Marketing Magic for Volunteer Programs*, 1984, Sue Vineyard, Heritage Arts Publishing, 1807 Prairie Ave., Downers Grove, IL 60515.

MOTIVATION

The art of understanding human motivation is rooted in an attitude of CARING about others . . . caring about their success, their feelings, their growth and development.

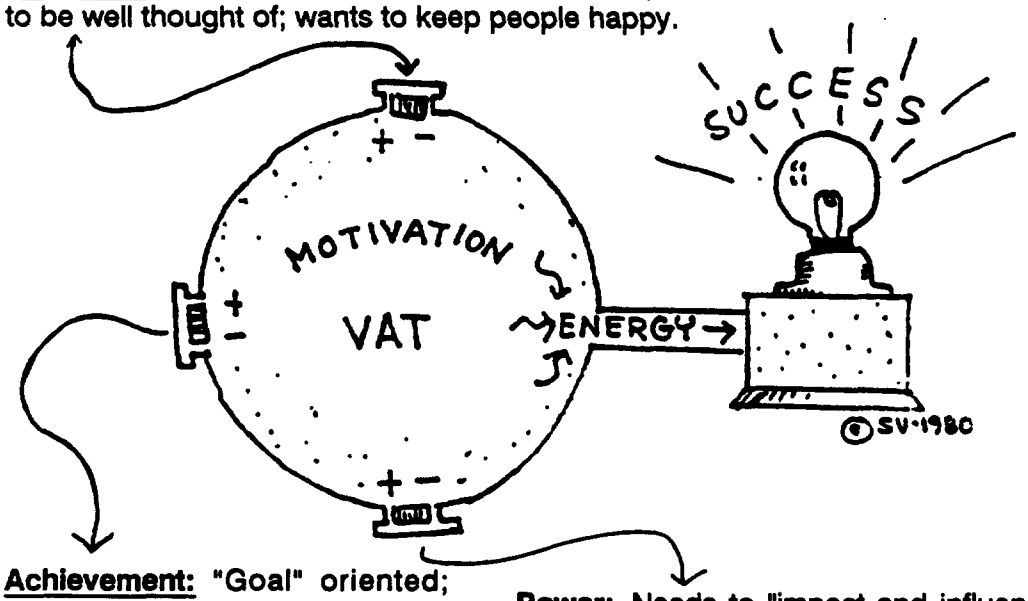
Two behavioral scientists shed light on what motivates (or stimulates) people and can help us understand what turns people "on" and "off" and what they need:

I. Dr. Abraham Maslow gives us his Hierarchy of Needs which has been adapted for volunteer understanding:



II. Dr. David McClelland helps us understand the three basic "motivations" inherent in all of us, with one being predominate in various aspects of our life:

Affiliation: A "people" person; wants relationships; needs to be well thought of; wants to keep people happy.



Achievement: "Goal" oriented; needs measurable success with "check points"; likes systems, facts, figures; likes to exceed past accomplishments.

Power: Needs to "impact and influence"; likes to persuade; requires o.k. to innovate, create, challenge; balances people/goals to achieve end results agreed on.

Three additional psychologists have described theories which add to our understanding of human motivation and help us round out our picture of what turns people "on."

Dr. Fredrick Herzberg's *Motivational/Hygiene Theory* lists those hygiene factors which in themselves do not motivate, but ABSENCE of which will de-motivate. Those factors include: pleasant physical surroundings, rewards, clear policies and guidelines, administration, security and status. To translate to our terms, his theory points to the importance of clear job designs for volunteers, achievable and well understood goals and objectives, positive working conditions, appropriate job titles, and formal and informal recognition.

The "Motivators" that Dr. Herzberg points to are those factors which need to be part of assigned work for that work to turn people "on" and keep them satisfied. They are: Achievement, Recognition for Accomplishments, Challenging Work, Growth and Development, and Increased Responsibility. (This 5th factor may not be a requirement of all volunteers . . . some people have a need to avoid further responsibility in volunteer work if their paid vocation demands great responsibility. As a Volunteer Director, it will be up to you to determine the appropriateness of this factor.)

Dr. Victor Vroom has expounded on his "Theory of Expectancy" which basically tells us that when reality does not live up to expectations, people feel "cheated," "uncomfortable," "de-motivated" and "let down." This helps us focus on the importance of setting achievable objectives and clear pictures of what can be accomplished and how the work is to be done.

The final theory is put forth by Japanese psychologist (and suicidologist) Dr. Inamura of Tokyo, and is titled "Theory of Significance" which is based on human being's need to feel they, or the work they do, is significant. Again, this speaks to our need as administrators to design jobs that not only really make a difference, but ways to let our volunteers know how significant they are . . . a true motivation for continued involvement. Too often, we do not let our volunteers see how their efforts fit into the "big picture." It is easy to see why the person that stuffs envelopes can feel insignificant unless they understand they are part of a chain of work that will attract potential donors to support the work of clients, etc.

Motivation is both an art and a science . . . the theories shared here give us a peek at how people respond, have needs and expectations and are attracted, by their own personal likes, to specific kinds of approaches and work assignments. The final art of motivation is however, that special attention given our volunteers as we listen to them express their own needs and motivators. It is this final art of caring deeply about matching volunteers to appropriate work that meets those needs that truly motivates people!

A person discovers self
only among friends.
— John O'Brien

Handouts and materials found in this Guidebook are to be duplicated by you and inserted in the Volunteer's Manual AT YOUR DISCRETION.

You choose what you would like them to have.

The following handouts are already part of their manual:

1. Guidelines for Establishing Relationships
2. Poem: "Friends"
3. Communicating With a Person With Mental Retardation
4. Open Your Heart
5. What is a Developmental Disability?
6. Types of Developmental Disabilities
7. Residents Bill of Rights
8. The Principle of Normalization
9. Missing the Mark: Normalization as Technology
10. Quality of Life
11. Principles of Volunteering
12. *PERSON TO PERSON* Job Description
13. Volunteer Responsibilities
14. Volunteer Activity Timelog
15. Monthly Time Report
16. Volunteer Expense Report
17. Volunteer Contributions Record
18. Volunteer Position Evaluation Form
19. Volunteer Assessment of *PERSON TO PERSON*
20. References

TIPS FOR TRAINERS

USING THIS MANUAL

This manual provides a curriculum for training volunteers to participate in friendship and advocacy relationships with people with developmental disabilities. These volunteers are individually matched on a one-to-one basis with people who are residing in community-based facilities and have unmet needs for friendship, for a means to normalization, for someone to speak out for them.

The goals of the training are to:

- give volunteers knowledge about people with developmental disabilities;
- give volunteers the tools to help integrate people with developmental disabilities into their communities and utilize available resources;
- develop an understanding of the advocacy role and skills in taking action.

Because there is so much variety in the way individuals train — based upon numbers of people being trained, their base of knowledge and their client's living arrangement — a major goal in the design of this manual is to allow for flexibility in its use. A single manual has been prepared including both instructions for trainers (on colored paper) and background materials and handouts that the trainer can copy for volunteers (on white paper). In so doing, the trainer has the flexibility to design the training according to identified needs. If some of the materials provided are not suitable for a particular program, they can be omitted or others substituted. A trainer can easily add materials such as brochures, lists of community resources for the designated area, facility forms which may differ; and the volunteer can later add information that is pertinent for a particular client or situation. By designing the manual in this manner, the set of handouts that a volunteer collects during the training accurately and completely reflects the program in which that trainee is involved.

TRAINER'S GUIDELINES

Guidelines on conducting training sessions and suggested activities are printed on colored paper. The left column is an

outline so that a trainer can see at a glance the sequence of activities. The written column provides detailed instructions. The wide right margin is for trainer's notes.

Instructions for activities that are used frequently, such as brainstorming, are in the introductory material.

HANDOUTS

Background or informational materials are printed on white paper so as to be easily reproduced for use as handouts. These materials are placed in the manual directly after trainer's guidelines. The handouts are numbered for easy reference.

The worksheets that volunteers will use during a training session are also printed on white paper and numbered in sequence with informational material. Using the materials is as easy as providing copies for participants after selecting which are appropriate for your session.

TRAINING ACTIVITIES

The activities have been planned to encourage group members to actively participate and to practice any skills presented. These activities take into account the lifelong experiences of the trainees. Lecture is used when the main purpose of a part of the training is to present information.

The activities are organized in sequence of usage. However, trainers should feel free to delete an exercise or add one according to the needs of their group. A trainer may be as creative and flexible in conducting the sessions as in selecting materials.

TRAINER'S RESPONSIBILITIES

PRIOR TO SESSION

1. Become familiar with the content of the training.
2. Write down an outline of topics to cover and points to make.
3. Inform all participants as well as any guests or staff of the date, time, place, and subject of training in enough time so they can make necessary arrangements.
4. Make any necessary arrangements for renting or using a meeting room, equipment, and materials.

5. Be personally responsible for seeing that all material and equipment arrives at the room where the session will be held.
6. Arrive at the room early enough to:
    - Organize handouts to be easily distributed;
    - Set up audiovisual equipment and test it; (Carry an extension cord)
    - Prepare refreshments;
    - Distribute paper and pencils;
    - Arrange the room the way you want it;
    - Arrange for registration area and someone to help the registration process.
7. Finish the above tasks in time to be ready to greet people as they arrive. Some people will arrive at least 15 minutes before the starting time so allow yourself plenty of time. It is better to have a few minutes to sit down and catch your breath than to be caught arranging chairs and breathlessly racing around the room.
8. If you are leading the session with other people, divide these duties carefully and specifically.
9. START ON TIME.

DURING THE SESSION

1. Plan the opening few minutes carefully. When it is the first time the group has met, you will want to use an introduction of some type. (See the warm-up activities listed in this "Tips" segment.) At subsequent meetings you can start with a warm-up and a summary of previous sessions.
2. Try to get each member of the group participating actively, but don't insist if a group member is uncomfortable.
3. Do not imply that there is a right answer or that participants are being tested.
4. Use open-ended questions such as "Does anyone have an idea?" or "How might you handle this?" or "What experience have you had?" This form of questioning is not threatening and does not imply there is a correct answer.

5. Whatever the quality of an individual's participation, do not criticize it. Find a way to be supportive and encouraging.
6. The trainer's role is to facilitate the discussion, not to dominate it.
7. Make an effort to draw out quiet group members but not to the point of making them uncomfortable. You might ask a quiet person a very simple question with an easy answer. Success will help build the person's confidence.
8. Try to prevent one or two persons from dominating the session. Encourage participation by asking individuals, "What has been your experience?" or "What do you think about _____?"
9. If you need to divide the group into smaller groups, the simplest way is to count off and have all ones in a group, all the twos in a second group and so on.
10. Hold to your agenda and move on to the next subject when it is time.
11. Do not allow the session to get out of hand. If a group member asks a question or wants to talk about something that is off the subject, cheerfully but firmly say that the group can take that up at the end of the session. Always leave time at the end for questions and comments and don't let a volunteer go away feeling frustrated because a burning problem was not dealt with. If someone has a concern that would be of no interest to the rest of the group, you might suggest that the person stay for a few minutes after the session and you can discuss it then.
12. Treat the group members with respect and be open to feedback.

ROOM ARRANGEMENT

Arrange the room so people will feel comfortable and there will be easy interaction between participants. Tables are helpful if people will be doing exercises which require pencil and paper. Develop an informal setting.

People do not want to feel that someone is talking down to them. Stand or sit on the same level as the group, not on a stage or behind a lectern. There should be no physical barriers.

Make sure that the temperature in the room is comfortable and the lighting is good.

TRAINING TECHNIQUES

BRAINSTORMING

Brainstorming is a spontaneous outpouring of ideas from all members of the group on a stated topic. It is effective in groups of five to fifteen people. Ideas are recorded as rapidly and noncritically as possible. Brainstorming can be used to stimulate group discussion or to identify alternatives when a group needs to make a decision.

Arrange for one person in each group to serve as a recorder. That person writes down ideas as fast as they are presented by the other group members.

Only one topic should be considered at a time. The leader should make the ground rules clear — post them. Rules must be rigidly observed.

Brainstorming rules are:

1. All ideas are acceptable.
2. No discussion of ideas.
3. No judgement of ideas. Don't comment, shake head, or show emotion.
4. Produce ideas at a "rapid-fire" pace.
5. Repetition is okay.
6. "Piggy-backing" is okay. That is adding to someone else's idea.
7. Set a time limit.

ACTION IDEAS

Action ideas are the points that each group member feels are significant for him or her. Provide a blank piece of paper or one with an idea picture on it. Tell the group to jot down

an idea at any time. Periodically have them compare one or two with a partner or update their listing.

Encourage the participants to write new information, old information, discoveries, and insights. It is important to keep the Action Ideas sheet in an easily accessible place.

PANEL

A panel is usually composed of three to five people. These people have special knowledge about a common subject. Each one prepares a brief presentation on an assigned topic and responds to questions from the audience. A moderator conducts the panel.

Each panelist should know why he or she has been invited and what specific information is to be shared with the group. Panelists should be told who else will be on a panel, what topics other members have been assigned, and some information about the audience.

Be sure each panelist is clear on time limits and be firm in controlling that aspect of the panel.

The moderator's responsibility is to keep the panel running smoothly, to signal when time is up or interrupt if time limits have been unreasonably exceeded. The moderator should be someone with skills in leading and facilitating discussions.

ROLE PLAY

Role playing is acting out a situation with group members taking the roles of different characters. It can be used to illustrate interpersonal problems, to promote better understanding of an idea or another person's feelings, or to practice a skill.

The trainer may prepare written descriptions of the role play situation — including facts, feelings, and opinions of the characters. The facts and roles may be presented orally, also.

Each person should have a few minutes to study the situation or to think about the character assigned.

The trainer may want to break the group into small groups and have simultaneous role plays. Some group members

can do the role play while others observe. If there are several groups, they should all begin role playing at the same time.

When casting parts, be sensitive to the strengths and weaknesses in the group. Asking for volunteers for different roles is a good way to begin.

Let the role play continue until it has provided the information or understanding that the group is seeking.

ICE BREAKERS (WARM-UP ACTIVITIES)

INTRODUCING PARTNERS

Distribute pencils and 3x5 cards to each participant.

Divide the group so that each person has a partner. Ask each person to find out some information about the other in order to introduce the partner to the group. Each person will have 2 minutes to find out the information from the other. In addition, participants should try to find out one unusual thing to tell about the person. After 4 minutes, go around the room and have each person introduce his or her partner to the whole group.

NURSERY RHYMES

Place the first half of a nursery rhyme or limerick on a 3x5 card. Place the second half on another card. Distribute the cards as people come into the room.

Ask the participants to circulate until they have found their match. Have each pair spend 5 minutes getting to know one another. The rhymes can be read to the group along with introductions of each other.

NAME TAG MIXER

As each participant enters the room, check off his or her name on the roster, but present a different person's name tag. Explain that they should seek one another out, and also introduce themselves to other participants as well. If the group is relatively small, have the paired individuals interview each other so they can introduce their counterparts to the rest of the group.

WHAT'S IN YOUR PURSE?

Instruct the participants to take three things from their wallets or purses that in some way describe them. Place the three items on the table in front of them.

Give each participant in turn a chance to say something about his or her life based upon the items carried, day after day, in the purse.

TRAINER'S INTRO

If the group is small and if you know something about each person, go around the room and introduce each member. Keep the introductions light and look for something interesting other than the usual facts about employment and family.

INTERVIEWS

Pair up the participants. Instruct them to interview each other on the basis of:

1. Three unusual things that have happened in their lives.
2. Special talents or hobbies they have.
3. The two most important job responsibilities that they have.
4. The person that they most admire in the world. (least admire)
5. A color and an animal that best describe who they are and how they feel.

TRAINING ADULTS

INTRODUCTION

Simple fact: ADULTS LEARN DIFFERENTLY THAN CHILDREN!

As you work with adults to train them either in recruitment or in working with volunteers or clients, it is critical that you draw on the basic principles of adult learning.

First, understand that there are three kinds of learners:

1. Auditory
2. Visual
3. Hands on

The type a person is determines the best and most effective route to get the learning points across. The auditory learner learns by hearing the trainer list key points and reinforces their learning by offering spoken feedback either to the trainer or with other learners. They tend to best recall what they have heard.

The visual learner learns through seeing key points written down, offered on an overhead projector or some type of visual communication (film, charts, graphs, etc.). They tend to recall what they have read or seen. They take particular interest in role playing or films of actual work with the same type of client they will be working with. Interestingly enough the auditory learner and the hands on folk also learn a great deal from such teaching aides.

The hands on person learns through applying spoken or written theory to actual practice. Since small group discussions often take theoretical learning into the practical stage, they respond to such exercises. The best way of course, for them to learn is to actually be trained "on the job."

In training adults, we find that the most effective method, which actually employs all three learning stances is to have the volunteer walk through the work with their supervisor or predecessor volunteer. It gives them first hand knowledge of the work that needs to be done, offers opportunities to

ask questions and instantly hear the answer (auditory learning), reinforces what they have read on the assignment (visual learning) and see it for themselves, and to experience the work first hand (hands on learning).

Frequently, the volunteer has never before experienced such an assignment and therefore in a sterile training atmosphere may not even know the questions to ask of the trainer. In a "walk through," experiential training, however, they will have more understanding of the work and be able to ask more knowledgeable questions.

ADULT LEARNING

As you train adults you also need to understand five ways in which adults differ from children in their approach to learning.

1. They have more experience: They have more examples and parallels to draw upon as they learn. Be sure to draw them into the learning by offering them the opportunity to share past experiences pertinent to the training. Often they can give a concrete example of a principle the trainer is speaking about and thereby clarify it to themselves and the training group.
2. They are ready to learn: Kids rarely see the value of what is being taught (unless it's something like "how to ride a bike") and therefore half of the teacher's job is getting and keeping them interested. This is not the case with adults...they are ready to learn, and therefore expect the trainer to teach them well.
3. They want it now!: Kids tend to feel that what they are being taught is something that they may or can use at some point in the distant future. Adults want their learning to be useful NOW! They expect to get up from the training table and use their new information immediately.
4. They want the learning to be practical: Adults have a common demand, too frequently unheard by trainers: "Cut to the chase!"..."Give me bare bones"..."Make sense!" Forget a lot of theory, or if you must use it, relate it in practical examples. Speak plainly and to the point...NEVER USE QUARTER WORDS WHEN NICKEL ONES WILL DO! Be specific, offer examples and ask for questions to make sure what you thought you said was

heard by the trainees. This is not the time to impress folks with your incredible depth of knowledge that might cloud the key points you need to get across.

5. Adults have a clearer self concept about themselves: They therefore know what skills they have, what they need and what things they do or don't do well. Listen to them, they are the experts on themselves. Let them tell you what they need to know beyond what basic information you give them. If they say they need to read more about people who are developmentally disabled in the category of their client, offer them suggested references. If they ask you to go over a particular point once again, do so, they are telling you it's not as clear as they would like it in their mind. Adults are more mature than kids and have gained confidence about themselves. Since these are qualities that you must have in such a special volunteer, learn as much about them as you can as they express their self confidence. (Occasionally you will find someone whose self perception is not realistic, and that is valuable information you need as you decide on placement. Watch for clues in interviewing and training situations.)

In short, adult learners have a greater depth and range of maturity, motivation and self concept. When acknowledged and tapped into during training opportunities, it cements the learning provided and enriches the training experience for all participants, including the trainer.

"Any human being,
anywhere, will blossom
into a hundred different
capabilities and talents,
simply by being given the
opportunity to use them."
— Doris Lessing

THE ORIENTATION

An orientation is usually a familiarization process — a chance to get acquainted with people, places and things.

The orientation as outlined in the *PERSON TO PERSON Guidebook* is the first opportunity volunteers have to meet other volunteers, learn more about developmental disabilities and mental retardation in particular, volunteer responsibilities, their client and the facility in which the client lives.

If the volunteers have the time and encouragement to interact during the orientation, they may develop their own support group. They may even establish supportive pairs or threesomes to schedule meetings after the first, second and third experience with clients to compare notes, discuss reactions, emotions, and frustrations. The group might plan an activity that they will enjoy together with their clients.

It is recommended that the orientation be divided into two sessions. The first session should be conducted in a comfortable setting with tables and chairs designed for interaction. The suggested topics and information supplied in this section of the *Guidebook* will make up a 2 1/2 hour orientation session and are:

PERSON TO PERSON Project
Collateral Organizations
Developmental Disabilities
Minnesota Vulnerable Adults Act
Normalization
Quality of Life Issues
Introduction to Advocacy
Volunteer Responsibilities
Liability Issues

The second orientation meeting design is dependent upon the facility assignments for volunteers. If people have clients from several different living facilities, the orientation to the facility may have to be individualized; if however, several volunteers will be associated with clients in the same facility, the group process and support interaction can continue. In either situation, the second orientation session should include:

Orientation to the Facility
- Policies and Procedures
- Physical Layout
- Introduction to Key Staff and Administration
- Volunteer/Facility Relationship

Meeting Residents
Responding to Questions or Concerns
(Any topics not covered in first session)

A thought to consider for the orientation is to complete session one prior to matching a volunteer with a client. This might increase knowledge about the volunteer and lead to a closer match. You may even want to structure your project to allow 2 or 3 meetings with a client prior to having the volunteer sign the job description agreement. Some of the volunteer concerns may be set aside after 3 visits and/or some potential volunteer may discover *PERSON TO PERSON* is NOT the right program for their volunteer efforts.

Because volunteers can lose enthusiasm if they have to wait too long for training and assignments after expressing interest in the program, orientation should take place within a month.

During all Orientation and Training sessions, it is important to be as realistic as possible about the capabilities of each client. Caution should be expressed to avoid unrealistic expectations and encouragement given to communicate initial feelings, fears, surprises, etc.

INTRODUCTION AND WARM-UP

PURPOSE
(15 min.)

To introduce volunteers to changes that affect society.

To introduce participants to one another.

To introduce *PERSON TO PERSON* and its development as a project.

METHOD

Trainer's Introductory Remarks

Group Warm-up Activity

LECTURE

Some of us know a lot of people. Others prefer to be close to only a few. We have all learned how to act around a wide variety of people. This is because we have grown up in a society, a social grouping of people. When we were very young we only knew members of our immediate family. Soon we got to know others in our neighborhood. Then we went to school and made friends there. Soon we were able to go out on our own and meet new people. We may have joined clubs. We started going to dances and other social events. We started working. We started dating. We may have moved away from home. We might have gotten married. We might have had children. As the years have gone by, we have been exposed to more and more people.

As all of this went on, we had a chance to learn new social skills. We learned how to make friends, how to choose who we wanted to be with, how to act in different social situations. So we have become socially competent. Some of us are better at this than others. Some of us have had more experiences. But, by and large, we all know how to behave in a variety of social situations most of the time. When we meet a very important person or we are trying something for the first time we may feel awkward, but we learn from our awkwardness, and chances are that the next time we are in a similar situation, we will do better. Because we have been exposed to an ever-increasing number of people — from different backgrounds, with different personalities, in many

different settings, and for a variety of purposes — we have become socially competent.

The vast majority of adults with mental retardation in our society have experienced varying degrees of segregation during their lives. For many institutionalization has resulted in almost total segregation. Others may have remained in their homes, but may have been "sheltered" or "over-protected." They may have attended segregated schools. They may work in segregated settings. They may even only be involved in segregated recreational activities. In other words, the majority of people with mental retardation have not had access to the wide variety of social growth experiences most people have been able to learn from.

Another factor we must take into account is that many people with mental retardation have experienced many broken or atypical relationships in their lives. For institutionalized children with mental retardation, Mom and Dad were replaced by staff people working on three shifts each day. These staff people had to be replaced on sick days, vacations, and days off. Chances are that most of these people left their jobs after a relatively short period of time through transfers, promotions, or terminations. Thus, new people constantly came onto the scene.

Brothers, sisters, and neighborhood friends were replaced by a huge group of other retarded persons, some more handicapped than themselves. Becoming an adult in this strange environment was difficult at best. For a person with mental retardation, who has difficulty in abstracting, adapting to his strange social environment had to have a tremendous negative effect on social learning.

There is another side to the coin, however. How often we hear that "society cannot accept retarded people," or that, "retarded people just can't make it in this cruel world." We have ignored the fact that because of segregation, society has not had a chance to come to know very many people with mental retardation. The average person on the street may have a cousin with mental retardation or have a friend with a brother or daughter with retardation. Generally, he or she will say kind things about these people. But, in reality, the person has had very little opportunity to get to know an

individual with mental retardation. This is the other side of the coin: the social cost of segregation.

So, segregation has made us all socially incompetent. Some of us have been denied access to social learning situations, some denied the opportunity to enrich our social skills. Few of us have had the opportunity to develop long term close relationships with people with mental retardation.

You have decided to change that aspect of your life. You have decided to become a *PERSON TO PERSON* Friend. We welcome you, will assist in giving you the chance to learn more about yourself while you learn about individuals with developmental disabilities, and want you to know from the beginning that one of our roles is to support your efforts.

GROUP WARM-UP ACTIVITY

Carefully select a warm-up activity to begin interaction in the group. You may want to keep it as simple as "name, best volunteer experience, and what drew you to the *PERSON TO PERSON* Project."

DEVELOPMENTAL DISABILITIES

PURPOSE
(45 min.)

To increase understanding of developmental disabilities.
To gain knowledge about mental retardation.
To clarify differences between legal and human rights.
To become aware of the Minnesota Vulnerable Adults Act.
To understand the principle of normalization.

METHOD

Trainer's Presentation
Work Sheets
Handouts
Discussion
Audio-Visuals

MATERIALS

Handouts

Developmental Disabilities
Types of Disabilities
Mental Retardation Fact Sheet
Myths and Facts
MN Vulnerable Adults Act
Normalization by Bengt Nirje

Video Tape Player/Television

A New Way of Thinking available through the Governor's Planning Council on Developmental Disabilities.

DISCUSSION

Begin the discussion by defining developmental disabilities from the Vulnerable Adults Act of 1984. (Use information from the handout.) Make significant points, ask for questions.

Briefly describe the five categories that are classified as developmental disabilities.

WORKSHEET

Distribute the *Myths and Facts* worksheet and the *Mental Retardation* information piece. Direct the participants to complete the worksheet using the information sheet to find the correct response. Give the group 5 minutes to complete this assignment. Go over the sheet with them. Answer questions.

RIGHTS

Point out the difference between legal rights as defined in the constitution as compared to human civil rights that we experience in day to day living. The rights of any person are not jeopardized because a person receives special services — all people are entitled to exercise their rights.

There are three examples of "Rights" included in this chapter. Select one that you feel the volunteers will understand; duplicate, distribute, and discuss. Explain to the volunteers that these are the personal rights that their clients should have. If any of these rights are denied, volunteers should discuss the reason for denial with facility staff so they have a good understanding of the reason for denial or perhaps it is actually due to an inability to exercise a particular right.

Point out to the group that as volunteers in a friendship relationship, the opportunity exists to teach our friends about their rights and assist them in exercising all of their rights.

VULNERABLE ADULTS ACT

Distribute the handout *Minnesota Vulnerable Adults Act.* Read through it with the group. Be sure they understand the information and their responsibilities. (Trainers may want to have a guest discuss the act or use an overhead projector with transparencies for variety.)

Emphasize to volunteers:

1. Volunteers must report observed abuse and/or neglect. It is the law!
2. All facilities have report forms and volunteers will be shown where they are located and given instructions on completing and filing during an orientation to the facility.
3. If forms are not available report that information to the case manager or volunteer services coordinator.

NORMALIZATION

There are several information sheets on normalization. It is a concept that the volunteers should understand because they will be a part of the process of normalization. Use the information provided in a way that is comfortable. Handing out the piece *Normalization* by Nirje and sharing the reading of it provides a concrete way to relate to normalization.

Reading the five vignettes on *Missing the Mark: Normalization as Technology* will serve to reinforce the concept.

SUMMARY

Several important basic pieces of information dealing with developmental disabilities and the people who live with them have been presented. As a summary ask the participants to work in pairs and list two facts they learned about developmental disabilities, mental retardation, human rights, the Vulnerable Adults Act and normalization. Ask for a volunteer pair, or two, to share their list with the entire group.

Show the video *A New Way of Thinking*. (See video list, end of book in *References*.)

Encourage participants to carefully read all handouts prior to their next meeting.

WHAT IS A DEVELOPMENTAL DISABILITY?

People with developmental disabilities are, first and foremost, people with ability. Without special assistance some people with developmental disabilities cannot take advantage of the freedoms and opportunities of our society. They are, however, fundamentally more like the rest of the population than they are different from it.

A developmental disability is a severe, chronic disability which:

- Is attributable to a mental or physical impairment or a combination of mental and physical impairments;
- Is manifested before the person attains age twenty-two;
- Is likely to continue indefinitely;
- Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency;

AND

- Reflects the person's need for a combination and sequence of special interdisciplinary or generic care, treatment of other services which are of lifelong or extended duration and are individually planned and coordinated.*

People with developmental disabilities, like all people, need:

- To be seen, first of all, as people;
- To experience love and friendship;
- To experience continuity in their lives, especially in relation to the people who are important to them.
- To be respected and treated with dignity;
- To have access to opportunities and information, to make choices and to exercise their rights;
- To learn those skills which are needed to participate, as much as possible, as valued members of their community;
- To have a decent and appropriate place to live;
- To have meaningful employment and contribute to the community;
- To have opportunities to continue to learn throughout their lives.

* Source: The Developmental Disabilities Act of 1984 (P.L. 98-527, Section 102)

In response to these basic needs, our hopes for the future and our thoughts about the quality of our lives are often concerned with three basic issues — HAVING A HOME, not just a roof over our heads; LEARNING skills which are useful to our lives and careers, not just going to school; and WORKING, not just keeping busy. There is a fourth basic issue which gives vitality and fullness to our lives — DEVELOPING AND SUSTAINING RELATIONSHIPS with people who depend on us and upon whom we can depend.

A real home is a place to live the most personal moments of our lives. A home provides security and comfort, allows us to make choices and express ourselves. The people who share our homes are usually the people with whom we choose to spend time, be ourselves and feel close.

Real learning is lifelong. It means learning to understand ourselves. Learning involves developing skills which are useful to us both as individuals and as members of communities. The people with whom we learn are also teachers. Many become friends we can count on throughout our lives.

Real work means earning a living, being productive and making a contribution to our community. The relationships we develop with the people with whom we work are important to us.

Having a home, learning and working — each involves us as members of a community who both receive the support of others and make contributions to the community. Each involves us in the continuing process of individual growth and expression. Each involves us in developing relationships.

Having a real friend means being involved with someone who chooses to spend time with you just because they want to and not because they are paid to do so. Real friends broaden our opportunities and enrich our lives. Real friends are hard to find. It takes most of us a long time through contact with many different people to find that small group of friends who really matter. Opportunities that lead to friendships are essential.

People with developmental disabilities often are more handicapped by the environment than by their disabilities. Historically, our thinking and actions have focused on the *in*abilities of people with developmental disabilities. The concern was with "fixing the person" or "curing the deficit." Over time that focus has shifted to building on *cap*abilities and assisting individuals to develop and use their abilities.

The most dramatic shift in our way of thinking is the recognition that the social and physical environments are often a greater issue than abilities and disabilities. This is especially true in considering the expectations others have of people with developmental disabilities, and what people do based on those expectations.

Governor's Planning Council on Developmental Disabilities.
A New Way of Thinking. St. Paul: 1987.

TYPES OF DEVELOPMENTAL DISABILITIES

AUTISM

Autism is a severe disorder of communication and behavior which appears during the early developmental stages. An autistic person usually has normal physical and motor development, but is unable to communicate verbally or non-verbally or to understand verbal language. Autistic persons also have altered ways of relating to people, objects and events. They may appear uninterested, aloof, and exhibit a lack of concentration. They may possess such repetitive behaviors as hand flapping, touching, twiddling of fingers and rocking behavior. Autism occurs in approximately five out of every 10,000 births and is four times more common in boys than girls.

CEREBRAL PALSY

Cerebral palsy is a type of developmental disability resulting from damage to the brain that may occur before, during, or after birth and results in the loss of control over voluntary muscles in the body. Difficulties with the control and coordination of muscles may center around such activities as sitting, standing, grasping and eating. In addition, short frustration tolerance may be another common behavioral characteristic.

EPILEPSY

The word "epilepsy" comes from the Greek word for seizures, and seizures are the primary symptom of all forms of epilepsy. Seizures are characterized by convulsions of the body's muscles, partial or total loss of consciousness, mental confusion, or disturbances of bodily functions which are usually controlled automatically by the brain and nervous system. They are caused by abnormal chemical-electrical discharges of the brain. Common behavioral characteristics as they relate to epilepsy include drowsiness, fatigue, embarrassment, changes in emotion, and alteration of a person's perception of familiarity or unfamiliarity. Epilepsy occurs in 1% of the general population. People with epilepsy have the same range in intelligence as others. Males and females are affected equally.

MENTAL RETARDATION

Mental retardation is a condition involving significant subaverage general intellectual functioning existing along with deficits in adaptive behavior occurring during the first 18 years of life. About 3% of the population, or more than 6 million children and adults, have mental retardation.

NEUROLOGICAL IMPAIRMENT

Neurological impairment refers to a group of disorders of the central nervous system and is characterized by dysfunction in one or more, but not all, skills affecting communicative, perceptual, cognitive, memory, attentional, motor control and appropriate social behaviors. Common behavioral characteristics of neurologically impaired persons include a lack of ability to attend, reduced ability to deal with abstract thinking, and specific disabilities involving reading, arithmetic, writing and spelling. In addition, neurologically impaired persons may exhibit hyperactivity, aggressiveness, immaturity and silliness. There are three major types of neurological impairment and they are classified as childhood aphasia, minimal brain dysfunction, and learning disability.

MENTAL RETARDATION
— MYTHS AND FACTS —

Place an "M" for myth or an "F" for fact in front of each statement.

_____ 1. People with mental retardation come from families with all different levels of intelligence.

_____ 2. Mental retardation can occur because of malnutrition, lead poisoning, or inadequate medical care.

_____ 3. People with mental retardation remain children forever.

_____ 4. Mental retardation is not a disease.

_____ 5. All people with mental retardation are mentally ill.

_____ 6. All individuals with mental retardation have the capacity to learn.

_____ 7. There are more than 6 million persons with mental retardation in the United States.

_____ 8. Down's Syndrome is a form of mental retardation.

_____ 9. Persons with mental retardation do not know what they want.

_____ 10. A person with mental retardation wants to stay home and watch T.V.

_____ 11. People with mental retardation do not want to associate with non-handicapped peers.

_____ 12. Fifty percent of mental retardation cases could be prevented using current knowledge.

_____ 13. For many years, the basic services which we all need for normal development have been denied to those with mental retardation.

_____ 14. People with mental retardation have abnormally strong sex drives which they can't control.

_____ 15. Individuals with mental retardation are able to learn appropriate social behavior.

_____ 16. People with mental retardation should not have the same rights as non-handicapped people.

_____ 17. Most individuals with mental retardation are quite similar to people without mental retardation.

FACT SHEET

What is Mental Retardation?

People with mental retardation mature at a below-average rate and experience unusual difficulty in learning, social adjustment and economic productivity. The most generally-accepted technical definition describes mental retardation as "significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the developmental period." In terms of IQ, individuals with mental retardation score below 70. This means that the measured intelligence of 97 percent of the general population is greater than that of persons with mental retardation. All areas of abilities are affected, and the condition exists from birth and/or early childhood.

Mental retardation is not a disease, nor should it be confused with mental illness. Children with mental retardation grow into adults with mental retardation; they do not remain "eternal children." The big difference is that they learn more slowly and with much greater difficulty.

How Prevalent is the Condition?

Persons with mental retardation constitute one of the largest handicapped groups in America. They include more than six million persons, and slightly more than 100,000 newborn children are likely to be added to this group each year unless far-reaching preventive measures are discovered and employed. Today, one out of every ten Americans has a family member with mental retardation.

Mental retardation is four times more common than rheumatic heart disease and nine times more prevalent than cerebral palsy. It affects 15 times as many people as total blindness and 10 times as many children and adults as polio did before the Salk vaccine.

Who are People with Mental Retardation?

Mental retardation cuts across the lines of race, educational, social and economic background. It can occur in anyone. As a matter of fact hereditary components are known to account for only a fraction of the cases of mental retardation.

What are the Causes of Mental Retardation?

Mental retardation can be caused by any condition which impairs development of the brain before birth, during birth or in the early childhood years. Well over 250 causes have already been discovered, but they account for only about one-fourth

of all known cases of mental retardation. In three-fourths of the cases, the specific cause remains unknown.

Some of the most common causes include:

Genetic irregularities – These result from abnormality of genes inherited from parents, or from other disorders of the genes caused during pregnancy by infections, over-exposure to x-rays, and other factors. Inborn errors of metabolism which may produce mental retardation, such as PKU (phenylketonurial), fall in this category. Chromosomal abnormalities have likewise been related to some forms of mental retardation, such as Down's Syndrome.

Problems During Pregnancy – Malnutrition, German measles, glandular disorders and many other illnesses of the mother during pregnancy frequently result in a child being born with mental retardation. Physical malformations of the brain or other organs originating in prenatal life may also result in mental retardation.

Problems at Birth – Extraordinarily prolonged labor, pelvic pressure, hemorrhages — any birth condition of unusual stress — may injure the infant's brain. Likewise, any reduction in the supply of oxygen to the infant's brain during birth may impair mental development. RH factor incompatibility between mother and child, if not promptly treated, can also lead to mental retardation.

Problems after Birth – Childhood diseases such as whooping cough, chicken pox, measles, meningitis, scarlet fever, encephalitis and polio can damage the brain, as can accidents, such as a blow to the head. Glandular imbalance or malnutrition may prevent normal development, while substances such as lead and mercury can produce irreparable damage to the brain and nervous system.

Environmental Factors – The President's Committee on Mental Retardation has concluded that 76 percent of our nation's citizens with mental retardation come from urban and rural poverty areas. Mental retardation can occur because of malnutrition, lead poisoning, disease-producing conditions, inadequate medical care and other health hazards associated with poverty situations. Also, children in disadvantaged areas are likely to be deprived of many common day-to-day experiences of other youngsters. Research suggests that such under-stimulation can result in irreversible damage and can serve as a cause of mental retardation.

What are the Degrees of Mental Retardation?

About 89 percent of persons with mental retardation are mildly mentally retarded and in many respects, quite similar to people without mental retardation. They differ primarily in rate and degree of intellectual development. While still young, their mental retardation is not readily apparent, and these children are usually not identified as mentally retarded until they enter public school. With proper education

and training these individuals can enter the competitive labor market and the mainstream of daily community life.

Persons with moderate mental retardation comprise about six percent of persons with mental retardation and are more obviously handicapped. Their mental retardation is usually apparent before age 5. However, appropriate educational opportunities throughout the developmental years can prepare these individuals for satisfying and productive lives in the community.

The remaining five percent of people with mental retardation are severely or profoundly mentally retarded. In addition to obvious intellectual impairment, they frequently have other handicaps — cerebral palsy, epilepsy, blindness or deafness. Technological advances have demonstrated that most people with severe and profound retardation can learn to care for their basic needs. They also can perform many useful work activities with supervision, and can otherwise adapt satisfactorily to normal patterns of life in the community.

Can Mental Retardation be Ameliorated?

All individuals with mental retardation have the capacity to learn, develop and grow. The great majority can become economically productive, fully participating members of society.

All need the same basic services which other human beings need for normal development. These services include education, vocational preparation, health services of all types, recreational opportunities, religious services and many others. Unfortunately, many persons with mental retardation have been denied access to these services or have been provided with inappropriate services, often at exorbitant costs to their families.

In addition to basic generic services, many persons with mental retardation need specialized services to meet extraordinary needs. Examples include vocational rehabilitation, sheltered workshops, work activity centers, evaluation centers, community-based residential services (small group homes), apartment training programs and special education. While more specialized services are needed then are available, there is also a need to provide these services in normal integrated environments.

Can Mental Retardation be Prevented?

Scientific developments have led some authorities to conclude that 50 percent of mental retardation cases could be prevented if current knowledge were fully implemented. Unfortunately, many of the known preventive approaches are not yet in wide use.

There is an urgent need not only to apply what is already known, but to discover means of preventing those many causes of mental retardation for which effective prevention is still unknown. Examples of specific approaches to prevention include:

- Damage due to Rh-factor incompatibility can be prevented by blood exchange in the infant at the time of birth and special immunization of the mother.
- Quick treatment in cases of lead poisoning or, preferable, action to prevent children from eating lead-based paint chips, or being otherwise exposed to dangerous lead levels can also be effective in preventing some cases.
- Measles vaccine — developed to combat rubella — can help if widely used.
- Early detection and dietary treatment is effective in some forms of inborn errors of metabolism, such as PKU and galactosemia.
- Improved nutrition of pregnant women and young infants can reduce the dangers of mental retardation from malnutrition.
- Surgical techniques have proven effective in preventing mental retardation resulting from accumulation of cerebrospinal fluid in the brain (hydrocephalus) and premature fusion of the cranial sutures (craniosynostosis).
- Better pediatric care, including antibiotics that control the high fever formerly associated with many dangerous children's diseases, also works to limit mental retardation.

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FUNCTIONAL AGES

In recent years, the phrase 'age-appropriate' has become widely used with regard to programs, services, and activities for people with mental retardation.

The word 'age' is usually associated with chronological age — the number of years the individual has lived. However, chronological age should not be the only one on which to base programs, services or expectations. There are a number of other ages which need consideration because it is possible for a person to function at different 'age' levels in different situations or settings. These different age levels impact upon the way an individual behaves or performs and his/her maturity, judgement and ability.

For example, a person may have a chronological age of 27, and educational age of 8 (which means that he/she is functioning at a 3rd grade level), a vocational age of approximately 12, a social age of 5 (exhibits inappropriate behavior in social situations, e.g. cries, temper tantrums, etc.), a sexual age of 27, a judgement age of 3, and a self-care age of 5.

Obviously these 7 ages: 1) chronological, 2) educational, 3) vocational, 4) social, 5) sexual, 6) judgement, 7) self-care, will vary from individual to individual and from circumstance to circumstance. By recognizing that there are degrees of mental retardation and that these degrees vary within each person, depending upon various factors, the concept of the 7 ages may be useful in providing greater understanding of why the individual behaves differently under different circumstances. This understanding can be helpful in establishing more realistic and attainable goals and more successes, while always allowing for further growth and development.

Written for *PERSON TO PERSON* by Miriam Karlins, consultant to the project.

CRITICAL ELEMENTS OF HUMAN LIBERTY/RIGHTS

1. The *right* to choose
2. The *right* to freedom of movement
3. The *right* to make and participate in decisions affecting oneself
4. The *right* to disagree
5. The *right* to refuse
6. The *right* to make mistakes
7. The *right* to speak out
8. The *right* to take risks
9. The *right* to insist on the evidence
10. The *right* to challenge the authorities
11. The *right* to develop potentialities
12. The *right* to independence

These are the rights which contribute to individual freedom and worth. Obviously there is a place for common sense and sound judgement by those persons who work with individuals who have mental retardation in determining to what extent these rights can be exercised and under what circumstances.

Human rights are recognized and practiced when persons with mental retardation are given opportunities and encouragement in the following processes:

- Decision making
- Exercise of judgement — self-determination
- Self-control
- Freedom of choice — options and alternatives
- Coping skills

Factors which damage a person's sense of self-esteem are:

- Humiliation
- Excessive use of authority
- Repression of freedom of expression
- Ignoring or devaluing a person's statements or concerns

Written for *PERSON TO PERSON* by Miriam Karlins, consultant to the project.

THE RESIDENTS' BILL OF RIGHTS

s document describes the rights of residents in Minnesota's community residential facilities which are licensed as health care facilities and certified as intermediate care facilities for mentally retarded (ICF/MR). These rights are set forth in M.S. 144.651-2, and in Volume 42, Code of Federal Regulations, Sections 442.403 and 442.404.

initions: "Resident" means a person who is admitted to a non-acute care facility including extended care facilities, nursing homes, and board and care homes for care required use of prolonged mental or physical illness or disability, recovery from injury or disease, or advancing age.

blic policy declaration: It is declared to be the public policy of this state that the interests of each resident be protected by a declaration of a Residents' Bill of Rights which shall ude but not be limited to the following.

t the intent of the legislature and the purpose of the Residents' Bill of Rights to promote the interests and well-being of residents of community facilities. No community facility require a resident to waive these rights as a condition of admission to the facility. Any guardian or conservator of a resident or, in the absence of a guardian or conservator, an erested person, may seek enforcement of these rights on behalf of a resident. An interested person may also seek enforcement of these rights on behalf of a resident who has a rdian or conservator through administrative agencies or in probate court or county court having jurisdiction over guardianships and conservatorships. Pending the outcome of an rcement proceeding, the community facility may, in good faith, comply with the instructions of a guardian or conservator. It is the intent of this section that every resident's civil religious liberties, including the right to independent personal decisions and knowledge of available choices, shall not be infringed and that the facility shall encourage and assist in fullest possible exercise of these rights.

resident is to be fully informed, as evidenced by written acknowledgement witnessed by a third party, prior to or at the time of admission and during the stay of these rights and of rules and regulations governing resident conduct and responsibilities. A copy of the law is to be given to the resident. The interests of the resident and, where appropriate, rdians, next of kin, sponsoring agencies, representative payees or the public shall be protected by, but not limited to, the following policies and procedures:

E RIGHT TO INFORMATION ABOUT RIGHTS. Residents shall be told at admission that there are legal rights for their protection during their stay at the facility or throughout ir course of treatment and maintenance in the community and that these are described in an accompanying written statement of the applicable rights and responsibilities set forth in section. In the case of patients admitted to the residential programs as defined in MN Statutes 253C.01, the written document shall also describe the right of a person 16 years old older to request release as provided in section 253B.04, subdivision 2, and shall list the names and telephone numbers of individuals and organizations that provide advocacy and al services for patients in residential programs. Upon receipt of this statement and a full explanation, the resident must acknowledge the receipt in writing. Residents already in the ility must be provided with written amended statements if these provisions are changed. Reasonable accommodations shall be made for those with communication impairments those who speak a language other than English. Current facility policies, inspection findings of state and local health authorities, and further explanation of the written statement rights shall be available to residents, their guardians or their chosen representatives upon reasonable request to the administrator or other designated staff person, consistent with pter 13, the data practices act, and section 626.557, relating to vulnerable adults.

E RIGHT TO COURTEOUS TREATMENT. Residents have the right to be treated with courtesy and respect for their individuality by employees of or persons providing service community residential facility.

E RIGHT TO APPROPRIATE MEDICAL AND PERSONAL CARE. Residents have the right to appropriate medical and personal care based on individual needs. Appropriate e for residents means care designed to enable residents to achieve their highest level of physical and mental functioning. This right is limited where the service is not reimbursable by blic or private resources.

OLATION AND RESTRAINTS. A minor who has been admitted to a residential program as defined in MN Statutes 253C.01 has the right to be free from physical restraint and lation except in emergency situations involving a likelihood that the resident will physically harm self or others. These procedures may not be used for disciplinary purposes, to en- ce program rules, or for the convenience of staff. Isolation or restraint may be used only upon prior authorization of a physician, psychiatrist, or licensed consulting psychologist, y when less restrictive measures are ineffective or not feasible and only for the shortest time necessary.

E RIGHT TO KNOW WHO IS PROVIDING PHYSICIANS' SERVICES. Residents shall have or be given, in writing, the name, business address, telephone number, and ialty, if any, of the physician responsible for coordination of their care. In cases where it is medically inadvisable, as documented by the attending physician in a resident's care ord, the information shall be given to the resident's guardian or other person designated by the resident as his or her representative.

E RIGHT TO KNOW WHO IS PROVIDING SERVICES. Residents who receive services from an outside provider are entitled, upon request, to be told the identity of the pro- er. Residents shall be informed, in writing, of any services which are provided to those residents by individuals, corporations, or organizations other than their facility. Informa- n shall include the name of the outside provider, the address, and a description of the service which may be rendered. In cases where it is medically inadvisable, as documented by attending physician in a resident's care record, the information shall be given to the resident's guardian or other person designated by the resident as his or her representative.

E RIGHT TO INFORMATION ABOUT TREATMENT. Residents shall be given by their physicians complete and current information concerning their diagnosis, treatment, rnatives, risks, and prognosis as required by the physician's legal duty to disclose. This information shall be in terms and language the resident can reasonably be expected to derstand. Residents may be accompanied by a family member or other chosen representative. This information shall include the likely medical or major psychological results of the atment and its alternatives. In cases where it is medically inadvisable, as documented by the attending physician in a resident's medical record, the information shall be given to the ident's guardian or other person designated by the resident as his or her representative. Individuals have the right to refuse this information. Every resident suffering from any form breast cancer shall be fully informed, prior to or at the time of admission and during her stay, of all alternative effective methods of treatment of which the treating physician is owledgeable, including surgical, radiological, or chemotherapeutic or combinations of treatments and the risks associated with each of these methods.

E RIGHT TO PARTICIPATE IN PLANNING ONE'S OWN TREATMENT. Residents shall have the right to participate in the planning of their health care. This right includes opportunity to discuss treatment and alternatives with individual caregivers, the opportunity to request and participate in formal care conferences, and the right to include a family mber or other chosen representative. In the event that the resident cannot be present, a family member or other representative chosen by the resident may be included in such nferences.

REATMENT PLAN. A minor who has been admitted to a residential program as defined in MN Statutes 253C.01 has the right to a written treatment plan that describes in havioral terms the case problems, the precise goals of the plan, and the procedures that will be utilized to minimize the length of time that the minor requires treatment. The plan all also state goals for release to a less restrictive facility and follow-up treatment measures and services, if appropriate. To the degree possible, the minor resident and his or her rents or guardian shall be involved in the development of the treatment and discharge plan.

HE RIGHT TO CONTINUITY OF CARE. Residents shall have the right to be cared for with reasonable regularity and continuity of staff assignments as far as facility policy ows.

HE RIGHT TO REFUSE CARE. Competent residents shall have the right to refuse treatment based on the information required above. Residents who refuse treatment, medica- n, or dietary restrictions shall be informed of the likely medical or major psychological results of the refusal, with documentation in the individual record. In cases where a resident incapable of understanding the circumstances but has not been adjudicated incompetent, or when legal requirements limit the right to refuse treatment, the conditions and cir- mstances shall be fully documented by the attending physician in the resident's medical record.

HE RIGHT TO REFUSE TO PARTICIPATE IN EXPERIMENTAL RESEARCH. Written, informed consent must be obtained prior to a resident's participation in experimental search. Residents have the right to refuse participation. Both consent and refusal shall be documented in the individual care record.

HE RIGHT TO BE FREE FROM ABUSE. Residents shall be free from mental and physical abuse as defined in the Vulnerable Adults Protection Act (Section 626.557, subd. 2d). Abuse" means any act which constitutes assault, sexual exploitation, or criminal sexual conduct as referenced in the Vulnerable Adults Act or the intentional and non-therapeutic fliction of physical pain or injury, or any persistent course of conduct intended to produce mental or emotional distress. Every resident shall also be free from non-therapeutic m'cal and physical restraints, except in two possible situations: 1) as authorized in writing after examination by a resident's physician for a specified and limited period of time, and ly when necessary to protect the resident from self-injury or injury to others; or 2) in fully documented emergencies if necessary to protect the resident from himself or others, if the e is authorized by a professional staff member identified in written policies and procedures as having the authority to do so, and the use is reported promptly to the resident's physi- an by the staff member.

HE RIGHT TO TREATMENT PRIVACY. Residents shall have the right to respectfulness and privacy as it relates to their medical and personal care program. Case discussion, onsultation, examination, and treatment are confidential and shall be conducted discreetly. Privacy shall be respected during toileting, bathing, and other activities of personal ygiene, except as needed for resident safety or assistance.

HE RIGHT TO CONFIDENTIALITY OF RECORDS. Residents shall be assured confidential treatment of their personal and medical records, and may approve or refuse their lease to any individual outside the facility. Residents shall be notified when personal records are requested by any individual outside the facility and may select someone to accom- ny them when the records or information are the subject of a personal interview. Copies of records and written information from the records shall be made available in accordance th this subdivision and the Minnesota statutes governing access to health records [144.335]. This right does not apply to complaint investigations and inspections by the Department Health, where required by third party contracts, or where otherwise provided by law.

HE RIGHT TO KNOW ABOUT SERVICES AVAILABLE. Residents shall be informed, prior to or at the time of admission and during their stay, of services which are included in e facility's basic per diem or daily room rate and that other services are available at additional charge. Facilities shall make every effort to assist residents in obtaining information garding whether the Medicare or Medical Assistance program will pay for any or all of the aforementioned services.

HE RIGHT TO RESPONSIVE SERVICE. Residents shall have the right to a prompt and reasonable response to their questions and requests.

HE RIGHT TO PERSONAL PRIVACY. Residents shall have the right to every consideration of their privacy, individuality, and cultural identity as related to their social, religious, nd psychological well-being. Facility staff shall respect the privacy of a resident's room by knocking on the door and seeking consent before entering, except in an emergency or here clearly inadvisable.

HE RIGHT TO HAVE GRIEVANCES HEARD. Residents shall be encouraged and assisted, throughout their stay in a facility or their course of treatment, to understand and exer- se their rights as residents and citizens. Residents may voice grievances and recommend changes in policies and services to facility staff and others of their choice, free from restraint, nterference, coercion, discrimination, or reprisal, including threat of discharge. Notice of the grievance procedure of the facility or program, as well as addresses and telephone umbers for the Office of Health Facility Complaints and the area nursing home ombudsman pursuant to the Older Americans Act, section 307(a) (12) shall be posted in a con- picuous place. Every residential program as defined in MN Statutes 253C.01, and every facility employing more than two people that provides out-patient mental health services shall ave a written internal grievance procedure that, at a minimum, sets forth the process to be followed; specifies time limits, including time limits for facility response; provides for the esident to have the assistance of an advocate; requires a written response to written grievances; and provides for a timely decision by an impartial decision maker if the grievance is ot otherwise resolved. Compliance by residential programs as defined in MN Statutes 253C.01 with section 144.691 is deemed to be compliance with the requirement for a written in- ernal grievance procedure.

ROTECTION AND ADVOCACY SERVICES. Residents shall have the right of reasonable access at reasonable times to any available rights protection services and advocacy ser- ices so that the resident may receive assistance in understanding, exercising, and protecting the rights described in this section and other law. This right shall include the opportunity or private communication between resident and a representative of the rights protection service or advocacy service.

HE RIGHT TO COMMUNICATE PRIVATELY. Residents may associate and communicate privately with persons of their choice and enter and, except as provided by the Min- esota Commitment Act, leave the facility as they choose. Residents shall have access, at their expense, to writing instruments, stationery, and postage. Personal mail shall be sent ithout interference and received unopened unless medically or programmatically contraindicated and documented by the physician in the medical record. There shall be access to a elephone where residents can make and receive calls as well as speak privately. Facilities which are unable to provide a private area shall make reasonable arrangements to accom- nodate the privacy of resident's calls. This right is limited where medically inadvisable, as documented by the attending physician in a resident's care record. Where programmatically mited by a facility abuse prevention plan pursuant to Section 626.557, subd. 14, clause 2, this right shall also be limited accordingly.

HE RIGHT TO HAVE AND USE PERSONAL PROPERTY. Residents may retain and use their personal clothing and possessions as space permits, unless to do so would infringe pon rights of other residents, and unless medically or programmatically contraindicated for documented medical, safety or programmatic reasons. The facility must either maintain central locked depository or provide individual locked storage areas in which residents may store their valuables for safekeeping. The facility may, but is not required to, provide ompensation for or replacement of lost or stolen items.

HE RIGHT NOT TO PERFORM SERVICES FOR THE FACILITY. Residents shall not perform labor or services for the facility unless those activities are included for therapeutic urposes and appropriately goal-related in their individual medical record.

HE RIGHT TO CHOOSE A SUPPLIER. A resident may purchase or rent goods or services not included in the per diem rate from a supplier of his or her choice unless otherwise rovided by law. The supplier shall insure that these purchases are sufficient to meet the medical or treatment needs of the patient.

HE RIGHT TO MANAGE FINANCIAL AFFAIRS. Competent residents may manage their personal financial affairs, or shall be given at least a quarterly accounting of financial ransactions on their behalf if they delegate this responsibility in accordance with the laws of Minnesota to the facility for any period of time.

HE RIGHT TO ASSOCIATE. Residents may meet with visitors and participate in activities of commercial, religious, political (as defined by the Minnesota statutes regarding voting hile residing in a community residential facility [203B.11]) and community groups without interference at their discretion if the activities do not infringe on the right to privacy of ther residents or are not programmatically contraindicated and documented in the resident's record. This includes the right to join with other individuals within and outside the acility to work for improvements in long term care.

HE RIGHT TO AN ADVISORY COUNCIL. Residents and their families shall have the right to organize, maintain, and participate in resident advisory and family councils. Each acility shall provide assistance and space for meetings. Council meetings shall be afforded privacy, with staff or visitors attending only upon the council's invitation. A staff person hall be designated the responsibility of providing this assistance and responding to written requests which result from council meetings. Resident and family councils shall be en- ouraged to make recommendations regarding facility policies.

HE RIGHTS OF MARRIED RESIDENTS. Residents, if married, shall be assured privacy for visits by their spouses and, if both spouses are residents of the facility, they shall be ermitted to share a room, unless medically contraindicated and documented by their physicians in the medical records.

HE RIGHTS OF TRANSFERS AND DISCHARGES. Residents shall not be arbitrarily transferred or discharged. Residents must be notified, in writing, of the proposed discharge or transfer and its justification no later than 30 days before discharge from the facility and seven days before transfer to another room within the facility. This notice shall include the esident's right to contest the proposed action, with the address and telephone number of the area nursing home ombudsman pursuant to the Older Americans Act [Section 307(a) 12)]. The resident, informed of this right, may choose to relocate before the notice period ends. The notice period may be shortened in situations outside of the facility's control, such s determination by utilization review, the accommodation of newly admitted residents, a change in the resident's medical or treatment program, the resident's own or another resi- ent's welfare, or nonpayment for stay unless prohibited by the public program or programs paying for the resident's care, as documented in the medical record. Facilities shall make reasonable effort to accommodate new residents without disrupting room assignments.

HE RIGHT TO KNOW THE RULES. Every resident shall be fully informed, prior to or at the time of admission and during the stay at a facility, of the rights and responsibilities et forth in this section of all rules governing resident conduct and responsibilities.

- Compliance with this Bill of Rights shall not be required whenever emergency conditions, as documented by the attending physician in a resident's care record, indicate that im- mediate medical treatment, including but not limited to surgical procedures, is necessary and it is impossible or impractical to comply because delay would endanger the resident's life, health or safety.

- A complaint regarding violations of any resident's right enumerated herein, or any statute or regulation, may be filed by contacting the Office of Health Facility Complaints. This office may be contacted at: Minnesota Department of Health, 717 S.E. Delaware Street, Minneapolis, Minnesota 55440; telephone (612) 623-5562.

- Inquiries by residents about medical care may be directed to the State Board of Medical Examiners, Room 352, 717 S.E. Delaware Street, Minneapolis, Minnesota 55440; telephone (612) 623-5534.

- Within the facility contact: _____

I hereby acknowledge receipt of a copy of this Residents' Bill of Rights and have been fully informed of such policies and rights.

Date: _____

_____
Signature of Resident

_____
Signature of Guardian or Conservator

Distributed by the Association of Residential Resources in Minnesota, 1885 University Avenue, St. Paul, Minnesota 55104

DISABLED PEOPLES' BILL OF RIGHTS

(American Coalition Citizens with Disabilities, 1979)

PREAMBLE

We believe that all people, disabled or not, should enjoy certain rights. Because people with disabilities have consistently been denied the right to fully participate in society as free and equal members, it is important to enumerate and affirm these rights, and to strive toward them daily. All people should be able to enjoy these rights, regardless of race, creed, color, sex, religion, or disabilities.

1. The right to live independent, active, and full lives.
2. The right to the equipment, assistance, and support services necessary for full productivity, provided in a way that promotes dignity and independence.
3. The right to an adequate income or wage, substantial enough to provide food, clothing, shelter, and other necessities of life.
4. The right to accessible, integrated, and convenient affordable housing.
5. The right to quality physical and mental health care.
6. The right to training and employment without prejudice or stereotypes.
7. The right to accessible transportation and freedom of movement.
8. The right to have children and a family.
9. The right to a free and appropriate public education.
10. The right to participate in and benefit from entertainment and recreation.
11. The right of equal access to and use of all businesses, facilities and activities in the community.
12. The right to communicate freely with all fellow citizens and those who provide services.
13. The right to a barrier free environment.
14. The right to legal representation and full protection of all legal rights.
15. The right to determine one's own future and make one's own life choices.
16. The right of access to all voting processes.

MINNESOTA VULNERABLE ADULTS ACT

Minnesota now has a law that requires all people in licensed occupations, and others, to report the abuse and neglect of a group of citizens known as vulnerable adults. Volunteers serving in the *PERSON TO PERSON* capacity are mandated to report abuse or neglect.

These people include the mentally or physically impaired, the elderly, or other adult persons who cannot protect themselves if abused or neglected by those who are supposed to care for them. They are the vulnerable adults who could be abused by those with whom they come into contact anywhere, anytime. All Minnesota citizens can report such abuse. You don't need a license to do that.

VULNERABLE ADULTS ARE:

Persons age 18 or older

- who live in licensed facilities such as nursing homes, hospitals, treatment centers for chemical dependency, mental retardation, mental illness or physical disabilities OR
- who receive services from licensed facilities such as developmental achievement centers or home health agencies OR
- who are in family settings and would not by themselves report abuse or neglect to them because of impaired physical or mental function, or because of emotional status.

ABUSE IS:

- *Physical abuse* — conduct that produces pain or injury and is not accidental
- *Verbal abuse* — repeated conduct that produces mental or emotional stress
- *Sexual abuse* — violation of criminal sexual conduct or prostitution statutes
- *Exploitation* — illegal use of a vulnerable adult's person or property through undue influence, duress, deception or fraud

NEGLECT IS:

- *Caretaker neglect* — failure of caretaker to provide necessary food, clothing, shelter, health care, or supervision
- *Self neglect* — absence of necessary food, clothing, shelter, health care or supervision

- *Exploitation thru neglect* — absence of necessary financial management, that might lead to exploitation

REPORTING YOUR CONCERNS:

All facilities have reporting forms on-site. Your supervisor will assist in the discussion and completion of a form or you can document the incident by recording:

what happened	where it happened
to whom it happened	who did the abuse
when it happened	who was responsible for the neglect

The volunteer and supervisor can make the report to the local county social services agency, law enforcement authorities, or the Minnesota Department of Human Services Adult Services Unit.

After you report, a process of investigation and protection will begin right away for the vulnerable adult.

REMEMBER: You are required by law to report abuse or neglect.

THE PRINCIPLE OF NORMALIZATION

One may define the ideological goal of the human services in terms of the principle of normalization. This principle can be stated as follows:

> The use of methods and settings which are valued and familiar, to offer each person life conditions and opportunities which are at least as good as those of the average citizen, and as much as possible to enhance and support each person's behavior, status and reputation. (Wolfensberger, 1972)

The principle of normalization implies that every person should have a home. Too often human service systems ask people to live in impersonal institutions or in community facilities which are distinctly unhome-like. Every person should be able to live in a comfortable setting which looks like, feels like, and is a valued home in the community. As much as possible, each person should be able to choose with whom to live, and as much as possible each person should be able to control the conditions of the home environment. Every person should be able to individualize his/her home setting so that the home becomes truly their own.

The principle of normalization implies that adults should be treated as adults. Too often human service systems teach adults to act like children, out of well-meaning but misguided attempts to make life easier for groups who are faced with difficulties. As the people learned to act as they were taught, like children, a vicious cycle was established. It is our responsibility to change this pattern and deal with people on a basis of respect by treating adults as adults, and by helping the people with whom we work to see themselves in an age-appropriate light. Every adult should be encouraged to acquire mature possessions, to build a mature home environment, and to engage in mature activities to the greatest extent possible.

The principle of normalization implies that every person should be challenged and should be enabled to learn. Too often human service systems have held low expectations for people, thus placing a low limit on the learning which could take place. Every person should have a strong, intensive, individualized learning program which will enable that person to gain more and more skills for more and more independence. Every person should be able to make her/his own choices as often as possible, even to take risks in decision making. Instead of providing maximum shelter and protection for a person, we need to encourage growth and development by providing challenges to learning. The principle of normalization implies that every person should be enabled to participate in the main stream of community life as much as possible. Too often human service systems have isolated people from the rest of society, removing opportunities for learning which would exist among the service consumers and among typical people as well.

Integration into the community will provide models for people who need to learn more social skills, and it will provide a chance for people in general to learn that service consumers are more like other people than different from other people. Every person should be enabled to participate individually or in small groups in all the resources of our society.

To sum up, the essence of the principle of normalization is equality: every person should have the right to equality of opportunity, to share equally in the benefits and difficulties of life in the human community. In our personal interactions and decisions as human service workers, and in our design of programmatic and systemic structures for service provision, we need to plan, act, and teach on that basis.

— Jack Yates

NORMALIZATION

Normalization means . . . A normal rhythm of the day.
You get out of bed in the morning, even if you are
Profoundly retarded and physically handicapped;
You get dressed,
And leave the house for school or work,
You don't stay home;
In the morning you anticipate events,
In the evening you think back on what you have accomplished:
The day is not a monotonous 24 hours with every minute endless.
You eat at normal times of the day and in a normal fashion;
Not just with a spoon, unless you are an infant;
Not in bed, but at a table;
Not early in the afternoon for the convenience of the staff.

Normalization means . . . A normal rhythm of the week.
You live in one place,
Go to work in another,
And participate in leisure activities in yet another.
You anticipate leisure activities on weekends,
and look forward to getting back to school
Or work on Monday.

Normalization means . . . A normal rhythm of the year.
A vacation to break routines of the year.
Seasonal changes bring with them a variety
Of types of food, work, cultural events, sports,
Leisure activities.
Just think . . . We thrive on these seasonal changes!

Normalization means . . . Normal developmental experiences
Of the life cycle:
In childhood, children, but not adults go to summer camps.
In adolescence one is interested in grooming, hairstyles,
Music, boy friends and girl friends.
In adulthood, life is filled with work and responsibilities.
In old age, one had memories to look back on, and can
Enjoy the wisdom of experience.

Normalization means . . . Having a range of choices,
Wishes, and desires respected and considered.

Adults have the freedom to decide
Where they would like to live,
What kind of job they would like to have, and can be best performed.
Whether they would prefer to go bowling with a group,
Instead of staying home to watch television.

Normalization means . . . Living in a world made of two sexes.
Children and adults both develop relationships with
Members of the opposite sex.
Teenagers become interested in having
Boy friends and girl friends.
Adults may fall in love, and decide to marry.

Normalization means . . . The right to normal economic standards.
All of us have basic financial privileges, and responsibility,
Are able to take advantage of
compensatory economic security means,
Such as child allowances, old age pensions, and
Minimum wage regulations.
We should have money to decide how to spend;
On personal luxuries, or necessities.

Normalization means . . . Living in normal housing
In a normal neighborhood.
Not in a large facility with 20, 50, or 100 other people
Because you are retarded,
and not isolated from the rest of the community.
Normal locations and normal size homes will give residents
Better opportunities for successful integration
With their communities.

— Bengt Nirje

COMMON MISUNDERSTANDINGS ABOUT NORMALIZATION

Understanding of normalization has suffered in recent years, due to a variety of misleading statements which have been proposed to define or explain it.

FALSE CLAIMS	CLARIFICATION
"NORMALIZATION MEANS MAKING PEOPLE 'NORMAL'."	Normalization does mean that people can often acquire more appropriate behavior and appearances through positive expectations and supporting environments and techniques. However, the principle does not claim to eliminate differences nor to "cure" handicaps. It is therefore applicable to all people, regardless of the severity or performance of their conditions.
"NORMALIZATION MEANS TREATING PEOPLE AS IF THEY WERE NOT HANDICAPPED, FOR EXAMPLE, BY EXPOSING THEM TO TOTAL INTEGRATION WITHOUT SUPPORTIVE SERVICES."	Normalization does not mean dumping people into society without the specialized forms of help they require. It does, however, constantly challenge us to find ways to provide the assistance at times and in settings where valued people are and with procedures which are as typical as possible.
"NORMALIZATION DENIES PEOPLE THE RIGHT TO BE DIFFERENT OR INDIVIDUALISTIC." OR (just the opposite) "NORMALIZATION MEANS THAT ANY BEHAVIOR, APPEARANCE, OR ACTIVITY IS ACCEPTABLE BECAUSE FREE CHOICE AND INDIVIDUAL DIFFERENCES ARE NORMAL."	Normalization requires that service programs and personal interactions enable and actively encourage people to have behaviors, characteristics, and experiences which are considered familiar or valued in our society. The forms of normative influence which may be used and the normative options which may be selected are diverse and allow for choice and individuality. Furthermore, normalization does not deny a person the right to choose a non-normative option, provided the alternatives and consequences are real and clearly recognized.

"NORMALIZATION MEANS MAKING THINGS 'NICE' FOR HANDICAPPED PEOPLE." OR "SEGREGATED SERVICES ARE ACCEPTABLE IF THEY ARE LIKE SIMILAR SERVICES FOR NON-DISABLED PEOPLE."	The primary focus of normalization is on creating social change — on increasing the physical presence and valued participation of handicapped people within the community. Well-meaning attempts to simulate the real world — even its most positive aspects — are consistent with the spirit of the principle.
"NORMALIZATION IS AN IMPRACTICAL IDEAL."	It is impossible to make progress towards a goal without clearly and systematically defining that goal and the means to reach it. Undoubtedly, normalization as an ideal at times will be in tension with "reality," but it is important that compromises which must be made be clearly recognized as such.
"NORMALIZATION IS COMMON SENSE, NEW." OR "NORMALIZATION IS THE SAME AS DEINSTITUTIONALIZATION, COMMUNITY SERVICES, MAINSTREAMING...WE'RE ALREADY DOING IT."	Any serious study of the implications of normalization would reveal that our society and our helping services have much to accomplish in order to carry out normalization. Concepts such as "deinstitutionalization," "community services," and "mainstreaming" focus on one service type, location, or technique without specifying the desired quality of life which is the goal. As a result, these concepts are often implemented in ways which are totally inconsistent with normalization.

By: Terri Johnson
Wisconsin Coalition for
Advocacy

MISSING THE MARK: NORMALIZATION AS TECHNOLOGY

William T. McCord and Wayne Marshall

The normalization principle was formulated in an attempt to teach society how to serve persons with mental retardation in ways that are meaningful, beneficial, and life-enhancing. Through misunderstanding and misinterpretation, sometimes unintentional and sometimes deliberate, the essence of the principle has faded and only the exterior trappings remain, a loss which is detrimental both to persons with mental retardation and to the people who serve them. For purposes of clarity, the word *normalization* is used throughout this article. The term *social role valorization* is being suggested by Wolfensberger as an alternative or replacement.

Although the following vignettes have attracted almost no attention in human service circles, they contain elements, from conception through implementation, of the true essence of normalization and, therefore, of the true essence of service to persons with mental retardation.

Susan, age 5, profoundly retarded and considered to be medically fragile, had lived most of her short life as an institutionalized ward of the state. Serious respiratory illness had almost claimed the life of this child, who was without family or friends. The social workers, physicians, nurses, attendants, and others who were involved with Susan at the time were shocked that a family would be sought for a child whom they expected to die after the onset of the next respiratory problem. They were skeptical that a family could be found to take Susan into their home, and were convinced that, in any case, Susan would not survive the change in environment.

For the past year, Susan has been the youngest daughter of a middle class couple and the sister of their four natural children. Susan has gained in weight and height, has had no respiratory difficulties, and most important of all, has become the center of attention among her new family members. Her fifth birthday was celebrated at home among a gathering of grandparents, parents, brothers, sisters, aunts, uncles, and cousins, all of whom joined together ho help her blow out the candles on a brightly decorated Smurf cake. This abandoned and rejected child now has a place of honor among people who cherish her presence.

Nancy, an 18-year-old girl, traveled a path similar to Susan's before she found a family who would love and care for her. Nancy spent most of her teenage years on a locked institutional ward for behavioral problems. Nancy learned to respond to the violence around her by lashing out at others and inflicting serious self-injury. She had no family, no visitors, and seemingly no person in the institution who had

a kind word to say about her. When people approached her without warning, she would quickly raise her hands to defend herself from anticipated violence. Institutional staff reported that she was becoming increasingly violent toward herself and others.

Nancy now lives with a family in Louisville. She proudly introduces visitors to her mother, father, three sisters, and especially to her three-year-old nephew and the family dog. The violent manifestations of her horrible life have ceased after two years of love, understanding, and tenacity on the part of her family. Nancy no longer mutilates herself. Instead, she takes pride in her appearance, particularly her newly styled hairdo which she is quick to point out is just like her sisters'. Nancy has become a delightful young woman with a winning smile and a host of family and friends who care about her. She is occasionally on the brink of violence, but her foster mother now recognizes its onset and can easily calm her. Nancy's family has given to her the sense of security and belonging which has broken the cycle of violence which defined her existence.

Mary, Joan, and Margaret spent 30 years living together in an institutional ward for persons functioning in the mild range of mental retardation. Deinstitutionalization separated the three women, with Mary and Joan each ending up in a minimally supervised apartment and Margaret living a marginal existence in an inner city institution euphemistically called a personal care home. A worker at a local agency knew the three women from their institutional past, recalled the strong bonds of friendship which linked them, and was instrumental in developing a group home for the three women. Mary, Joan and Margaret, now in their 50's, have been reunited and are sharing their lives with a live-in house manager and house assistants. Their rekindled friendship has been a source of joy and excitement to people associated with the house, including an increasing number of interested neighbors.

What has been learned from the changes in the lives of each of these five persons with mental retardation? To everyone's astonishment, as almost overnight improvement can occur in the physical and emotional well-being of people who live in loving and nurturing environments. Susan enjoyed an immediate improvement in her health. Nancy learned to control her anger. Mary, Joan and Margaret once again found a reason to be interested in what life has to offer. But the most significant lesson learned, one not anticipated when the placements were made, was that these types of personal relationships can become reciprocal. People with mental retardation can give as much as they receive.

Susan's new mother told us that her presence has brought the family closer together because the care she needs and the improvements she makes give each of them something purposeful on which to focus their attention. Nancy's new parents can talk for hours about the joy she has given to the family. They are sure

that Nancy's outgoing, nobody-is-a-stranger approach to life has helped to broaden the personality of their painfully shy 18-year-old daughter. As Nancy's mother explains, "When you go for a walk with Nancy around the block, she makes sure that you meet everyone who happens to pass." Mary, Joan and Margaret have become the three wise women of the home. Sitting together over morning coffee, the youthful live-in house manager and the house assistant listen with respect and admiration as the three older women recount stories about rising each morning at 3:00 A.M. and working until sunset milking cows and tending to other farm chores which were a part of their institutional workday.

These five persons with mental retardation have enhanced the lives of the persons with whom they live, just as their own lives have been enhanced. Their stories are being replicated by other persons with mental retardation, not only in Louisville but in other towns, cities, and states across North America. Unfortunately, the complex technological approach to service provision so common in this age trivializes and masks the significance to persons with mental retardation of these and other incidents. Furthermore, the relationships usually develop despite the service system, not because of it, because the service system teaches its workers that these events, albeit nice, are relatively insignificant.

COLLATERAL ORGANIZATIONS

PURPOSE (10 min.) To introduce volunteers to the variety of agencies/organizations that impact the lives of people with developmental disabilities.

METHOD Trainer Led Discussion

MATERIALS Handout *Collateral Organizations*

DISCUSSION Distribute the handout *Collateral Organizations*. Briefly describe each of the agencies, answer questions and encourage use of available resources, especially the library of the Council on Developmental Disabilities and multiple resources at the Association for Retarded Citizens (ARC).

COLLATERAL ORGANIZATIONS

The DEPARTMENT OF HUMAN SERVICES, in partnership with the Federal Government, county, and other public, private, and community agencies throughout Minnesota, is a state agency directed by law to assist those citizens whose personal or family resources are not adequate to meet their basic human needs. It is committed to help them attain the maximum degree of self-sufficiency consistent with their individual capabilities. To these ends, the Department will promote the dignity, safety, and rights of the individual, and will assure public accountability and trust through responsible use of resources.

The MINNESOTA GOVERNOR'S PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES represents a broadly based approach to planning and promoting better coordination of services for persons with developmental disabilities. The overall mission is to enable persons with developmental disabilities to increase their independence, productivity, and integration into the community.

LEGAL ADVOCACY FOR DEVELOPMENTALLY DISABLED PERSONS IN MINNESOTA (DDA Project) has been designated by the Governor of Minnesota as the protection and advocacy agency for the state. The Project staff concentrate on direct representation of persons who have developmental disabilities, legislative and administrative advocacy, and consumer and professional education and training. A major focus of the Project activity at present is to assure the availability of quality community-based services for people who have developmental disabilities.

The OFFICE OF OMBUDSMAN FOR MENTAL HEALTH AND MENTAL RETARDATION is an independent and autonomous state agency. The Office reviews and investigates complaints in an objective, impartial manner. The Office can investigate complaints from any source concerning the actions of an agency, facility, or program that provides services or treatment for mental illness, mental retardation, chemical dependency, or emotional disturbance. These complaints may deal with individual client complaints or complaints of a more general or systemic nature.

The ASSOCIATION FOR RETARDED CITIZENS (ARC) is a national voluntary movement. Its aims are to ensure full participation in society by people with mental retardation through promoting a system of support and self sufficiency and advocating for people's rights. In Minnesota, there is a statewide ARC as well as 58 county units providing services. Minnesota was the birthplace of the ARC movement in the early 1950's and remains a leader in ARC programs and services to people with mental retardation and their families.

COUNTY SOCIAL SERVICES is the county agency providing funding and support services for people with developmental disabilities. The CASE MANAGER coordinates the individualized arrangements including the determination of need for a volunteer friend. The case manager is a county social worker who has been assigned to work with people with developmental disabilities and their families to obtain services that are individualized and connect them to their communities.

QUALITY OF LIFE

PURPOSE
(20 min)

To define and understand Quality of Life issues.

METHOD

Full group discussion
Overhead and Transparencies

MATERIALS

Newsprint or Transparency listing topic for consideration
Overhead Projector and Screen
Transparencies for Quality of Life issues
Handout *Quality of Life*
(same information as on transparency)

INTRO

Each of us is concerned about the quality of our life. Is it satisfying, does it have value, does it build our self-esteem and add to our individual dignity?

GENERAL DISCUSSION

Quality of life is concerned with the appropriateness and the quality of care, programs, services, living conditions, and relationships. It is concerned with how the individual experiences and perceives his/her day-to-day existence in a facility or program.

It has to do with the capacity of that facility and/or program to enhance or impair the individual's performance and what it may do to strengthen or weaken self-esteem, dignity and other human rights.

It is related to the human and humane processes involved in normal human functioning — including human rights and freedom.

Ask the group "How do you measure your quality of life? What factors are important to you?" Areas to encourage considering:

Home
Work
Education and Personal Growth
Community Service
Personal Relationships

Rights
Decision Making

Distribute Handout on *Quality of Life* and/or use transparencies to reinforce the discussion.

Close discussion stressing that the same opportunities, experiences and activities that determine our quality of life also contribute to the quality of life for persons with disabilities. It is part of the volunteer's responsibility as a friend to maintain and enhance the lifestyle of a *PERSON TO PERSON* client. As volunteer friends, the right to equal opportunities, life-enhancing experiences and meaningful activities must be of primary importance for our clients.

CATEGORIES OF CURRENT CRITERIA QUALITY OF LIFE

Adapted from:
Minnesota Governor's Planning Council
on Developmental Disabilities

AGE/ABILITY-APPROPRIATE

1. Activities/tasks would be appropriate for non-disabled peers.

2. Staff models appropriate adult behaviors (address people as adults, use age appropriate reinforcers).

3. Decorations and materials are appropriate for non-disabled peers.

4. Schedule and routine are based on schedule of adults who are not disabled.

5. Goals are reasonable and obtainable.

6. Personal preferences and choices are recognized and respected.

7. "Partial Participation" is encouraged (gets bread out to make a sandwich).

PRODUCTIVITY

MEASURES:

1. Number of hours worked by week/month/year
2. Wages (hourly/piece rate)
3. Changes in wages over time
4. Length of time on job
5. Income covers his/her living needs

INDEPENDENCE

MEASURES:

1. Services are as least intrusive as possible

2. Reduction in need for services over time

3. Reduction in cost of specialized support or training

4. Activities lead to personal growth, development, and personal satisfaction

5. A means of communication exists to allow daily interaction with primary people (speech, signings, adaptive devices)

6. A means of mobility exists to move about home and community environments

FUNCTIONAL

MEASURES:

1. Tasks and activities are relevant to daily life and use real materials.

2. People are taught how to spend their money, how to prepare food, clean house, shop, and skills to live on own.

3. People have to learn to make decisions.

INTEGRATION

MEASURES:

1. Amount of time spent in integrated settings.

2. Use of generic resources (transportation, parks, recreation, library).

3. Number of interactions with non-handicapped peers — there are opportunities to have interactions with non-handicapped peers.

4. Number of people with disabilities is less than 3% of total people in a setting (such as a work force).

5. Opportunities for friendships with non-paid, non-disabled peers.

6. Support occurs in heterogenous groupings.

COMMUNITY REFERENCED

1. Skills must be taught in a variety of environments because generalizability can be zero from one environment to the next.

2. Activities and training occur in natural environments (at a minimum in community living, supported employment, and recreation/leisure).

CHOICE AND DECISION MAKING

1. Participation in decisions about use of personal income.

2. Participation in decisions about home, choice of location, furnishings, and decor.

3. Lifestyle choices encourage wellness — nutrition, weight, smoking, stress relief, emotional support, and appearance.

4. Participation in decisions that affect day to day living.

QUALITY OF LIFE

The Minnesota Governor's Planning Council on Developmental Disabilities offers the following guidelines when evaluating the quality of life received through the service delivery system. Services must promote:

Age/Ability-Appropriateness

- Activities/tasks would be appropriate for non-disabled peers.
- Staff model appropriate adult behaviors (address people as adults, use age appropriate reinforcers).
- Decorations and materials are appropriate for non-disabled peers.
- Schedule and routine are based on schedule of adults who are not disabled.
- Goals that are reasonable and obtainable.
- Personal preferences and choices are recognized and respected.
- Partial participation is encouraged (gets bread out to make a sandwich).

Productivity

- Activities are meaningful and functional
- Number of hours worked by week/month/year
- Wages (hourly/piece rate)
- Changes in wages over time
- Length of time on job
- Income covers his/her living needs

Independence

- Services are as least intrusive as possible
- Reduction in need for services over time
- Reduction in cost of specialized support or training
- Activities lead to personal growth, development, and personal satisfaction
- A means of communication exists to allow daily interaction with primary people (speech, signings, adaptive devices)
- A means of mobility exists to move about home and community environments

Functional Activities

- Tasks and activities are relevant to daily life and use real materials
- People are taught how to spend their money, how to prepare food, clean house, shop and other skills to live on their own.
- People have to learn to make decisions.

Integration

- Amount of time spent in integrated settings.
- Use of generic resources (transportation, parks, recreation, Adult Education, library).
- Number of interactions with non-handicapped peers — there are opportunities to have interactions with non-handicapped peers.
- Number of people with disabilities is less than 3% of total people in a setting (such as work force).
- Opportunities for friendships with non-paid, non-disabled peers.
- Support occurs in heterogenous groupings.

Learning in Natural Environments

- Skills must be taught in a variety of environments because of limited ability to generalize from one environment to the next.
- Activities and training occur in natural environments (at a minimum in community living, supported employment, and recreation/leisure).

Choice and Decision Making

- Participation in decisions about use of personal income.
- Participation in decisions about home, choice of location, furnishings, and decor.
- Lifestyle choices encourage wellness — nutrition, weight, smoking, stress relief, emotional support, and appearance.
- Participation in decisions that affect day to day living.

ADVOCACY

PURPOSE (20 MIN.)

To define advocacy

To explain what an advocate does

To compare advocacy and monitoring

METHOD

Brainstorm

Discussion

MATERIALS

Brainstorm Rules (see Tips for Trainers)

Three (3) sheets of newsprint each having one advocacy question listed on it (see questions below)

Paper and Pencils for Participants

Partnership for Quality Services Brochure (available from ARC in local communities)

BRAINSTORM

Advocacy is a commonly used word in our society. It has many different meanings and people use the word in a variety of ways.

Ask the group to brainstorm meanings of advocacy. Post the following questions — each one on a separate sheet of newsprint.

What is advocacy?
Who is an advocate?
Why does someone advocate?

Ask the group to brainstorm one question at a time. Go over rules of brainstorming. If you use the Brainstorm Technique frequently, it's a good idea to post the rules on newsprint and/or have a handout on brainstorm rules. Tell the group to select a person to record all ideas generated.

Give the group 10 minutes to brainstorm. Move them along after each 3 minute period. After 10 minutes, shorter time if there is a prolonged break in idea generating, bring groups

together to share ideas. If there has been only one group, wait until the brainstorming is complete then discuss responses.

Different groups will present a variety of points of view. Note the common themes on newsprint by each question. Responses may include: By the question "What is advocacy?" your notes may be "speaking up for someone or something; helping; going to court; support; defender." By the question "Who is an advocate?' you may write "parent; friend; lawyer; student; self" or the response may be more general "anyone who represents his or her own or another persons interests." And by "Why does someone advocate?: responses might be "to help; to protect rights; to foster change."

The one-to-one relationship you will be establishing enables you to notice the needs of your friend — whether it be the need for a clean shirt or a way out of isolation. As an advocate you can help bring your friend's needs to the attention of a staff person or a member of the management team.

It is so important to ADVOCATE, not alienate. It is appropriate to make suggestions for your friend's well-being and to do it with courtesy and respect. Maintaining a good rapport with staff, being a part of the team working for the benefit of your friend, will make it easy to communicate his/her needs.

Advocacy is a pro-active activity. Good advocacy is purposeful, intelligent and specific. Consider needs, advantages to be gained, possible methods, and then commit to follow the issue to solution, even if it may not be the one you originally sought. Remember, your advocacy is for the good of your friend, not personal and not biased or unrealistic.

DISCUSSION

Another concept sometimes closely associated with advocacy is that of *monitoring*.

ARC Minnesota has a volunteer monitoring project entitled *PARTNERSHIP FOR QUALITY SERVICES* (PQS). PQS activates community volunteers to visit and evaluate programs

for persons with developmental disabilities. Volunteer monitors are trained to make evaluations based upon specific "quality of life" indicators. As part of a volunteer, client, provider team, volunteers visit one residential, vocational or educational facility 3-4 times over the course of one year. They confer with service providers to discuss their findings and receive feedback.

PARTNERSHIP FOR QUALITY SERVICES and *PERSON TO PERSON* are both projects that provide volunteer opportunities to impact the lifestyles of people with developmental disabilities as they become actively involved in our communities.

VOLUNTEER RESPONSIBILITIES

PURPOSE
(15 min)

To understand the responsibilities of being a *PERSON TO PERSON* volunteer

METHOD

Brainstorm
Trainer led group discussion

MATERIALS

Easel, Newsprint, Markers
Rules of Brainstorming

BRAINSTORM

Divide the group into small groups of 5 or 6 people. Instruct them to brainstorm "responsibilities of a *PERSON TO PERSON* volunteer." Go over the rules of brainstorming (see Tips for Trainers). Have each group select a recorder to write each idea. Give the participants 6 minutes to complete the brainstorming. Share the information by calling for ONE response from each group. Continue round robin until there are no new responsibilities to share.

BE SURE THE FOLLOWING ITEMS ARE INCLUDED:

GATHER INFORMATION ABOUT CLIENT

General nature of the disability
Special needs
Behavior problems
Strengths of client

It is important to have enough accurate information about your client so that expectations of him or her, of the relationship, and of possibilities are realistic. If questions arise, consult with the staff person who is closest to your client.

CONFIDENTIALITY

All personal information should be treated as confidential.

DEPENDABILITY

In order to build a trusting relationship, you must be dependable. The client, staff, your supervisor, all must

know that if you are expected on a particular day at a specified time you will be there. If you say you will do something, it will be done.

FINANCIAL OBLIGATION

1. Volunteer pays portion of expenses incurred in an activity.
2. Client should pay own way.
3. Volunteer may want to treat on occasion.
4. Each relationship will differ and judgement should be used.

LEGAL OBLIGATIONS

Exercise reasonable care, consider safety in all activities, operate automobile safely.

TO END THE RELATIONSHIP

Notify supervisor and/or volunteer services coordinator as far in advance as possible so the transition can be smooth. Never terminate a relationship through the mail, by stopping visits without an explanation or by any impersonal approach.

CONTACT WITH STAFF

Your responsibility is to have a good working relationship with a facility staff person who serves as your supervisor and a professional for your client. Your contact may be more frequent initially as your relationship with your client begins and there is greater need for staff support. As you gain experience and confidence, the contact may become less frequent.

The chances are good that you are going to experience some feelings and emotions that may surprise you. From elation over a small accomplishment to feeling low over a lack of response, it is important to communicate those feelings. You may be amazed by how many others are feeling the same. If the program coordinator has not specified a "get together" time after your first and/or second meeting with your client, ask that it be done. Speaking with other volunteers in the program

will also help to validate and work through your feelings.

When you need help for any reason, seek it from the supervisor, the volunteer services coordinator, or the case manager.

RECORDKEEPING

It is hard to predict when a record of volunteer experience will be important. There are many ways in which the information can be used for the benefit of the volunteer, for tax deduction information, for reference purposes, for monitoring performance. Training, service hours, and evaluation provide relevant information when writing resumes.

If a problem or concern arises, documentation is a necessity. Evaluation of the *PERSON TO PERSON* Program cannot be accomplished without the statistical documentation of volunteer service which you will provide.

In the training session, all record forms will be discussed and any questions answered. You will be ready to use the forms when you schedule your first meeting with your client.

The *PERSON TO PERSON* friend is a volunteer to a person who has developmental disabilities. If there is a conflict, your loyalty should be with the client. Communication lines should always be kept open with program and facility staff to quickly solve any problem situations as a team.

PERSON TO PERSON
VOLUNTEER RESPONSIBILITIES

In addition to the duties listed on the job description for which you are responsible, there are a few responsibilities that are significant for *PERSON TO PERSON* volunteers. They are listed here for easy reference.

1. Gather information about client.
   - General Nature of Disability
   - Special Needs
   - Strengths
   - Behavior Problems
2. All personal information should be treated as CONFIDENTIAL.
3. In order to build a trusting relationship, you must be DEPENDABLE.
4. Your financial obligation will be to pay for your expenses for any activities you engage in.
5. Consider safety in all activities. Operate an automobile safely.
6. If there is a need to end the relationship, for any reason, notify the supervisor and/or the volunteer services coordinator as far in advance as possible.
7. A good working relationship with the staff in a residence, with the case manager and other professionals is your responsibility — stay in contact.
8. Use the forms provided to keep good records for the program and its future, as well as for your personal use.

PRINCIPLES OF VOLUNTEERING

Volunteer work is done within an organization of people, organized with a plan and a purpose.

It enables volunteers to give service to others in an organized way, but it also demands of volunteers acceptance of teammates and adjustment to an organizational framework.

It allows volunteers the privilege of representing the agency/facility, but it also demands loyalty to the agency/facility and a clear understanding of its purposes.

It offers volunteers training, supervision, and recognition, but it also demands commitment to the work and an inner discipline that holds the volunteer faithful to that commitment.

It gives to volunteers an opportunity for growth, but it also demands the best a volunteer has to give at all times.

It endows volunteers with responsibility for others, but is also demands that volunteers hold themselves responsible to others.

VOLUNTEER LIABILITY

PURPOSE (10 min.)

To respond to concerns about liability issues and volunteers

METHOD

Trainer led group discussion

MATERIALS

Handout *Volunteer Liability*

DISCUSSION

Distribute Handout *Volunteer Liability*. Without reading the handout to the participants, emphasize the information that describes the legal definition of the term "volunteer" and the way in which that impacts agency/volunteer working relationship.

Draw attention to Minnesota Statute 317.201 and 466.07. Explain both statute sections and respond to questions about them.

If liability questions arise for which you have no answer, tell the volunteers that you will get the answer for them the next time you meet — BE SURE TO FOLLOW THROUGH.

VOLUNTEER LIABILITY

Volunteers are "covered" under two sections of the Minnesota Statutes for actions they perform. **Minnesota Statute 317.201** covers **private agency volunteers** and provides **immunity** from prosecution for good faith civil actions by the volunteer provided 1) the volunteer was working within their assigned duties, 2) did not breach a contractual obligation, 3) violated no federal statute, 4) did not breach a fiduciary duty, and 5) violated no state criminal statutes. This statute also does not limit liability for physical injury or wrongful death which is personally and directly caused by an individual or willful or reckless misconduct.

Minnesota Statute 466.07 covers **public agency volunteers** and provides **indemnity** from prosecution for the volunteer. This means that the agency is to provide legal defense and pay damages as the court assigns provided the volunteer was working within their assigned duties and violated to criminal statutes or federal statute.

In addition, because of the newness of these statutes, it is recommended that agencies continue to provide any coverage now in existence to cover volunteer liability. Some concern exists as to possible tests of the legislation finding it thrown out or otherwise revised.

Public agencies which utilize volunteers should also be aware of **Minnesota Statute 176.011.** This statute mandates workers compensation coverage for volunteers performing services similar to paid staff for public agencies. The awarding of benefits is based upon positions comparable to the unpaid position responsibilities the injured volunteer performed. Claims are handled in a manner consistent with paid positions.

Excess auto insurance is provided by agencies on some occasions. No Minnesota law **requires** such coverage but Minnesota insurance law prevails in regard to minimum basic auto coverage which volunteers should carry. In many cases, agencies require higher limits than state law. Please note: the Minnesota Insurance Commissioner has determined that persons who use their vehicle to perform volunteer work may not be discriminated against just for doing volunteer work. Their premium rates may not be raised, insurance may not be cancelled, and policy claims may not be denied.

If you have further questions, contact the Minnesota Office of Volunteer Services at 296-4731 (metro) or 1-800-651-9747 or DHS' Chief of Volunteer Services at (612) 297-4275.

"Friends...
They know how to set me free
Wanting me to be
All that I can be
Things that I can't see
In me."

— Joe Bass

TRAINING

As the coordinator of training, planning the time slots for each orientation and training session requires special thought. Consideration should be given to times which will accommodate the greatest numbers of volunteers.

A series of evening sessions scheduled within a two week period (or a relatively short time frame to maintain motivation, interest, focus, and enthusiasm) might be a convenient time selection. Sequential Saturday mornings, two or three depending on numbers of people being trained and length of time scheduled for each morning, are a realistic possibility. You may even want to consider a Friday evening, all day Saturday combination Orientation and Training, followed by a facility orientation the next week. Another thought, you may find it beneficial to run two simultaneous (morning/evening) trainings to meet the variety of time needs presented by your volunteers.

Your creativity should enable you to design the Orientation and Training sessions to be convenient for the most people, to encourage learning and build anticipation for the job.

A reminder to begin each session with a "warm-up" activity. Outline the topics that will be covered so the progression is evident to all. Encourage participation, discussion and questions.

JOB DESCRIPTION

PURPOSE (15 min.)

To understand the elements in the job description.

METHODS

General Discussion (may want to consider using a visual, in addition to the job description handout).

MATERIALS

Job Description

Any other use of visuals

DISCUSSION

If job descriptions were carefully reviewed during interviews, it may not be necessary to do so during training.

A general discussion of each element in the job description should be conducted. Explain items under duties and qualifications. Encourage questions. If a concern is voiced over an item you may want to negotiate a change with the individual in private.

PERSON TO PERSON
JOB DESCRIPTION

JOB TITLE:

PERSON TO PERSON Friend.

FUNCTION:

To enhance the life of a person with developmental disabilities by sharing social and recreational opportunities.

To speak for the needs of the client when appropriate.

DUTIES:

Participate in initial orientation and training as well as ongoing in-service training.

Learn background, history, and pertinent information about client.

Visit friend at least twice a month.

Interact in the facility and in the community.

Communicate with staff regarding changes (positive or negative), concerns, or ideas you have regarding friend and advocate when necessary.

Follow the record keeping procedures as defined.

Maintain confidentiality.

Provide one (1) month notice to supervisor prior to terminating position.

QUALIFICATIONS:

Caring, compassionate, and sensitive to the needs of people with developmental disabilities.

Commitment to visit regularly and plan in partnership with friend/client.

Ability to relate well to people.

If driving, possession of a valid driver's license, a good driving record, and appropriate insurance.

Willingness to make a one year commitment

Possess good communication skills, maturity, patience and the ability to adapt.

TIME REQUIRED:

Minimum of six to eight hours each month for one year.

SUPERVISION:

Individually determined.

Interviewing, placement, and training facilitated by a volunteer services coordinator.

Actual supervision on the job may be provided by staff persons at the facility, a case manager, or a volunteer services coordinator.

BENEFITS:

Opportunity to assist integration into the community for people with developmental disabilities.

Opportunity to enhance the quality of life of another person.

Documented experience and performance appraisal for use as future reference.

Opportunity to participate in training seminars to build skills and knowledge.

COMMENTS:

VOLUNTEER

SUPERVISOR

DATE

PERSON TO PERSON RELATIONSHIP

PURPOSE (45 min.)

To understand the relationship.

To clarify the responsibility involved in the relationship.

To develop an awareness of non-verbal communication.

METHOD

Large and Small group discussions

Overhead with Transparencies

Non-verbal Communication Exercise

Handouts

MATERIALS

Overhead, screen, transparency *Friends Can Help*

Handouts:

Nonverbal Communication

Guidelines for Establishing Relationships With People With Developmental Disabilities

Poem

Yardstick

Slips of paper with instructions for non-verbal behavior

EXERCISE

Your *PERSON TO PERSON* friendship is a special kind of one-to-one relationship. Think about a very close friend. What makes that relationship special? What do you bring to that relationship? What do you receive from it? Board the responses to any of the questions if they have relevance to the relationship that is being defined. For instance, if a response is "I can depend on my friend," you may want to write that on newsprint as it directly relates to the relationships being discussed.

Divide the group into two groups. One group will deal with "Ways in which this relationship will be similar to other relationships people have. " The other group will discuss "Ways in which this relationship will differ from other relation-

ships people have." Give the groups five minutes to discuss and list their responses. Share the ideas generated.

Preboard on newsprint or use a transparency with the following points:

— CLEAR EXPECTATIONS OF EACH OTHER
— UNNECESSARY TO ALWAYS SAY YES
— DON'T MAKE PROMISES YOU CAN'T KEEP

Emphasize the fact that clear expectations of each other are a necessity in this relationship. If there are misunderstandings, it is the responsibility of the volunteer to talk them out with the client.

Secondly, the volunteer should not feel as if all requests must be fulfilled. Respond calmly and firmly to unreasonable requests. An example: Your friend says, "I'd like you to come over every week." Your response could be, "You'd like us to meet more often than we do. I'd like to stick with the every other week schedule as we planned.

Just as with any relationship you have, it is important to:

1. Be on time.
2. Carry out plans that you made.
3. If you're going to be absent, tell your friend in advance if possible.
4. Much of the responsibility of the relationship is yours as the volunteer — remember to stay in touch.

In many ways your COMMON SENSE will guide you through the initial phase of this relationship. Be yourself — be friendly, but don't push — know that it may take a while for your friend to "warm up."

Go over the *FRIENDS CAN HELP* information either as a transparency and/or a handout. Discuss those items where questions may arise.

FRIENDS CAN HELP

By giving people with developmental disabilities a relationship with a member of the community

By sharing activities that are a part of community living

By seeing that a person with developmental disabilities receives all the needed services

By helping people with disabilities learn useful skills

By informing people with disabilities of their rights and giving them the information they need to make appropriate decisions and take action

By representing a vulnerable person

By letting other people see through example that being with a person with developmental disabilities isn't scary or uncomfortable

By being a part of the case management team

By accepting people with disabilities, thereby helping them accept themselves and feel that they are a part of society

NONVERBAL COMMUNICATION

As we interact with others, we constantly send nonverbal messages through our body movements, facial expressions, and gestures. The ability to send these nonverbal signals is innate, but nonverbal communication is also a skill that can be improved through practice. It is important that we send the right messages to our friends as well as being able to accurately interpret the nonverbal messages they are sending.

(Trainers may want to highlight in some way the nonverbal ways to communicate as they are discussed.)

PERSONAL SPACE

EYE CONTACT

GESTURES

TOUCHING

FACIAL EXPRESSIONS

PERSONAL SPACE — the invisible personal territory surrounding us. The boundaries of your personal space contract and expand depending on your emotions, the activity you are involved in, your cultural background, and whether the relationship is intimate, personal, social, or public.

Have each person select a partner. Each pair stands about 15 feet apart. They begin a conversation. As the conversation proceeds, Partner A walks slowly up to Partner B (standing) until they make physical contact. Partner A then backs slowly away to the place where he or she feels comfortable. The distance between A and B is measured. Then the partners repeat the exercise, with Partner B walking forward and then backing away to the comfort spot. Almost always the partners' distance preferences vary.

There is a maximum and minimum distance for most people. Too close and we feel engulfed, too far and we feel rejected.

EYE CONTACT — the amount of eye contact we use can convey emotions and attitudes. The more eye contact you have, the more likely the other person will see you as friendly, mature, and sincere.

GESTURES — the many body movements we use to support our verbal communication. These gestures either serve to clarify a speaker's ideas or they express emotions and attitudes. Condescending gestures — such as patting the head of an adult with mental retardation — will damage a relationship.

TOUCHING — Society defines the type of touching which is appropriate to a particular situation.

FACIAL EXPRESSION — perhaps the most important and the most carefully controlled nonverbal signal. The face can display a world of emotions.

EXERCISE

Choose one of the following exercises to increase awareness and understanding of nonverbal communication.

EXERCISE 1

Ask volunteers to find someone in the room you would like to "talk to" and without using spoken words, sounds, or writing, let them know something about you. When they all have partners, tell them to sit down facing one another and introduce yourself by telling your partner something about yourself, but remember, you cannot use words or spoken sounds. After three minutes reverse roles and the other member of the pair tells, without words, something about him/herself.

After another three minutes, the trainer should instruct the participants to now use words. See if you were able to understand what your partner was saying. Also share how it felt not to use spoken words and why you chose the way you did to introduce yourself.

The whole group can relate how it felt trying to understand a nontalking person.

EXERCISE 2

Divide into groups of five or six people.

Give each person a list of five nonverbal signals. Instruct the group to take turns identifying the meaning of the signals sent. Each person will have an opportunity to send and receive several nonverbal signals.

Discussion: Are you surprised at the number of distinct body language signals you can identify? Do you think most messages are interpreted the same way by all people?

People with disabilities send nonverbal messages, as well as receive them. Physical or mental disabilities, or a lack of experience, may prevent people from displaying socially acceptable nonverbal signals, especially those which are used to convey liking. Their body language may give the impression that they are bored, indifferent, or even hostile. Misinterpreting these unintentional and sometimes peculiar behaviors may affect the way you react to people who are disabled. Appearance and behavior may conflict in a puzzling way. When a person's appearance sends the message, "This is an adult," we unconsciously expect adult behavior and we may be frustrated when the person doesn't meet this expectation.

Inappropriate behaviors may occur — don't panic. You may feel uncomfortable and that is a natural reaction. Respond calmly and firmly without making moralistic judgments. It isn't fair to impose your beliefs and values on your friends. Remember, as in many friendships, you are a role model — new skills can be learned from your examples — and new behaviors may be exhibited.

Distribute *GUIDELINES FOR ESTABLISHING RELATIONSHIPS...* Handout. Go over each item. Answer questions as they arise.

Read *FRIENDS* poem.

A

1. Slowly nod your head several times.
2. Put both thumbs up, hands cupped, smile.
3. Sit forward in your chair, looking straight at your listener.
4. Shrug your shoulders with your palms facing up.
5. Slump in your chair, looking at your fingers.

B

1. Keeping your head straight, look slowly towards the ceiling and back to the listener.
2. Raise one eyebrow while looking at the speaker.
3. Keep your lips together while letting your head lean to almost touch your shoulder.
4. Fold your arms across your chest and stare at the speaker.
5. Smile and nod.

C

1. Rotate your head slowly from side to side.
2. Let your chin touch your chest; look up at the speaker with a frown.
3. Nod your head quickly up and down.
4. Narrow your eyes and stare at the speaker with a frown.
5. Look sideways at the speaker.

D

1. Arch your neck forward and turn your head to the side.
2. Roll your eyes towards the ceiling while smiling.
3. Look at the speaker while putting both hands to your mouth.
4. Put your hands out, palms up, and smile.
5. Tap your fingers on the desk.

E

1. Roll your eyes and sigh.
2. Tilt your head down and sideways while looking at the speaker.
3. Point your finger and shake it from side to side.
4. Puff your cheeks while shaking your head.
5. Turn away from the speaker and sigh.

F

1. Point one finger towards the ceiling at your lips.
2. Cross your leg and swing it quickly several times.
3. Sigh while looking sideways.
4. Cup your fingers at your chin and nod your head slowly.
5. Bite your fingernails.

GUIDELINES FOR ESTABLISHING RELATIONSHIPS WITH PEOPLE WITH DEVELOPMENTAL DISABILITIES

- Show interest in client as another person — thoughts, feelings, desires, events.
- Emphasize and try to increase the client's appropriate or more normal behaviors.
- Encourage age/ability-appropriate recreational activities.
- Assist the client to set realistic goals. If necessary, devise modifications of activities that will assure some measure of success and consequent enjoyment.
- Build upon the self-confidence derived from the achievement and enjoyment derived from familiar activities with the gradual introduction of new activities.
- Foster a client's positive self-image by allowing for an appropriate measure of independence with regard to participation in recreational activities once necessary instructions/explanations are given.
- Generously praise all successes and attempts. Offer correction in the most constructive terms possible with unlimited patience.
- Offer instruction and direction simply and clearly.
- Be alert to an activity that may be running too long and conclude it before boredom and disinterest set in.
- Recognize and respect the client's right to choose which activity to engage in.
- Encourage the client to use the recreational resources available in the local community.
- Take advantage of the opportunities to develop social competencies inherent in community oriented activities. Through discussion before and after the activity, prepare the client for what to expect and to assess the experience.
- Some outings should involve small groups of volunteers and clients to be consistent with "typical" social behavior.

Friends
Thursday afternoon
Helping me get by
Teaching me to fly
Higher than I've ever been
Before.

Friends
They know how to set me free
Wanting me to be
All that I can be
Things that I can't see
In me.

I'm bound in chains
Of my own making
And friends can help me break those chains.
Their love can take me to the mountain
And bring me sunshine
When it rains.

It's
So easy when you realize
Any day is Thursday
Any place, a mountain
When you're with the ones you call
Your
Friends.

— Joseph F. Bass, Jr.

BUILDING RELATIONSHIPS

STAFF/VOLUNTEER/CLIENT

PURPOSE
(60 min.)

To learn about specific ways to build strong relationships
To increase listening and responding skills

METHOD

Exercise
Small group discussion
Lecture
Overhead Projector

MATERIALS

List of *Blocks to Developing Trust and Communication*
Role Play Handout
Easel, Newsprint, Markers
Overhead, Screen, Transparency

INTRODUCTION

PERSON TO PERSON is about relationships. The friendship with a person who has disabilities, the working relationship with a staff person. The more we understand the factors that build and strengthen relationships, the greater our chances for successful ones will be.

EXERCISE
(30 min.)

Handout copies of *Blocks to Developing Trust and Effective Communication* to everyone. Tell them to read through their copy and then go back and check off the 5 items that appear to be the most serious to them.

Divide the group into small groups of 4 or 5 people.

In the small groups, each person should share his/her reasons for choosing the five "blocks" that were selected as the most serious for each group member. (Allow 10 to 15 minutes for this part of the exercise. Check out the groups to see if they are finished before going on. People get very involved in this task and want to complete it.)

Each person now has 3 minutes to recheck and change their list in light of the group discussion. (Sometimes a small group will reach consensus and will agree as a group.)

Each person has 5 votes to cast for the "blocks" which they consider to be the most serious. Write 1 - 23 on newsprint.

Tally the vote and decide which 5 blocks the entire group has chosen as most serious.

Again in small groups, develop one or more helpful ways to overcome each of the five selected blocks to trust and communication. (Allow 8 to 10 minutes, less if people seem to be finished.)

For a final round of sharing, record on newsprint the various ways developed to overcome the selected blocks.

Poor communication and a lack of trust are often the result of a number of combined factors. The following is a list of some of those factors.

Please Check Five Items Which You Believe are the Most Serious BLOCKS to Communication and Trust Building. If you have others you wish to add to the list, please do so.

____1. Cultural differences exist between members.

____2. Professional differences exist between communicators.

____3. Communicators have different beliefs.

____4. The speaker does not agree with what is being said or the policy behind it.

____5. The speaker or listener is preoccupied.

____6. The speaker or listener have very different vocabularies and jargon.

____7. People are unintentionally unable to say what they mean.

____8. The speaker has little knowledge of the subject.

____9. Either person is inadequately prepared.

____10. There are economic, class differences between individuals.

____11. The listener is not interested.

____12. Status differences (staff/client, leader/member) exist between communicators.

____13. There are negative feelings between communicators.

____14. One person tends to always agree with everyone.

____15. Someone is unintentionally miscommunicating.

____16. There exists some sort of interference or distraction.

____17. Time pressures exist.

____18. A difficulty in communicating difficult concepts or ideas exists.

____19. The same words have different meanings to different group members.

____20. Communicators belong to different ethnic groups.

____21. Differences in age exist between group members.

____22. Great differences in life experiences and educational background exist.

____23. People have different goals, objectives and agendas.

____24. _____. (Add any others)

LISTENING (30 min.)

Listening is an essential ingredient of communication. (Call attention to the listening responses from the "Blocks" exercise.) Whether we are dealing with clients on a personal level or discussing a plan of action with a professional staff person, good listening skills will contribute to our relationship. Most of us do not listen well — we tend to remember only about half of a conversation.

ROLE PLAY

This exercise is to identify what happens during a conversation when the parties are not listening.

Explain that the purpose of this exercise is NOT TO LISTEN to the other person but to concentrate on getting your point of view across as quickly as possible.

Break the group into pairs. Give one person in each pair the situation for the person who needs an air conditioner repaired. Give the other person the situation for the plumbing and heating employee.

Give the pairs about 2 minutes to study their roles and to decide what they are going to say.

Have all participants begin at the same time, and allow them to interact for about 4 minutes before you stop them. Be sure that participants in each pair are NOT listening to one another.

As a group, identify some of the characteristics of not listening (loud voices, no eye contact) and how the pairs felt when they were not listened to (angry, frustrated, helpless, desperate).

HOT AIR: PERSON WHO NEEDS THE AIR CONDITIONER REPAIRED

You have just moved into your new home and you were trying to unpack your household goods when you discovered that your air conditioner does not work. You have driven your car to the A-1 Plumbing and Heating Company to get some help. You do not know anyone else in town and you must have someone come and fix the air conditioner as the weather report states that it will be 104 degrees this afternoon. You do not know anything about air conditioners, but you are sure this is a simple problem that any repair person could solve. Your spouse has told you not to come back without help so you feel you must use any method to convince the person at the repair shop to help you. Remember that the object of this exercise is NOT TO LISTEN to the other person.

BLOWING STEAM: PLUMBING AND HEATING EMPLOYEE

You work for the A-1 Plumbing and Heating Company. Your job is very specialized and in fact you only now about fixing water heaters. You have been left in charge of the store for the day. You have already had two calls from people who have problems with their air conditioners.

You have decided that the next person who comes in with an air conditioning problem must be made to understand that you know nothing about such a problem and you will absolutely refuse to give them any advice about their problem. They must understand that you cannot help them in any way.

Remember the object of this exercise in NOT TO LISTEN to the other person.

LISTENING SKILLS

You can improve your listening habits by developing a few basic skills. One essential skill is the ability to block out distractions. You must be able to concentrate on the ideas being presented in spite of background noise, uncomfortable seats or preoccupation with your own thoughts.

Good listening requires much more than passively letting sound waves enter your ears. You must be as actively involved as the speaker. Think while you listen. Identify the speaker's most important points and relate them to your own ideas and experiences.

The response you give to a speaker determines whether your communication continues. Some responses, even when the responder means well, cut off further communication. Such responses include evaluation "you should..." "you are wrong...," advice "why don't you...," direction "you have to...," moralizing "you ought to...," criticism "if you had only...," analysis "what you need is...," and one-upmanship "you think your problem is bad, you should hear about mine." These evaluating and criticizing responses make people defensive and resistant to sharing more. The advising and directing responses cut off communication by "solving" and thereby ending the problem. They also prevent the speaker from working out his or her own problem by talking it through.

LISTENER RESPONSES OVERHEAD

There are basically 5 ways you can respond to a speaker in order to understand and encourage the speaker to continue. Go over "Listener Responses" using transparency.

PASSIVE LISTENING lets the speaker know you are still "with" him or her.

DIALOGUE SUSTAINING responses are appropriate if a speaker seems to need reassurance that you are interested.

ECHOING is a restatement of speaker's expressed emotion using his or her own words.

ACTIVE LISTENING is providing feedback on the emotion the speaker seems to be experiencing. Your feedback helps the person to get in touch with feelings and then to work out solutions independently. Active listening takes time. It also means accepting the speaker's feelings without moralizing or trying to change the person.

PARAPHRASING is one way to check your understanding of the speaker's ideas. This is most appropriate when the speaker pauses and is waiting for you to comment.

For practice, read the statements below one at a time (make up additional examples). Before you read each statement, give one person in the group a slip of paper on which you have written a type of listener response. That person is to respond to your statement with the type of response identified on the paper. Ask other group members to identify the type of response that the person gives.

Let as many people as possible have turns responding. (Break into smaller groups if the group is too large to get all involved.)

STATEMENT

1. I'd like to apply for that job at the grocery store, but I always choke at interviews.

   ECHOING RESPONSE

2. I used to really enjoy that Chinese restaurant.

   DIALOGUE SUSTAINING RESPONSE

3. We had a great time together taking a walk by the river. The wild flowers had just begun blooming, and we saw a family of ducks.

   PASSIVE LISTENING RESPONSE

4. No matter how hard I try I can't seem to get my client to show any affection or caring.

   ACTIVE LISTENING RESPONSE

5. All my friends have been wearing makeup for ages, but my mother won't even let me wear lipstick.

   PARAPHRASING RESPONSE

Answer any questions the group may have about the types of responses and when to use them. Call attention to the responses and the way they allow the speaker to continue talking. Compare the result if the response to #1 had been to give a solution ("You'll just have to be confident and relaxed in the interview."); or if the response to #3 had been to moralize ("You ought to spend more time with your client."); or if #5 response had been judgmental ("Your mother is right — you are too young.").

Listener Reponses

Passive Listening

1. Nonverbal signals
   a. head nodding
   b. smiling
   c. leaning forward
2. Verbal signals
   a. "I see"
   b. "really"
   c. "yes"
   d. "mm-hmm"

Dialogue Sustaining

Respond with "I'd like to hear more about that" or say "and" or "but" using a questioning inflection to encourage the speaker to continue.

Speaker: I was planning to get a job . . .

Listener: but?

Speaker: But my mother doesn't have time to drive me to work.

Echoing

Restate what the speaker has said using the speaker's own words.

Speaker: I feel scared when I meet new people. Everyone stares at me.

Listener: You feel scared when you meet new people and they stare at you.

Active Listening

Describe the emotion the speaker seems to be experiencing. Lead-in phrases to use are: "You seem to really feel_____." "It sounds as if you feel _____ right now."

Speaker: Everybody tells me what to do. I wish I could do what I want.

Listener: I gather you are pretty irritated right now.

Paraphrasing

Restate what the speaker has said using your own words.

Speaker: No matter what I do my teacher puts me down. I guess I can't do anything right!

Listener: Am I getting this right? You feel that nothing you do pleases your teacher.

ATTITUDE and COMMUNICATION

A good relationship between two people increases the chance for communication. You listen better if you care about the person who is speaking; also, you are inclined to be open and honest if a listener is responding with respect and understanding. Whether your relationship is personal or professional, communication is more likely to take place if you relate to the other person with empathy, respect, and authenticity.

EMPATHY

Empathy is recognizing another person's feelings. What are some ways that you can communicate empathy? (Responses may be undivided attention, nonverbal behavior, passive listening responses.)

RESPECT

Respect, the second crucial ingredient in a good relationship, is the unconditional acceptance of another person's behavior, beliefs, opinions, and feelings. This is a "no strings attached" attitude; your continued regard is not based on the person meeting your standards of behavior or beliefs. Acceptance is not the same as agreement. You can disagree with someone and still accept that person's right to his or her own opinions.

Being accepting is sometimes hard to do. Most of us have prejudices, whether we are aware of them or not. You don't have to condone a person's lifestyle, beliefs or behavior, but you should respect his or her right to choose how to think and act. What are some ways in which we show respect? (Being empathetic, nonjudgmental, don't criticize, be sincere.)

Acknowledging your client's strengths and abilities also shows respect. Your relationship should be a partnership with each of you contributing equally. Patronizing or dominating your client undermines this relationship. If all of your communication is to provide solutions and advice and to impose your own ideas, you belittle your client's ability to accept responsibility. Your respect motivates your client to seek answers to his or her own problems.

AUTHENTICITY

Being authentic means being natural, open, and nondefensive. However, it does not mean that you reveal all of your thoughts and feelings all of the time; those you do choose to express must be genuine. Sharing positive feelings with your client is almost always appropriate. Relating your per-

sonal experiences, when they are relevant to your client's problem, is another way to communicate authentically. Body language can also be effective in conveying your genuine care and concern. A pat on the back, a hug, or shaking hands may be an appropriate way to express your feelings if physical contact does not make your client uncomfortable.

SUMMARY

Listening and responding with care and concern, respecting another person and effectively demonstrating that respect, and being genuine and sincere and conveying that are some of the basics to building a trusting relationship with a client, with a professional, in fact, with any other human being.

COMMUNICATING WITH PEOPLE WITH DEVELOPMENTAL DISABILITIES

PURPOSE (30 min.)

To gain skill in communicating with persons with developmental disabilities to increase the chances of a successful relationship.

METHOD

Group Discussion

Handouts

MATERIALS

Copies of *Communicating Tips* for those disabilities to be covered.

INTRO

All of the information on communication relates to one's ability to effectively communicate with clients, as well as others with whom relationships are established. There are some special techniques to facilitate communication when specialized problems are present.

Distribute *Communication With People With Mental Retardation* and any other "Tip" sheets you want to cover.

You may determine that some of this information would be more easily understood and learned at an in-service or when the volunteer has more experience and greater need for the information. If so, only use materials that will benefit the volunteer without overwhelming him or her.

Read the tips aloud, one at a time, and demonstrate or illustrate each point. Encourage examples from any who have had experience and questions that arise will add to the information shared.

The tips provide information on things volunteers can do to foster effective communication. To gain skill in using these tips, practice needs to take place. Suggestions for specific ways to involve volunteers in the discussion are given below. Try to structure the discussion so it is as relevant as possible for real situations. Use the question, "Has anyone experienced this type of situation?" as you go over the tips.

Encourage participants to add tips based on their experiences.

EXAMPLES FOR PEOPLE WITH RETARDATION

Tip #1. Ask volunteers to look around the room you are in to see whether there would be ways to minimize distractions in this setting.

Tip #2. Demonstrate by touching the arm of one of the group members. Ask one of them to demonstrate turning the face of a person toward them and getting eye contact. Let each person practice with the person sitting next to him or her.

Tip #3. Ask a group member to illustrate speaking first nonexpressively and then expressively the words, "I drove my friend's little sports car today."

Tip #4. Ask a volunteer to play the role of a low verbal person learning the task of folding a piece of paper in half, then in half again, as one might fold a four-panel brochure. First demonstrate the task. Then manipulate the person's arms and hands to do the job. Be sure to give verbal directions while demonstrating and giving sensory cues.

Tip #5. Demonstrate by rereading the tip with exaggerated inflections and excessively slow speech.

Tip #6. Ask a volunteer what one might say instead of, "Let's get dressed now."

Continue with remaining tips.

HEARING IMPAIRED

Playing a record or tape that simulates what a person who is hearing impaired hears will help participants understand the listed tips. (Recordings are available from the public library, speech and hearing clinics or educational service centers.)

VISUALLY IMPAIRED

The vision loss and its consequences for communication can be simulated by using blindfolds. You can illustrate the tips by having one volunteer role play a person who is blind and two volunteers role play people with normal sight, one whom the person who is blind knows and one to whom he or she will be introduced. The three, after introductions, should make plans to go to a restaurant together, arranging a date, place, time, and transportation, and asking each other's preferences about type of food and expenses. (Any role play situation that requires interaction between three people will accomplish the desired results.)

After the three role players have completed their plans, discuss as a group how and when they used some of the suggestions in the tips. The person who played the role of being blind can tell how he or she felt at different times, which cues helped most, least, caused discomfort. Group members should contribute their observations.

PHYSICALLY HANDICAPPED

These tips are harder to demonstrate and illustrate than the tips on other disabilities because it is hard to simulate a motor speech disorder without seeming to ridicule and because the tips suggest appropriate attitudes and responses rather than overt behavior. Therefore, you will probably have to rely on reading over the tips and encouraging questions and discussion.

You may want to invite a communication specialist to demonstrate some of the nonspeech modes of communication during this session or at a later time during in-service training.

COMMUNICATING WITH A PERSON WITH MENTAL RETARDATION

The effects of mental retardation on speech and language development may be so mild that the person has no speech problems or only minor articulation errors; or the effects may be so severe that the person will never develop functional speech.

Some people who lack the ability to speak or write (expressive language) have the ability to understand what is said to them (receptive language).

Assess your client's verbal skills with an open mind. If the person has normal skills, you may not need to adjust your usual communication style. But if there are limitations, you must make extra efforts so that your friend will understand the communications. You need to take the time to explain and to listen in order to develop a relationship.

In your efforts toward normalization, you will help your client gain language ability and social interaction skills.

TIPS

1. Try to keep your surroundings free from distractions. Remove any unnecessary objects in the area and keep background noise to a minimum. For example, turn off the radio and shut the window to reduce street sounds.

   If the person is too distracted by things happening in the room, you may need to move to another room or change location within the room. For example, in a busy coffee shop you might move to an isolated corner or sit with your backs to the activities.

2. Establish eye contact before you begin to speak, and maintain it as long as possible.

   Say the person's name often.

   Touch the person lightly on the arm or shoulder when you seem to be losing his or her attention. It may be necessary to move the face of a person with severe mental retardation or a highly distractible person toward you.

3. Speak expressively with appropriate gestures, facial expressions, and body movements. These nonverbal cues add information that make your ideas easier to understand. For example, when you say, "Let's go eat," to a person with a limited understanding of speech, you might gesture spooning food into your mouth.

4. Communicating with a person who does not have expressive language and who does not seem to respond

to what you say requires frequent sensory cues. For example, mimic the activity you are talking about with gestures, physically move the person's hands, head, or feet to perform the activity you are describing, and try to get eye contact. Touch, hug, and pat in order to guide and affirm, combining these cues with the appropriate verbal comments. Resist your impulse to stop talking. Even if there is no apparent response, hearing your speech is good training for a person with retardation.

5. Speak slowly and clearly, but don't exaggerate the inflection or tone of your voice. Exaggerations call attention to themselves rather than to what you are saying and are distracting and confusing.

6. Speak in "here and now" concrete terms. Give specific examples and demonstrate whenever possible. Instead of saying, "It's time to clean up" say, "Wash your hands in the bathroom now." Refer to "chair" instead of "furniture"; "apple" instead of "fruit"; "Mrs. Smith: instead of "your teacher."

7. Emphasize key words. For example, say, "Please bring me the *blue* glass."

   Repeat important statements, and use different words if the listener does not understand.

8. Be positive in giving directions. Instead of saying "Don't kick," say, "I'd like you to keep your feet on the floor." In this way you give the person a goal rather than calling attention to (and possible reinforcing) inappropriate behavior.

9. Give directions immediately before the activity to be performed and avoid lists of things to do. If you say before you go into a restaurant, "When we get in the restaurant, you will first need to wash your hands, then come back to the table and unfold your napkin...," the retarded person may not remember and act on these directions without prompting. Instead, give the directions one at a time when you want the task performed.

10. Check frequently to be sure the person is understanding. It is pointless to ask, "Do you understand?" Instead, ask the person to repeat what you have said or ask a question that requires a specific answer, such as, "What are you supposed to do tomorrow?"

11. Ask open-ended and either-or questions rather than questions that can be answered with *yes* or *no*. Retarded people have a tendency to say *yes* when given a choice of yes or no, so such a response does not necessarily give you the right information. Instead, let the person describe a situation or give a choice of answers neither of which is obviously the right one. Be sure the alternatives you give cover all the possible situations.

Examples

yes-no question

Did the man bite your arm? (the response will likely be yes)

open-ended question

Tell me what happened this morning. (the person must describe the situation)

either-or questions

Did this problem happen today or yesterday?

Are you talking about a man or a woman?

(neither alternative is obviously better; therefore the choice the person makes is likely to be accurate)

12. Don't pretend to understand. It is better to ask the person to repeat what he or she has said several times than to agree with something you don't understand. (You may be unpleasantly surprised when you find out what you have agreed to!) Say, "Tell me again." If you don't get a completely understandable answer, build from a particular point you can confirm. For example, ask, "Am I getting this right? This morning someone bit your arm."

13. Smile, nod, and lean forward while the speaker is talking. These signs that you are interested encourage the person to continue.

14. Be prepared to wait. The person with mental retardation may function slowly. Do not anticipate the speaker's response and finish sentences for him or her. Sometimes suggesting a key word the speaker is having trouble with will help the speaker keep going, but people with retardation need to gain experience and confidence in their own speech.

15. When you note signs of fatigue, irritability, or disinterest, it is a good idea to change activities, slow down, make the task simpler, or take a break. One such sign is increased distractibility. Another sign is continued repetition of a response when it is no longer appropriate (for example, "want to go home," "time to go home," "want to go home").

16. Don't give a choice if you are not sincere. For example, don't say, "Would you like to come with me?" if the person *must* go with you. Instead say, "Let's go back to the cottage now." Giving choices when there are real options is good, though, because it reinforces decision-making. For example, say, "Would you like to come with me or would you like to stay at school?"

17. Sometimes the speech or behavior of a person with retardation will be bizarre or otherwise inappropriate. The reason may be either

lack of information and social skills or desire to get attention. How you respond will depend in part on the reason.

It is important to correct inappropriate speech or behavior resulting from lack of information. If you don't correct it you are essentially giving your approval and increasing the likelihood that it will happen again. For example, if a person with retardation is on a public bus and begins to pat a stranger, try to divert her/his attention and break the chain of events. You might do this by saying, "Please bring me my purse." Then explain with empathy and with regard for the person's self-esteem what the appropriate behavior is. For example, say, "That little girl you were touching is pretty, isn't she? But people don't touch each other until they are good friends. See how all the other people on the bus are holding their hands in their laps."

If the inappropriate behavior or speech is attention-getting, ignore it and direct the person to an appropriate topic or task. You might walk away, continue with what you are doing, repeat what you have been asking, or ask the person to do something that will interrupt the behavior or speech.

Give the person abundant attention when he or she behaves and speaks appropriately to diminish the need for negative attention.

18. Treat adults with mental retardation as adults, not as children. Use their proper names, and show respect when you introduce them to others. Consider the varying degrees of respect conveyed by the following instructions:

    "This is Billy. He's retarded."

    "This is Billy."

    "I'd like you to meet Bill Brown."

    When you praise an adult, do it appropriately. "You did a fine job" is certainly more appropriate for an adult than "That's a good boy." Avoid talking down to an adult who is retarded.

19. Talk *to* the person with mental retardation, not *about* him or her. No matter what the person's level of understanding, it is rude to discuss a person when he or she is present.

COMMUNICATING WITH A PERSON WHO IS HEARING IMPAIRED

Although some people who are hearing impaired possess adequate speech for basic social expression, those with profound hearing losses often do not learn to speak intelligible. Thus, many persons who are deaf use written or manual communication as a supplement to or substitute for speech.

Manual communication refers to several systems in which hand or body movements represent ideas, objects, actions, etc. Fingerspelling and sign language are other forms of communication. There is close attention paid to visible speech cues, facial expressions, and gestures.

Whatever special communication techniques your client uses, there are several things you can do to be more effective.

TIPS

1. The room should be sufficiently quiet to permit your voice to be heard with little difficulty. If there is background noise, such as footsteps, conversational babble, traffic rumbling by, loud heating and cooling units, minimize it as much as possible (close windows, turn off furnaces, move to a quieter room). Background noise may prevent the person who is hearing impaired who is from using residual hearing. Echo is less of a problem in small rooms and in rooms with carpet and drapery.

2. Position yourself directly in front of the person to whom you are speaking, rather than behind or to the side of him or her. Keep the distance between you as small as possible. Speechreading is easiest at five feet or less.

3. Try not to stand in front of a light source (for example, a window). Light behind you may throw shadows on your face and distort the normal movements of your mouth. The light should shine on your face rather than in the eyes of the person attempting to understand you.

4. Establish eye contact before you begin to speak. You may need to attract your listener's attention with a light touch on the arm or shoulder.

5. Provide a clear view of your face. Avoid actions which hide your mouth and reduce the accuracy of speechreading: resting your head on your hand, turning your head, waving your hands, smoking, chewing, and holding things in front of your face. Certain physical features can also affect speechreading. A moustache or beard may

hinder speechreading by partially obscuring the mouth; lipstick may define the lips and enhance speechreading.

6. Speak clearly but naturally. Use your normal speed and loudness level unless asked to change. Speakers sometimes use a very slow rate, exaggerate their mouth movements, or shout, hoping to improve understanding. Actually, these efforts are more confusing than helpful.

7. Speak expressively; use gestures, facial expression, and body movements to convey mood and feeling. Persons who are deaf may misunderstand figures of speech ("the *foot of a mountain*"), puns, and sarcasm because they cannot hear the accompanying variations in tone, inflection, and stress. Thus, shrugging your shoulders, raising your eyebrows, or shaking your fist may relay an idea more accurately than words alone. Avoid exaggerated gestures, however, because these distract the attention of the speechreader from the basic point of focus — the face.

8. Use short, simple, complete sentences. Keep your language precise and concrete, rather than abstract. A general term such as "food" is more abstract than the word "apple," which refers to a specific fruit. Abstract words have vague meanings (for example, "nourishment in solid form"), which are difficult for the person with hearing impairment to grasp. Words which have many different meanings, such as "great," "down," and "over," are also confusing to the individual who has the hearing impairment.

9. Repeat key words and statements and avoid changing the subject abruptly. Check comprehension frequently by asking questions or asking the listener to repeat what you have said. Persons who are deaf may pretend to understand when they do not (just as many hearing people do). When a person who is hearing impaired joins a group, make sure he or she knows the subject being talked about.

10. When an individual with a hearing impairment has difficulty understanding an important point, rephrase the idea rather than repeat the same words. Only one third of English sounds are visible to the speechreader. Words such as "king" and "her" cannot be speechread because they contain sounds which are produced by hidden movements inside the mouth. Many of the sounds which are visible are homophenous; that is, they look exactly like one or two other sounds. Therefore, the words "Pete," "beet," "mean," "bead," "bean," and "meat" appear the same to the speechreader.

11. If your listener is able to use some residual hearing, you may find it useful to lower your pitch somewhat. A high pitched voice (usually a woman's voice) is more difficult to understand.

12. Lacking the auditory feedback we use to monitor our own voices, the person with a severe hearing impairment may develop speech which is excessively loud, high pitched, monotonous, breathy, and nasal. If you have difficulty understanding a speaker with a hearing impairment, ask an open-ended question (for example, "Would you tell me about your family?"). A lengthy answer may give you time to become accustomed to the person's speech and language patterns. When you cannot understand a statement, ask the person to repeat or elaborate on what he or she has said. If this fails, a gestural or written mode of communication may be more effective than speech.

13. Do not assume that a deaf person's communication problems indicate a lack of intelligence. A profound hearing loss disrupts language acquisition to such an extent that an adult who is deaf rarely has the verbal skills of a hearing 10-year-old child. The most obvious deficits in the language of the hearing impaired are a limited vocabulary and difficulty with syntax (arranging words into sentences). Reasons often cited for these problems are a lack of language stimulation and the fact that the syntactic rules American Sign Language are quite different from the rules of English.

14. If you know any sign language, ask the person with whom you are talking if he or she would like for you to use it. Some people prefer to communicate through speech alone. Even if both of you agree to use signs, you may have difficulty communicating if you have learned different systems. Sign systems currently used in the United States include: American Sign Language (ASL), Systematic Sign Language, Signing Exact English, Seeing Essential English, Linguistics of Visual English, Signed English, and Manual English.

15. If your client communicates through signing, an interpreter may be necessary. An interpreter does not think for the person who is hearing impaired, but translates the conversation. When using an interpreter, look at your client and carry on a conversation as if speaking to a person with normal hearing.

16. Watch for signs of fatigue in your listener. Following a conversation requires greater effort on the part of the individual who is hearing impaired, and the stress may make him or her tired, irritable, and tense. In addition, *tinnitus*, a noise or ringing in the ears, may be so annoying that it increases fatigue.

COMMUNICATING WITH A PERSON WHO IS VISUALLY IMPAIRED

Most people find it obvious that a disability which affects speech or hearing will interfere seriously with effective communication. The effect of visual impairment, however, may not be so obvious. Some people speak to a person who is blind as if he or she were unable to speak or hear normally. People may exaggerate their pronunciation, shout, or whisper in front of a person who is blind.

TIPS

1. Introduce a person who is blind just as you would anyone else. It is inappropriate and also unnecessary to say, for example, "This is Jim Jones. Jim is blind."

2. Use words such as "look" and "see" comfortably. These words are a part of English vocabulary and it is unnatural to avoid using them.

3. When approaching a person with a visual handicap, always state your name. Unless he or she knows you well, do not expect a person who is blind to be able to identify you by your voice, especially in noisy surroundings.

4. Let the person with a visual problem know when you are about to leave. Do not walk away without saying anything.

5. If the person you are talking to has some limited vision, do not stand with your back to a window. The glare may be uncomfortable and cause eye fatigue for the person who has some vision.

6. A person with a visual handicap may need verbal cues to help compensate for the loss of information usually obtained from facial expressions, gestures, and body movements. For example, persons with normal sight know when a question is directed toward them because the speaker looks at them. A person who is blind may not realize that a questions meant for him or her unless you preface it with his or her name ("Bob, what is your address?").

7. We normally judge whether a person is paying attention by the amount of eye contact used. When speaking to a person with a visual handicap, repeat his or her name often and ask questions to be sure he or she is "with" you.

8. Vision impairment does not necessarily mean a lack of intelligence. Be cautious in making assumptions and evaluations.

COMMUNICATING WITH A PERSON WHO IS PHYSICALLY HANDICAPPED

The majority of people who have motor damage, especially those with cerebral palsy, have mild to moderate communication difficulties. Damage to the central nervous system may interfere with the production of speech sounds and with the rhythm and rate of speech. The most common characteristics of motor speech disorders are imprecise production of consonant sounds, slow effortful speech, and difficulty in control of pitch and loudness. When muscle function is impaired, speech may be accompanied by facial distortions, drooling, and random body movements.

These behaviors often distract listeners and make them feel uncomfortable; you may have to make a conscious effort to pay attention to what the speaker is saying. Also, the physical tension associated with speaking and the difficulty in being understood often discourage people with handicaps from attempting to communicate; to overcome this reluctance, you need to be accepting, relaxed, and interested.

TIPS

1. When you meet a person with an unfamiliar disability, you may have to consciously avoid staring. At the same time, it is a mistake to avoid eye contact because you feel uncomfortable. Instead, look at the person in the same way you look at a nondisabled person, with eye contact and a smile or greeting.

2. Speech intelligibility of a person with motor speech disorder will often improve after you become accustomed to the distorted speech pattern. You can obtain a good sample of the person's speech by asking a question which requires a lengthy answer (for example, "What do you enjoy doing?") or by having him or her read aloud.

3. Allow a long response time from someone who has a motor speech disorder. A physical disability may increase the time needed to initiate speech.

4. Do not be offended if a person who speaks with some physical tension seems reluctant to converse. This may be because of the great effort the person expends in order to speak. Encourage the person to speak and create an accepting atmosphere by using eye contact, smiling, leaning forward, and nodding.

5. If the person uses a nonspeech communication system, become acquainted with the way the system works and benefits. If you have reservations about nonvocal com-

munication, you are likely to convey this attitude to the person who is handicapped. If, on the other hand, you are willing to accept the nonvocal method as a functional means of communicating, you will convey your respect to your protege or client. This can only enhance your relationship with him or her.

6. Respect the personal space of a person with a physical handicap. You must be close enough to be easily seen and heard, but realize that a person with a physical handicap may not be able to protect his or her personal space. Personal space includes any equipment an individual uses; leaning on a person's wheelchair, for example, is rude and may even seem threatening.

7. If the person who is handicapped must remain seated, try to sit also so that you can maintain the same eye level. Even if you maintain a comfortable distance, you may still appear to be threatening and dominant if you stand. This is the teacher-pupil or boss-employee position.

8. Be sensitive about touching someone with a neurological handicap. A pat on the back or a hug is a pleasant, positive experience for most people, but for someone with neurological damage, another person's touch may be irritating or even frightening. This does not mean that you should avoid touching completely; just move slowly so you don't startle the person and use firm pressure (a light touch may tickle).

9. To keep the attention of a hyperactive or distractible person, call the person's name frequently or touch him or her on the arm or shoulder. If the person cannot focus attention on one activity, limit the number of distractions, such as unnecessary furniture and equipment, bright, patterned wallpaper or carpet, or an uncovered window.

10. If you note signs of fatigue, anxiety, irritability, or disinterest, change activities, slow down, make the task simpler, or take a break. Perseveration (the continued repetition of a response when it is no longer appropriate) is likely to occur when an individual is tired, when situations change rapidly, or when a task is too difficult.

11. Physical handicaps and speech disorders do not mean a lack of intelligence. Focus on the person's abilities, not disabilities.

SERVING AS AN ADVOCATE

PURPOSE
(30 min.)

To understand the role of the volunteer advocate in the *PERSON TO PERSON* Project.

To understand advocacy from the perspective of the facility administrators and staff.

METHOD

Trainers Review with Group
Group Brainstorm
Handouts

MATERIALS

Easel, Newsprint, Markers
Handout *Defining Community Residential Advocacy*

REVIEW

Briefly review information about advocacy that was discussed at the orientation meeting. This can be done by asking the group for responses or by the Trainer giving the necessary information or using the newsprint from the orientation to review: What is advocacy? Who is an advocate? Why does some one advocate?

Point out that all of us need an advocate at some time. Many of us are self advocates — we are able to represent our own interests in some situations. Many people with developmental disabilities have learned the skills necessary to be self-advocates, in fact in the relationship role you will be establishing, assisting your friend to be an advocate for his or her needs might be appropriate.

BRAINSTORM

Brainstorm responses to the following statements, record on newsprint.

People with developmental disabilities often need advocates because:

(Responses may include)

—their problems are greater

—sometimes their abilities are lower because of the disability or because of feelings of inferiority and habits of submissiveness.

—society creates physical and attitudinal barriers

—many have been excluded and separated, they lack experience in normal human interactions

—their rights have been limited

Volunteers make good advocates because:
(Responses may include)

—they have different resources and skills to meet needs

—they can have personal relationships with the person who is handicapped, as a member of the community.

—they bring enthusiasm, expertise, and caring

—they have set aside time that staff doesn't have to work in community advocacy for people with developmental disabilities.

HANDOUT ADVOCACY WORKSHEET

Summarize discussion and point out the diversity of advocacy needs for people with developmental disabilities as well as the variety of forms of advocacy.

Distribute handout *Defining Community Residential Advocacy*. Tell the participants to read the definitions and fill in the line with the appropriate term from the list at the top of the page. (This exercise can also be done as a full group.) When completed, give correct responses and answer questions.

The correct answers are, in order:

advocacy
protective services
self-advocacy
expressive citizen advocacy
systems advocacy
legal advocacy
instrumental citizen advocacy

Discuss in more detail the two types of citizen advocacy which will make up their roles as *PERSON TO PERSON* friends. Remind the volunteers that as a change agent, a friend/advocate should not move too quickly and expect miraculous changes overnight. Adequate time and patience is necessary for establishing sound relationships founded on trust and mutual respect.

COMMUNITY RESIDENTIAL ADVOCACY

Match the term with the definition below. Write the term in the blank above the definition.

legal advocacy	expressive citizen advocacy
self-advocacy	systems advocacy
protective services advocacy	instrumental citizen advocacy

1. _____
Speaking and acting on behalf of oneself or another person or a cause.

2. _____
Services which assist individuals who are unable to manage their own resources or to protect themselves from neglect, exploitation, or hazards. Examples of such services are outreach and referrals, counseling, case management, legal aid, guardianship, housekeeping assistance.

3. _____
Representing one's own rights and interests and seeking solutions to a problem oneself. This form of advocacy is the goal of all other forms of advocacy.

4. _____
A one-to-one relationship between a mature, competent volunteer and a person with developmental disabilities in which the advocate defends the rights and interests of the person with a disability and provides emotional and social support. This advocate is viewed as an important link to the nonhandicapped world and provides a broadening of social horizons.

5. _____
Influencing social and political systems to bring about change for groups of people. Usually a coalition of people, but sometimes an individual, will seek changes, such as changes in laws establishing group homes where there have been none.

6. _____
Litigating and legislating to establish the legal rights of people with developmental disabilities and to insure that those rights are not vio-

lated. This form of advocacy may be used to benefit individuals or classes of people.

7. _____
Representing the practical problem-solving interests of a person with developmental disabilities. Represents interests or rights in relation to the services, goods, opportunities, and other benefits that the larger community provides. A dynamic, changing role that adjusts to needs of a client.

REPORTING PROCESS

PURPOSE (30 min.)

To learn to report concerns, suggestions, problems or compliments after realistic appraisals and careful thought

METHOD

Analyze and discuss scenarios

Review and discuss actual experiences some of the participants may have had

MATERIALS

Scenarios Handout

ACTIVITY

Select as many of the following scenarios to analyze and discuss as time permits. Add any from your experiences or those of colleagues. Read the scene aloud or ask a variety of people to read a particular scene. Allow 3 to 5 minutes after a case is presented for individuals to list on paper possible ways to handle the situation. Discuss the variety of actions presented. Determine, together, the best actions to take.

SUMMARY

Whatever the situation may be, it is important to act thoughtfully, not in haste, consider all possibilities for action and the consequences of each. Remember basic communication skills of listening and responding.

REPORTING PROCESS — SCENARIOS

For the third time in five visits you find your friend still dressed in pajamas at 11:00 a.m. You are concerned about it. What should you do?

Your friend asks for money for snacks each time you visit. According to the information you have, spending money should be available.

There is a warm, friendly, caring atmosphere at the facility in which your friend lives. Each time you enter you are greeted by residents and staff. There is a general sense of well being. You feel that each person is contributing to make his/her home comfortable. Should you share that feeling? With whom?

Your friend frequently talks about cooking, but complains because he/she is not allowed in the kitchen. What should you do?

What should your plan of action be if your friend complains to you:

> Roommate takes things from drawers and uses them without permission. Several things have been broken.
>
> Same roommate calls your friend "low grade." Keeps your friend awake at night grumbling under his/her breath about your friend, saying unkind things.
>
> Friend complains constantly about roommate. You have become very concerned about the effects of this roommate on your friend. What should your investigative process be?

Your friend likes to be responsible for refilling paper towel holders, toilet paper, etc. in the bathrooms at his/her residence and has been told he/she can no longer do that. Your friend complains to you about the situation. What can you do in your role as an advocate?

You meet with your friend on a regular basis. Your client lives in a group home and has indicated on several occasions that he/she desires a single room. You are aware that there is no space in the group home for a single room and at this time there are no other group home openings. You are aware that your client has a right to his/her own bedroom. What should you do?

You are participating in a group activity with your friend who resides in a group home. The home sends one staff person, one other volunteer and you as their

Reporting Process — Scenarios, page 2

staff/client ratio for 20 clients — it's overwhelming! Do you go? Do you accept the additional people who you do not know? How do you handle this situation for the best results for all parties including you?

You are out with your friend. It's time for medication. No arrangements have been made for administering the medicine. What do you do?

Friend tells volunteer, "I don't have a billfold anymore. Would you bring me one?"

Volunteer asks, "What happened to your billfold?"

Friend says, "Someone stoled it."

What other questions would you ask your friend? If no satisfactory answer, who would you go to with this problem? If the answer is staff counselor, social worker, etc., what if that staff person is the one that took the billfold? Should you as a volunteer advocate search for possible guilty parties?

(This is an actual experience of a volunteer friend. The client gives away any billfold ever received.)

IDENTIFYING COMMUNITY RESOURCES

PURPOSE (30 min.)

To identify services in the community in health, education, welfare, recreation, and religion.

To show *PERSON TO PERSON* Friends how much they already know about available services and thereby see themselves as good resources.

METHOD

Pair or individual activities

Presentations by agency personnel

MATERIALS

Newsprint — each sheet headed by one category of services (listed below)

Or: Individual lists of the categories of community services with space for participants to fill in specific services

Felt tip pens

Easels and masking tape

Directory or list of agencies, organizations and publications in your community providing human services

Handout *COMMUNITY ORIENTED ACTIVITIES*

ACTIVITY

There may be times when volunteers must assist friends finding a service in the community. This exercise increases awareness of the variety of services available to ALL people living in the area.

IDENTIFYING COMMUNITY RESOURCES

Before the session, print the categories of community services listed below on newsprint, one category per sheet. You may use any or all of the following categories, or add your own.

- Clinics
- continuing ed
- counseling
- recreation
- vocational guidance
- financial services
- family services
- health services
- legal services
- employment

Place the charts on tables or tape them to the walls.

Divide the group into pairs. Have each pair walk from newsprint to newsprint and write down community services which fit into the category on the heading. Pairs do not have to work in any particular order, and they can come back to a chart if they think of something after they have passed it. They do not have to work at every chart, only those where they have something to write down. Allow about 15 minutes.

When the pairs have finished their lists, call the group together to review the lists they have made. Go over one list at a time and discuss what is on it. For example, under employment, the list may read: state employment commission, newspaper want ads, municipal employment agency, personnel offices at area colleges. The whole group may be able to think of other services. If you know of some that have been left out, you might name them. If, in spite of your instructions, group members have overlooked some agencies not associated with handicaps, ask: "Why didn't we think of these?" "Would we use such resources ourselves?" "Could they serve people with developmental disabilities as well?"

OPTION 2

Instead of having pairs work together to identify community resources, you may have individuals work alone, writing down their lists of resources on pieces of paper. This alternative is feasible especially if you cannot provide a directory of community services. Group members can keep their own lists as the start of such a directory. (Good option when you are training only one volunteer but want to vary presentation methods.)

Write the categories of community services listed above on one sheet of paper and include space for participants to fill in specific agencies, organizations, and publications for each category. Pass out sheets to all participants and ask them to fill in the spaces.

After about 15 minutes, discuss as a group the individual lists, one category at a time, according to the directions given above.

HANDOUT

DIRECTORY OF COMMUNITY RESOURCES

If your city has a directory of community services, you may want to get copies for each volunteer. Sometimes umbrella groups will have lists of services within their specialty. For example, the local ARC may have a list of all agencies in the area which deal with people with mental retardation.

AGENCY PERSONNEL

Invite two or three people from different agencies to talk to the group about how the agencies work, whom they serve, and how they can help people with developmental disabilities.

In addition to giving useful information to volunteers, this activity may make cooperation from the agencies more likely.

OPTIONAL HANDOUT

List of Community Oriented Activities

COMMUNITY ORIENTED ACTIVITIES

Excursions or Tours

- Farms
- Public buildings
- Industries
- Police station
- Airport
- University campus
- Radio station
- Fire house
- Amusement parks
- Zoo
- Greenhouses
- Points of scenic interest
- Points of historic interest
- Television station

Knowing About and Using Local Businesses and Facilities

- Post office
- Community park
- Concert hall
- Shopping center
- Library
- Museum
- Restaurants
- Theatres
- Swimming pool, beach
- Barber shop/beauty parlor
- Community center

Public Transportation

- Buses
- Airplanes
- Taxis
- Trains

Community Events and Social Activities

- Local athletic contests
- Church socials, suppers
- Art exhibits
- Concerts
- Parades
- Circus
- Sport shows
- Talent shows
- Pet shows
- Visiting friends/neighbors
- Horse shows, rodeos
- Holiday, seasonal programs
- Fashion shows
- Carnivals and fairs
- Plays
- Auctions
- Home and garden shows
- Picnics

Sports and Recreation (don't forget being a spectator)

Softball
Kite flying
Field hockey
Canoeing
Archery
Frisbee
Bicycling
Cross country skiing
Volley ball
Badminton
Horseback riding
Horseshoes
Tumbling
Ice skating
Tobaganning
Golf and miniature golf
Croquet
Track and field events
Shuffleboard
Basketball
Ping pong
Football
Tennis
Soccer
Boating
Billiards
Tetherball
Swimming
Baton twirling
Sledding
Roller skating
Bowling
Gymnastics
Darts
Trampoline
Hiking

Clubs

Camera club
Athletics
Church groups
Bird watching
Cooking
Music
Dramatic
Neighborhood centers
Scouting
Choirs
Collectors clubs
YMCA/YWCA
Weight Watchers
Sport collectors
Hobby

Outdoor Activities

Astronomy
Fishing
Camping
Back packing
Bird watching
Bicycling
Gardening
Mineral study
Plant identification
Insect study
Animal study

City beautification
Volunteer service
Clean-up squad

Indoor Activities

Craft and arts	Table games
Bingo	Checkers
Jigsaw puzzles — Adult	Card games
Monopoly	Dominoes
Television	Listening to music
Listening to radio	Photography
Playing an instrument	Music lessons

"Observing and seeing
are not identical
Observing means paying
strict attention
to something . . ."

RECORDKEEPING SYSTEM

The forms provided for *PERSON TO PERSON* are listed below.

1. Client Needs Assessment
2. Client Information
3. Volunteer Application Form
4. Volunteer Interview Form
5. Vehicle Insurance Form
6. Volunteer Reference Form
7. Agency/Volunteer Agreement
8. Volunteer Time/Activity Log*
9. Volunteer Monthly Time Report*
10. Volunteer Expense Report*
11. Volunteer Contribution Record*
12. Volunteer Position Evaluation Form*
13. Volunteer Evaluation (by Supervisor)
14. Volunteer Assessment of *PERSON TO PERSON**
15. Exit Interview

Those forms that are for volunteer usage (8, 9, 10, 11, 12, and 14) are located in the Volunteer Manual single copies only. Several should be reproduced and distributed to each volunteer.

These records will provide a system of support for the *PERSON TO PERSON* Program, the volunteer, the agency/facility, and the community.

In using the forms, a management system will be in place for *PERSON TO PERSON* and the information gained through the system will be of value in all aspects of program growth and development.

* Indicates forms that volunteers will use.

RECORDKEEPING SYSTEM

PURPOSE (45 min.)

To introduce volunteers to the *PERSON TO PERSON* recordkeeping system.

To familiarize volunteers with the forms they will be using.

METHOD

Discussion.

Question and answer period.

MATERIALS

The documentation forms in the *PERSON TO PERSON* Guidebook. (Copies of forms the volunteers will use are in the Volunteer Manual.)

TRAINER'S REMARKS

Recordkeeping can be a very satisfying part of your job. The forms that are included in your Volunteer Manual will allow you to document your achievements.

What uses of the documented information might be important for you as a volunteer in *PERSON TO PERSON*?

List responses on newsprint. They should include — for resumes, tax returns, to identify skills developed, to identify skills or knowledge still needed.

From the volunteer's point of view, recordkeeping enables you to have more complete feedback from your supervisor, provides information for letters of recommendation, and allows for proof of volunteer expenses which you may itemize on your taxes.

For those who manage volunteer programs, documentation provides us with a system to recognize the volunteers. Recordkeeping helps us to evaluate the entire *PERSON TO PERSON* Program as we look at volunteer participation and satisfaction.

Because the records provide hard data — facts — to the agency or facility, it can serve as a motivator to the staff to form stronger relationships with volunteers as they recognize the significant contributions made. And ultimately the

community benefits because the program serves to enhance the total community.

HANDOUTS

Go over each of the handouts answering any questions that arise. Clarify those records that the volunteers keep in their files, those that go to a supervisor and those that go to a volunteer coordinator.

NEEDS ASSESSMENT FOR *PERSON TO PERSON* VOLUNTEER PROGRAM

1. Clients present contacts:	None	Once/ Week	Once/ Month	Twice Year/ or Less
a. Immediate family				
b. Other relatives				
c. Good friend or companion outside of "home living" area				
d. Good friend or companion in "living area"				
e. Social Worker				
f. Other: _____				
2. Clients desire for *PERSON TO PERSON* Program	**Alot**	**Somewhat**	**Indifferent**	**Hates**
a. Client loves to talk				
b. Client wants *PERSON TO PERSON* volunteer				
c. Client would participate in "activities" with volunteer				

3. Would client goals be addressed in *PERSON TO PERSON* Program?

List goals:

1. _____

2. _____

3. _____

Client's first name and last initial: _____

Client's address: _____

_____

_____

Client's Casemanager: _____

CLIENT INFORMATION FOR *PERSON TO PERSON* VOLUNTEER PROGRAM

1. List things client likes to talk about.

   _____

2. List activities, hobbies, skills, etc., client likes to do or would like to do.

   _____

3. List of activities and subjects client should not do and doesn't like to talk about.

   _____

4. List areas (personal or life in general) client is sensitive about and either positively or negatively overreacts.

   _____

5. Does client have medical restrictions or problems?

   _____

   IF SO, what time does medication have to be taken? Can volunteer ensure medication is taken?

   _____

6. What time is the client busy and can't go with or visit with the volunteer?

   _____

7. How often should volunteer visit client?

   _____

   2 or more visits/week _____ 1 visit/week _____

   2 visits/month _____ 1 visit/month _____ unknown _____

8. What general age range should the volunteer be in?

   _____

9. Is the client particularly vulnerable to any type of abuse?

   _____

Client's first name and last initial: _____

Address: _____

_____

Casemanager: _____

VOLUNTEER APPLICATION FORM
PERSON TO PERSON

Date: _____

Mr.
Mrs.
Ms. _____
FIRST MIDDLE LAST

Address _____
STREET or RFD CITY STATE ZIP

Place of Employment _____ Work Phone _____

Home Phone _____ S.S.# _____

Emergency Name and Phone _____

Education: High School ☐ College ☐ Major: _____

Other Schooling or Special Training _____

Interests or Hobbies _____

Skills (be specific) _____

Have you done volunteer work before? _____ What? _____

Where? _____

Availability: Sun. Mon. Tues. Wed. Thurs. Fri. Sat.

Morning: _____

Afternoon: _____

Evening: _____

Weekly ☐ Twice Monthly ☐ Monthly ☐ Other _____

How did you hear about *PERSON TO PERSON*? _____

Do you have access to an automobile you can use for volunteer work?

☐ Yes ☐ No ☐ Occasionally

Driver's License Number _____

References: (Give full names and addresses)

1. _____
2. _____
3. _____

Please return this form to: _____

_____

VOLUNTEER INTERVIEW RECORD
PERSON TO PERSON

Volunteer _____ Phone _____

Interviewer _____ Date _____

I. Review of Application Form — to clarify information on form or add any comments, make corrections.

_____

_____

II. Non-Directive Questions

1. What attracted you to *PERSON TO PERSON*? _____

   _____

2. What would you like to get out of your volunteer experience?
   What would make you feel like you've been successful? _____

   _____

3. What have you enjoyed most about your previous volunteer work? About your paid jobs? _____

   _____

4. Describe the relationship you would like with your supervisor? _____

   _____

5. What skills do you feel you can contribute? _____

6. Have you ever had a relationship with a person with developmental disabilities?

   _____

   Explain that relationship _____

7. Are there characteristics you would prefer in your client?
   ☐ Male ☐ Female Age: _____ Other: _____

8. What would you like to know about the program, agency? _____

   _____

9. What does it mean to you to "be a friend" to a person with developmental disabilities? _____

   _____

   _____

VOLUNTEER INTERVIEW RECORD
PERSON TO PERSON
Page 2

To be completed after interview.

III. Interviewer Assessment

Appearance:
☐ Poised, neat ☐ Acceptable ☐ Unkempt

Physical Restrictions: _____

Reactions to Questions: _____

Helpful, interested, volunteers information _____

Answers questions _____ Evasive _____

Confused _____

Disposition:

Outgoing, pleasant, confident _____

Reserved _____ Withdrawn moody _____

Suspicious, antagonistic _____

Interpersonal Skills:

Adept at dealing with others _____

Relatively at ease with others _____

Suspicious, antagonistic _____

IV. Recommended Action

Place as:

PERSON TO PERSON Volunteer: _____

Schedule for second interview: _____

Review information with Case Manager: _____

Investigate further: _____

Refer to: _____

Not candidate for *PERSON TO PERSON* Volunteer: _____

V. Notification

Volunteer notified of decision: _____

Name: _____

Date & Method: _____

VEHICLE INSURANCE

Below is a list of those physical impairments that Minnesota Law requires to be filed. We are asking that you help us by letting us know if you have any of the following disabilities. PLEASE CIRCLE ANY THAT APPLY TO YOU.

1. Epilepsy
2. Diabetes
3. Hemophilia (bleeder)
4. Cardiac disease
5. Partial or entire absence of thumb, finger, hand, foot, arm, or leg.
6. Lack of sight in one or both eyes or vision in either eye not correctable to 20/40
7. Residual disability from poliomyelitis
8. Cerebral palsy
9. Multiple sclerosis
10. Parkinson's disease
11. Cerebral vascular accidents (stroke)
12. Chronic osteomyelitis (recurrent bone disease)
13. Muscular dystrophy
14. Thrombophlebitis (blood clots)
15. Any other physical impairment for which at least fifty weeks or more of permanent partial disability benefits would be payable if the physical impairment were evaluated according to standards used in Worker's Compensation proceedings. Specify _____
16. Any other physical impairment of permanent nature which the Commission may prescribe by rule. Specify _____
17. I have no physical impairments.

_____ _____

Date Signature

In making this application to be a volunteer, I understand that I am not an agent or employee of _____, and I agree that if my services involve transporting any person, that I will maintain liability and no fault insurance upon my vehicle pursuant to the statutory requirements of the State of Minnesota. I further understand that this form is not an application for employment, and that _____ provides no auto insurance coverage for volunteers, and further does not agree to indemnify said volunteer for any legal liability arising out of transporting any person as a volunteer. I will apprise _____ as changes occur in my insurer name or coverage.

_____ _____

Insurance Company Policy Number

_____ _____

Agent's Name Phone

_____ _____

Agent's Address Zip

_____ _____

Volunteer's Signature Date

PERSON TO PERSON
VOLUNTEER REFERENCE

Name of Applicant _____

1. How long have you known the applicant? _____
2. In what capacity have you known applicant? _____
3. When was the last time you had contact with this person? _____
4. How well do you know applicant?

   ☐ Very well ☐ Well ☐ Little ☐ Very Little
5. How frequent is your contact with this person? (i.e. weekly, monthly, yearly)

   By Phone _____ In Person _____
6. Check as many of the following that you feel best describe the applicant:

☐ outgoing	☐ shy	☐ cooperative	☐ uncooperative
☐ patient	☐ impatient	☐ flexible	☐ rigid
☐ happy	☐ unhappy	☐ creative	☐ unimaginative
☐ confident	☐ lacks confidence	☐ stable	☐ unstable
☐ even tempered	☐ moody	☐ empathetic	☐ insensitive
☐ gregarious	☐ loner	☐ leader	☐ follower
☐ well-adjusted	☐ aggressive	☐ assertive	☐ passive

   Any problem areas: _____

   _____
7. How would you describe the applicant's friendship relationships?

   ☐ Very meaningful ☐ Meaningful ☐ Unimportant ☐ No friends ☐ Unknown
8. How would you describe applicant's relationship with people in general:

   ☐ Excellent ☐ Good ☐ Average ☐ Fair ☐ Poor ☐ Unknown

   Comments: _____
9. How responsible is applicant?

   ☐ Very ☐ Usually ☐ Seldom ☐ Irresponsible ☐ Unknown
10. Describe applicant's judgment: ☐ Uses excellent judgment ☐ Uses good judgment ☐ Uses fair judgment ☐ Uses poor judgment ☐ Unknown
11. To what extent does applicant follow through on commitments?

    ☐ Always ☐ Usually ☐ Sometimes ☐ Seldom ☐ Never ☐ Unknown
12. To your knowledge, has the applicant ever abused the use of drugs or alcohol?

    ☐ Yes ☐ No - If yes, please explain: _____

13. Do you know of any reason why the applicant would not serve well as a volunteer?

_____

14. If you can comment, describe this applicant's strong points in working in a one-to-one relationship with a person who has a developmental disability: _____

_____

15. If you have any additional information or comments that you feel would be helpful to us, please include them in the space below, or if you would like to discuss any information further, please call the Volunteer Services Coordinator, at: _____

The information you provide on the volunteer is between you and our agency. It is not shared with the volunteer.

Thank you for your cooperation.

_____ _____

Date Your signature

VOLUNTEER:

By signing below, I give my permission to _____ provide a character reference for information regarding my skills to be a volunteer for *PERSON TO PERSON.*

_____ _____

Date Your signature

AGENCY/VOLUNTEER AGREEMENT

This agreement is intended to indicate the seriousness with which we treat our volunteers. The intent of the agreement is to assure you both of our deep appreciation of your services and to indicate our commitment to do the very best we can to make your volunteer experience here a productive and rewarding one.

I. Agency

We, _____ (agency), agree to accept the services of _____ (volunteer) beginning _____, and we commit to the following:

1. To provide adequate information, training, and assistance for the volunteer to be able to meet the responsibilities of their position.
2. To ensure diligent supervisory aid to the volunteer and to provide feedback on performance.
3. To respect the skills, dignity and individual needs of the volunteer, and to do our best to adjust to these individual requirements.
4. To be receptive to any comments from the volunteer regarding ways in which we might mutually better accomplish our respective tasks.
5. To treat the volunteer as an equal partner with agency staff, jointly responsible for completion of the agency mission.

II. Volunteer

I, _____, agree to serve as a volunteer and commit to the following:

1. To perform my volunteer duties to the best of my ability.
2. To adhere to agency rules and procedures, including record-keeping requirements and confidentiality of agency and client information.
3. To meet time and duty commitments, or to provide adequate notice so that alternate arrangements can be made.

III. Agreed to:

_____	_____
Volunteer	*Staff Representative*
_____	_____
Date	*Date*

This agreement may be cancelled at any time at the discretion of either of the parties, but will expire automatically on _____ unless renewed by both parties.

PERSON TO PERSON
VOLUNTEER ACTIVITY/TIME LOG

Volunteer _____ Client _____

DATE	TIME SPENT TOGETHER	ACTIVITIES	COMMENTS/CONCERNS

Supervisor _____

PERSON TO PERSON VOLUNTEER MONTHLY TIME REPORT

Name _____ Job Title _____

Facility _____ Supervisor _____

Total Hours _____ Number of Clients Served _____

Month/Year _____

Please insert number of hours worked on each date:

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16

17	18	19	20	21	22	23	24	25	26	27	28	29	30	31

Comments:

Return to Volunteer Coordinator via supervisor on first day of the month

VOLUNTEER EXPENSE REPORT

This form is to be utilized to record those expenses you incur while volunteering for us *for which you wish to be reimbursed.* The types of expenses for which we provide reimbursement are:

1. _____
2. _____
3. _____
4. _____

DATE	TYPE OF EXPENDITURE	AMOUNT

TOTAL

These represent an accurate account of my expenses.

_____
VOLUNTEER

_____
DATE

Approved for reimbursement.

_____
STAFF

_____
DATE

Cash/Payment Received

_____
VOLUNTEER SIGNATURE

_____
CHECK/PAYMENT ISSUED

Volunteer Contributions Record

This form is to be utilized to record donations of money, in-kind contributions, and expenses incurred while volunteering for which you are not being reimbursed by our agency. Please complete the form and submit it to _____ so that we can attest to the contribution. We will then return a signed copy for you to include in your tax records.

DATE	NATURE OF CONTRIBUTION	AMOUNT
	TOTAL	

I verify that these represent an accurate portrayal of my contributions:

_____
VOLUNTEER

_____
DATE

I verify that these represent contributions received by our agency:

_____
STAFF

_____
AGENCY

_____
DATE

Volunteer Position Evaluation Form

Name of Volunteer: _____ Period Covered by Evaluation: _____

Position: _____ Date of Evaluation: _____

Position Goals

	Not Met		Satisfactory		Superior
1. _____	1	2	3	4	5
2. _____	1	2	3	4	5
3. _____	1	2	3	4	5
4. _____	1	2	3	4	5
5. _____	1	2	3	4	5

Work Relationships

	Needs Improvement		Satisfactory		Excellent
1. Relations with other volunteers	1	2	3	4	5
2. Relations with staff	1	2	3	4	5
3. Relations with clients	1	2	3	4	5
4. Meeting commitments on hours and task deadlines	1	2	3	4	5
5. Initiative	1	2	3	4	5
6. Flexibility	1	2	3	4	5

Comments by supervisor regarding above areas:

_____

_____

Comments by volunteer regarding above areas:

_____

_____

Overall, how does the volunteer feel about remaining in this position?

_____

_____

What else can be done to support the volunteer in this position or to move the volunteer to a new position?

_____

Signed:

_____ _____

Supervisor Volunteer (Optional)

_____ _____

Date Date

Scheduled date of the next evaluation. ____

PERSON TO PERSON
VOLUNTEER EVALUATION

DATE:

TO:

FROM:

SUBJECT: Volunteer Evaluation

The evaluations for volunteer staff for the year of _____ are due.

Volunteer's Name:_____

Please complete the following:

1. Confidentiality
   a. ☐ Always maintains confidentiality.
   b. ☐ Makes mistakes in the type and amount of information that is shared.
   c. ☐ Does not maintain confidentiality at all.
2. Appropriate Behavior
   a. ☐ Always models appropriate behavior and expects the same behavior from clients (taking into consideration the clients disability or disease).
   b. ☐ Always models appropriate behavior, but is too lenient of clients behavior.
   c. ☐ Models appropriate behavior most of time.
   d. ☐ Sometimes models appropriate behavior.
3. Supervision
   a. ☐ Maintains good working relationship with supervisor.
   b. ☐ Accepts supervision, but not much communication.
   c. ☐ Sometimes doesn't accept supervision.
   d. ☐ May have caused harm to other staff or clients by not accepting supervision.

4. Reports observations to professional staff
   a. ☐ Spends some time each working day communicating observations to staff.
   b. ☐ Reports all necessary observations to professional staff.
   c. ☐ Sometimes reports observations to professional staff.
   d. ☐ Doesn't report to professional staff.
5. Attendance
   a. ☐ Always on time or notifies in time.
   b. ☐ Occasionally late.
   c. ☐ Often late or absent but notifies in time.
   d. ☐ Often absent and fails to notify.
6. Volunteer/Client Relationship — please describe: _____

_____

_____ _____

Signature Date

VOLUNTEER ASSESSMENT OF *PERSON TO PERSON*

As part of a continual effort to improve our program, we would like your responses to the following questions. All responses will be kept completely confidential. Your signature is optional.

1. How long have you been with the program? _____
2. What is the best experience you have had while volunteering? What is the worst experience? _____
   _____
   _____
3. To what extent do you think volunteers are accepted by staff?
   ☐ Well accepted ☐ Generally not well accepted, some exceptions
   ☐ Mixed reception ☐ Generally not well, some exceptions
   ☐ Not well accepted
4. To what extent do you think volunteers are accepted by clients?
   ☐ Well accepted ☐ Mixed reception ☐ Not well accepted
5. To what extent do you think volunteers feel comfortable with their client match?
   ☐ Comfortable ☐ Not very comfortable ☐ Don't know
6. Do you feel that volunteers receive sufficient orientation to the facility when they begin to work?
   ☐ Yes ☐ No ☐ Don't know
7. Do you feel that volunteers receive enough training to be comfortable in their relationship?
   ☐ Yes ☐ No ☐ Don't know
8. In your experience, does your volunteer job match the description of work given to you when you were interviewed?
   ☐ Yes ☐ Somewhat ☐ No
9. Do you find your volunteer work to be interesting, challenging, and rewarding?
   ☐ Yes ☐ Somewhat ☐ No
10. Do you think that volunteers are provided with sufficient feedback by supervisors?
    ☐ Yes ☐ Somewhat ☐ No ☐ Don't know
11. Can you suggest any ways that we might use to recruit new volunteers?
    _____
    _____
12. Overall, how would you rate the *PERSON TO PERSON* Program?
    Please circle. 1=Poor, 7=Great.
    1 2 3 4 5 6 7
13. Any comments or suggestions you would like to make _____
    _____
    _____

EXIT INTERVIEW QUESTIONNAIRE

We are always striving to improve the performance of our volunteer management system. As one of our volunteers, we would appreciate your help in identifying areas in which we might do better. Please be as complete and honest as you can in answering the following questions—all of the information collected will be kept strictly confidential, but it it will be utilized to ensure that others who volunteer will receive the best possible treatment.

How long did you volunteer with us? _____

Types of volunteer positions held:

1. _____
2. _____
3. _____
4. _____

Why are you leaving? (Check all that apply)

- ❑ Job accomplished
- ❑ Didn't like the job I was given
- ❑ Moving to a new location
- ❑ Didn't feel well utilized
- ❑ Need a change
- ❑ Other time commitments
- ❑ Other: _____

What did you like best about volunteering with us?

_____
_____
_____
_____

What suggestions would you make for changes or improvements in our volunteer effort?

_____
_____
_____
_____

Overall, how would you rate your experience in volunteering with us?

TERRIBLE			AVERAGE			GREAT
1	2	3	4	5	6	7

Please return this form to:

Name: _____

Address: _____

ON-GOING IN-SERVICE TRAINING

On-going training for *PERSON TO PERSON* volunteers will provide the volunteers (and staff if they chose to attend), with new skills and information, a reward for time and talent expended, and may serve to motivate continued involvement in the project.

Through the Orientation, the volunteer became familiar with the agency, the system, developmental disabilities, and volunteer responsibilities.

The initial training provided the volunteer with the tools to begin a relationship.

As the established *PERSON TO PERSON* relationship grows, more information will be desired and needed. Included here are a wide range of topics for consideration as planning for in-service occurs. It is recommended that decisions on areas to be covered at a specific training are made by the volunteers and staff support team and all are invited to attend.

When planning the presentation — use the resources (people, organizations, agencies, education systems, audiovisuals), and combinations of resources available to deliver the information. Limit the session to one and a half to two hours in length.

Do not feel limited by these suggestions:

Sexuality

Volunteers — Taking Care of Yourself
- Saying "No"
- Setting Limits

Safety, CPR, First Aid, Accident Prevention, Defensive Driving

Responding to Seizures

Continual Team Building for Staff/Volunteer Relationships

Terminating Relationships

Community Activities/Resource Update

New Developments in Service Provision for People with Developmental Disabilities

Guardianship/Conservatorship

Involving Your Family/Friends

Transferring/Aiding the Person with a Physical Handicap

Negotiation Skills

REFERENCES

Material in this book has been adapted from sources cited and a variety of references including:

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Minnesota State Planning Agency, *A New Way of Thinking*. St. Paul, 1987.

Minnesota State Planning Agency, *Community Residential Advocacy for Persons with Developmental Disabilities: Current Status and Future Development*. St. Paul. April, 1981.

Office of Mental Retardation and Developmental Disabilities, *Instructional Curriculum Modules in Community Based Training*. Albany, NY, Bureau of Staff Development and Training. 1980.

Pennsylvania Developmental Disabilities Planning Council, *A Story That I Heard*, A Compendium of Stories, Essays, and Poetry About People With Disabilities and American Life, Collected by David B. Schwartz. July, 1987.

Research and Training Center in Mental Retardation, *Action Through Advocacy*, Texas Tech University. 1980.

State of Minnesota, Department of Energy, Planning, and Development, The Governor's Planning Council on Developmental Disabilities, *Developmental Disabilities and Public Policy: A Review of Policymakers*, St. Paul. 1983.

Vineyard, Sue. *Beyond Banquets, Plaques & Pins: Creative Ways to Recognize Volunteers*, Heritage Arts/VMSystems, Downers Grove, IL 60515. 1989 Rev.Ed.

Vineyard, Sue. *Marketing Magic for Volunteer Programs*, Heritage Arts/VMSystems, Downers Grove, IL 60515. 1985.

Vineyard, Sue & McCurley, Steve. *101 Tips on Volunteer Recruitment*, 1988, Heritage Arts/VMSystems, 1807 Prairie Ave., Downers Grove, IL 60515.

VIDEOS

A Guide to Dependent Feeding — Betsy Reggio Davis, OTR
Ment. Ret./Dev. Dis. Administration,
State of Maryland — Time: 10:00

A New Way of Thinking
MN Governor's Planning Council on Dev. Dis. — Jan. 87 — Time: 23:00

An Interview with Herb Lovett; Adapting Behavioral Approaches to the Social Context.
MN Governor's Planning Council on Dev. Dis. — Oct. 87 — Time: 39.49

Basic Volunteer Management — Sue Vineyard,
Heritage Arts, Downers Grove, IL. — May 89 — Time: 75:00

Behavior Management Techniques with B.A.
Bethesda Lutheran Home, Watertown, WI — Time: 39:30

The Case Management Team: Building Community Connections
Toni Lippert, MN Governor's Planning
Council on Dev. Dis. — Nov. 87 — Time: 13:00

Confidentiality with Karen Fitz-Patrick
Bethesda Lutheran Home, Watertown, WI — Sept. 88 — Time: 27:00

Epilepsy: First Aid for Seizures (Shows 3 major types of seizures and first aid for each) National Epilepsy Foundation — Time: 15:40

It's My Life with Kathleen McGwinn Dispelling the Misconceptions of MR
Bethesda Lutheran Home, Watertown, WI — July 87 — Time: 26:50

It's Never Too Early, It's Never Too Late, Personal Futures Planning
St. Paul Metropolitan Council for Dev. Dis. — 1988 — Time:11.40

Learning Characteristics of People who are Mentally Retarded
Bethesda Lutheran Home, Watertown, WI — Oct. 88 — Time: 34:55

Mental Retardation with Dr. John Heffelfinger and Kathleen McGwinn
Bethesda Lutheran Home, Watertown, WI — Feb. 88 — Time: 53:58

Normalization with Kathleen McGwinn
Bethesda Lutheran Home, Watertown, WI — Time: 26.15

Occupational Therapy Makes A Difference with Paula Galaviz
Bethesda Lutheran Home, Watertown, WI — Dec. 87 — Time: 54:45

Regular Lives. Tom Goodwin & Geraldine Wurzburg,
Syracuse University
WETA Television 26, Radio FM 91,
Washington, D.C. — 1988 — Time: 28:33

Resident Rights with Kathleen McGwinn, Dean Kirst and Shirley
Bethesda Lutheran Home, Watertown, WI — March 88 — Time: 35.00

Safety — Accident Prevention with D. Sindberg & Staff
Bethesda Lutheran Service — Aug. 87 — Time: 24:00

Supported Employment — It's Working Out &
Richard and Donna
MN Governor's Planning Council on
Dev. Dis., 1988 — Time: 14.30 — Time: 11.10

Tools for Life, How Technology Helps People with Disabilities
MN Governor's Planning Council on Dev. Dis. — Time: 19.00

Tornado Awareness
Bethesda Lutheran Services — April 88 — Time: 24:42

What Is Active Treatment with Kathleen McGwinn
Bethesda Lutheran Home, Watertown, WI — Aug. 87 — Time: 22:30

Writing Objectives with Kathleen McGwinn and Karen Fitz-Patrick
Bethesda Lutheran Home, Watertown, WI — June 88 — Time: 39.15