PERSON TO PERSON

VOLUNTEER MANUAL

Written by Jackie Sinykin & Sue Vineyard
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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.
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 or 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 inabilities 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 capabilities 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.

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.
THE RESIDENTS' BILL OF RIGHTS

This 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 the mentally retarded (ICF/MR). These rights are set forth in M.S. 144.631-2.1, and in Volume 42, Code of Federal Regulations, Sections 442.403 and 442.404.

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

Public 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 include but not be limited to the following:

- It is 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 may 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 interested 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 guardian or conservator through administrative agencies or in probate court or county court having jurisdiction over guardianships and conservatorships. Pending the outcome of an enforcement 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 and 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 the fullest possible exercise of these rights.

- THE 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 their course of treatment and maintenance, in any service which are provided to those residents by individuals, corporations, or organizations other than the facility. Information shall include the names 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 the 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.

- THE RIGHT TO KNOW WHO IS PROVIDING PHYSICIANS' SERVICES. Residents shall have or be given, in writing, the name, business address, telephone number, and specialty, 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 record, the information shall be given to the resident's guardian or other person designated by the resident as his or her representative.

- THE RIGHT TO REFUSE CARE. Competent residents shall have the right to refuse treatment based on the information required above. Residents who refuse treatment, medication, 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 is incapable of understanding the circumstances but has not been adjudged incompetent, or when legal requirements limit the right to refuse treatment, the conditions and circumstances shall be fully documented by the attending physician in the resident's medical record.

- THE RIGHT TO 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 infliction 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 chemical and pharmacologic interventions in two possible situations: (1) as authorized in writing after examination by a resident's physicians for a specified and limited period of time, and only when necessary to protect the resident from self-injury or injury to others; or (2) in documented emergencies if necessary to protect the resident from himself or others. If the use 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 physician by the staff member.

- THE 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, consultation, examination, and treatment are confidential and shall be conducted discreetly. Privacy shall be respected during toileting, bathing, and other activities of personal hygiene, except as needed for resident safety or assistance.
RIGHT TO CONFIDENTIALITY OF RECORDS. Residents shall be assured confidential treatment of their personal and medical records, and may approve or refuse their release 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 accompany 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 with 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 of Health, where required by third party contracts, or where otherwise provided by law.

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 the 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 in obtaining information whether the Medicare or Medical Assistance program will pay for any or all of the aforementioned services.

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

RIGHT TO PERSONAL PRIVACY. Residents shall have the right in every consideration of their privacy, individuality, and cultural identity as related to their social, religious, and philosophical 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 clearly unavoidable.

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 exercise 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, coercion, discrimination, or reprisal, including threat of discharge. Notice of the grievance procedure of the facility, as well as addresses and telephone numbers 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 conspicuous 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 write an 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 right to have the assistance of an advocate; requires a written response to grievances; and provides for a timely decision by an impartial decision maker if the grievance is unresolved. Compliance by residential programs as defined in MN Statutes 253C.01 with section 144.491 is deemed to be compliance with the requirement for a written grievance procedure.

SECTION AND ADVOCACY SERVICES. Residents shall have the right of reasonable access at reasonable times to any available rights protection services and advocacy services to the extent 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 to communicate between resident and a representative of the rights protection service or advocacy service.

RIGHT TO COMMUNICATE PRIVILGPLY. Residents may associate and communicate privately with persons of their choice and enter and, except as provided by the Minn. 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 at interference and received unopened unless medically or programmatically contraindicated and documented by the physician in the medical record. There shall be access to a one 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 accommodate the privacy of resident's calls. This right is limited where medically unavoidable, as documented by the attending physician in a resident's care record. Where programmatically limited by a facility abuse prevention plan pursuant to Section 626.597, subd. 14, clause 2, this right shall also be limited accordingly.

RIGHT TO HAVE AND USE PERSONAL PROPERTY. Residents may retain and use their personal clothing and possessions as space permits, unless it is directed to infringe rights of other residents, and unless medically or programmatically contraindicated for documented medical, safety or programmatic reasons. The facility must either maintain a 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 mausoleum for or replacement of lost or stolen items.

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 use and appropriately goal-related in their individual medical record.

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 prohibited by law. The supplier shall assure that these purchases are sufficient to meet the medical or treatment needs of the patient.

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

RIGHT TO ASSOCIATE. Residents may meet with visitors and participate in activities of commercial, religious, political, or social nature as defined by the Minnesota statutes regarding voting 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 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 facility to work for improvements in long term care.

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 council 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 shall represent the facility with the responsibility of providing this assistance and responding to written requests which result from council meetings. Resident and family councils shall be urged to make recommendations regarding facility policies.

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 informed to share a room, unless medically contraindicated and documented by the physicians in the medical records.

RIGHTS OF TRANSFERS AND DISCHARGES. Residents shall not be arbitrarily transferred or discharged. Residents shall not be transferred or discharged after notice 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 resident'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)]. The notice shall be given prior to the resident's discharge, and unless prohibited by 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.

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 set forth in this section of all rules governing resident conduct and responsibilities.

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. The resident's complaint shall be in writing and mailed to the address of the Minnesota Department of Health, 717 S.E. Delaware Street, Minneapolis, Minnesota 55403; telephone 612-623-5562.

Complaints 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. The resident's complaint shall be in writing and mailed to the address of the Minnesota Department of Health, 717 S.E. Delaware Street, Minneapolis, Minnesota 55403; telephone 612-623-5562.

Examples of grievances about medical care may be directed to the State Board of Medical Examiners, Room 352, 717 S.E. Delaware Street, Minneapolis, Minnesota 55401; telephone 612-623-5534.

The facility contact: ____________________________________________

[Signature of Resident]

[Signature of Guardian or Conservator]

This agreement is in accordance with the laws of Minnesota, 1985 University Avenue, St. Paul, Minnesota 55104.

[By the Association of Residential Resources in Minnesota, 1985 University Avenue, St. Paul, Minnesota 55104]
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
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 to 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.
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.
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 it also demands that volunteers hold themselves responsible to others.
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

90
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.
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.
# PERSON TO PERSON
## VOLUNTEER ACTIVITY/TIME LOG

<table>
<thead>
<tr>
<th>DATE</th>
<th>TIME SPENT TOGETHER</th>
<th>ACTIVITIES</th>
<th>COMMENTS/CONCERNS</th>
</tr>
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</table>

Volunteer __________________________________________ Client __________________________

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:

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Comments:

Return to Volunteer Coordinator via supervisor on first day of the month
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 ____________________________

__________________________________________________________________________
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. 

<table>
<thead>
<tr>
<th>DATE</th>
<th>TYPE OF EXPENDITURE</th>
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These represent an accurate account of my expenses. Approved for reimbursement.

Volunteer

Staff

Date

Date

Cash/Payment Received

Volunteer Signature

Check/Payment Issued

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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.

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<tr>
<th>DATE</th>
<th>NATURE OF CONTRIBUTION</th>
<th>AMOUNT</th>
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I verify that these represent an accurate portrayal of my contributions:

Volunteer

I verify that these represent contributions received by our agency:

Staff

Agency

Date

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VOLUNTEER POSITION EVALUATION FORM

NAME OF VOLUNTEER: ____________________________________________

PERIOD COVERED BY EVALUATION: ________________________________

POSITION: ______________________________________________________

DATE OF EVALUATION: __________________________________________

POSITION GOALS

<table>
<thead>
<tr>
<th>Not Met</th>
<th>Satisfactory</th>
<th>Superior</th>
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<tr>
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POSITION GOALS

<table>
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<tr>
<th>Work Relationships</th>
<th>Needs Improvement</th>
<th>Satisfactory</th>
<th>Excellent</th>
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<tbody>
<tr>
<td>1. Relations with other volunteers</td>
<td>1 2 3 4 5</td>
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<tr>
<td>2. Relations with staff</td>
<td>1 2 3 4 5</td>
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<tr>
<td>3. Relations with clients</td>
<td>1 2 3 4 5</td>
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<tr>
<td>4. Meeting commitments on hours and task deadlines</td>
<td>1 2 3 4 5</td>
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<td>5. Initiative</td>
<td>1 2 3 4 5</td>
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<tr>
<td>6. Flexibility</td>
<td>1 2 3 4 5</td>
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</table>

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

DATE

Volunteer (Optional)

DATE

Scheduled date of the next evaluation.______________________________

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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 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
- Moving to a new location
- Didn't like the job I was given
- Didn't feel well utilized
- Need a change
- 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?

<table>
<thead>
<tr>
<th>Terrible</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>Average</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>Great</th>
<th>7</th>
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</thead>
</table>

Please return this form to:
Name:__________________________________________
Address:________________________________________

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REFERENCES

Material in this book has been adapted from sources cited and a variety of references including:


Research and Training Center in Mental Retardation, Action Through Advocacy, Texas Tech University. 1980.


