Creating Visions

Personal Assistant Training Guide

Sally L. Burton, Ed.D.

With consultation by
Marsha Katz
Bob Liston
Verna Spayth
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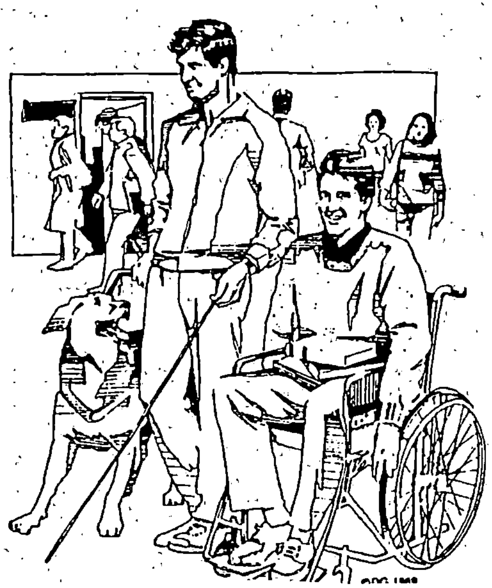
of the Washtenaw Association
for Community Advocacy



Developed in part
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Michigan Developmental Disabilities Council
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How Do You Assist the Person You Work for to Create a Vision for Themselves Which Includes All that They Want Out of Life?

Introduction

The philosophy used to develop this training guide is that each individual should be at the center of the service system. The Creating Visions Training Program is promoted with the goal of better assisting individuals with disabilities throughout the community to live the life that they choose. Through the Creating Visions Program, we share with you the importance that all persons might live with the assistance which fits their needs, from a qualified and competent personal assistant.

The Creating Visions Direct Care Training Project promotes the following through this training guide for all individuals providing and receiving personal assistance:

Ethics of Personal Assistance

Independence

Dignity

In the following modules, you, the personal assistant, will learn the purpose of personal assistance and how your values and knowledge affect the quality of life for the persons you assist.

- Module One: Ethical Approaches Towards Assisting Persons with Disabilities
- Module Two: Overview of Developmental Disabilities and Family Needs
- Module Three: Positive Supports for the Entire Person (PSEP)
- Module Four: Strategies for Increasing a Positive Life

Module One

Ethical Approaches Towards Assisting Persons with Disabilities

In this module we will explore the role that personal assistance may play in all individuals living the sort of life that they want to live with the amount and type of support which fits <u>their</u> needs. Historically, persons with disabilities and other challenges have received services that are directed by <u>other</u> persons and agencies as opposed to self-determined needs. Personal assistance is directed by the employer (the person to whom you are providing assistance), which means that services are typically employer-determined and defined.

Each person has a vision for their life and you may be asking how you can assist your employer in what their vision may hold. A vision is defined by Webster as "the power of seeing, a mental image, the ability to see something." What do you see for yourself? As a personal assistant, it is important to realize that the wants and desires that you have for yourself may very often be the same as the person who employs you. A person with a disability has the right to pursue all that life has to offer, just as you do!

Answer yes or no to the following questions. Be ready to discuss your responses and share your goals.

1. Do you want a job that you can go to every day?
2. Do you want good health care?
3. Do you want security from poverty and loneliness?
4. Do you want recreational opportunities?
5. Do you want social opportunities?
6. Do you want to be a part of the community?
7. Do you want to feel good about who you are and your accomplishments?
8. Do you want companionship and affection in your life?
9. Do you want to learn and grow?
10. Have you developed your full potential, or do you feel that you can do more in your life?

Congratulations to you!

If you answered yes to most of these questions then you are a person who shares the belief that all persons are constantly striving to reach their full potential. All people can live in their own home in the community, no matter how severe their disability, if adequate support systems are available. As a personal assistant, you may assist your employer in reaching their success.

PROGRAM DESCRIPTION

Personal Assistance services are designed to support all persons to live independently. Racino (1991) defines personal assistance as:

> Whatever a person needs to live fully within the community (as defined by the individual) to ensure dignity, self-determination, respect, and full participation, throughout his or her lifespan.

If your values conflict with the philosophy of personal assistance, please reevaluate your choice of employment and what you would hope to gain from assisting persons with disabilities.

Personal assistance is a service which offers support to persons with disabilities who strive to live independently. The overall goal of personal assistance is to "encourage" the development of maximum self-determination and independence possibly by the individual and authorize services only to the extent necessitated by the individuals functional limitations utilizing natural supports where possible (Michigan Dept. of Social Services Manual, pg.2).

Personal assistance is provided to enable all individuals to live independently in their own home or apartment. As a personal assistant, your job may be to assist your employer with daily living skills.

Activities of Daily Living include:

- Eating
- Toileting
- Bathing
- Grooming
- Dressing
- Transferring
- Mobility
- Taking medication
- Meal preparation/clean up
- Shopping/errands
- Laundry
- Housework

You may be employed by an individual or married couple to assist them in activities that are necessary to function in her/her/their environment. Remember the purpose of personal assistance is to put a person with a disability on equal footing with non-disabled individuals.

As a personal assistant, you may be employed by various individuals with disabilities. Each person who employs you will require different amounts and types of supports depending on the level of need. For example, persons who employ you may be: a) cognitively impaired (learning, memory, language); b) sensory impaired (vision, hearing); c) physically impaired; d) emotionally impaired.

A person with cognitive impairments may not need any physical assistance with daily living activities, but <u>may</u> require reminders of assistance in reading or writing a shopping list or safeguards for health safety. Persons with cognitive impairments are usually presumed to be incapable of making choices and decisions, but assistance and support in these areas may be all that are required. A person who has physical impairments <u>may</u> require assistance in eating, grooming or toileting. It is important to realize that there is no set criteria for what various persons with disabilities may require in daily living assistance. A person with severe cognitive or sensory impairments may require you, the personal assistant, to observe the behavior of your employer in order for you to assess their needs. Remember, "behavior is communication." If you can't determine your employer's choices through their language or behavior, then interpret the demonstrated behavior as their communication. An individual with no cognitive impairment, but with some physical impairments, requires no observational skills for you to assess their need. A simple question, "What do you want for me to do?" is all that is required for the majority of persons who will employ you.

In the following activity, complete the sentence and describe the person that you assist.

1. The person I assist communicates by:

2. Typical days for the person I assist include:

3. My employer participates in the following community activities:

4. My employer has family involvement consisting of:

5. The most positive contribution I make to my employer is:

It is important for you to know your employer in order for you to assist them in their life. If the person who employs you has cognitive and language disabilities, then it may be appropriate for you to observe them in order to interpret what safeguards you will need in order to protect the person who employs you from unsatisfactory experiences. (Please see modules three and four for additional information on this topic).

Understanding The Creating Visions Philosophy

To develop an understanding of the Creating Visions Training philosophy, it is important to remember the following:

All persons want to be Independent;
All persons want to fully participate in life; and
All persons are protected by laws from unjust treatment and discrimination.

The quality of life for persons with disabilities consists of the same factors and relationships that are important to persons without disabilities (Gorman and Strully, 1989)[1]. Independence, the ability to make choices and be around persons who value and care for us in the community, is what life is all about, no matter who we are.

Independence

Independence is the ability to live one's own life within his/her abilities in a manner consistent with one's own values and preferences (Turnbull & Turnbull, 1986)[2]. This does not mean that all people will want to or should live in a house or apartment by themselves. However, if living in a house or apartment with given supports is consistent with a person's desires, then it should be undertaken. And **you**, the personal assistant, should be ready and able to assist the individual with his or her choice. Independence should then be synonymous with freedom of choice, self-determination, and autonomy from

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[1]. Gorman, W. L. & Strully, J. (1989). Independence, Integration, and Productivity: The Past, Present and Future. (Monograph) University of Colorado Health Sciences Center, Denver, CO.

[2]. Turnbull, A. P. & Turnbull, H. R. (1986). *Families, Professionals and Exceptionality: A special partnership*. Columbus, OH: Merrill.

outside interference (Gaylin & Macklin, 1981)[3]. Specific needs should be defined by the person with a disability with the underlying premise that each person in unique, and not by agencies and professionals who may judge and determine an individual's level of independence based on the bias that only persons with certain "attributes" can live independently.

Society portrays personal independence as an individual able to perform all tasks without any assistance. Scotch (1984)[4] feels that independence can mean choosing to do tasks with or without assistance which is the basis of personal assistance. It may also mean choosing whom one will ask for assistance. It must be emphasized that it is the choice of the employer how various daily living activities are accomplished. Personal assistants in most cases should not make judgements regarding how a task should be performed, or at what level their employer should participate. The purpose of Personal Assistance is to put persons with disabilities on an equal footing with non-disabled persons, and for their employers to choose how that assistance is delivered.

Principle of Partial Participation

Professionals have taken on an "all or nothing" attitude in regards to persons with developmental disabilities; either the person can perform a task or they can't. All persons would complete tasks on their own given the choice, but this may not be possible due to physical limitations. Baumgart, Brown and

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[3]. Gaylin, W. & Macklin, R. (1981). Mental Retardation and Sterilization: A problem of competency and paternalism. Plenum Press.

[4]. Scotch, E. (1984). Professionals as Providers: Some Thoughts on Disability and Idealogy. *Rehabilitation Psychology, 29,* 211-216.

colleagues (1982)[5] discovered that in many situations, skills and activities in school, home, and the community were not attempted unless there were reasonable assurances that a person with a disability would be able to perform all the required skills. As a personal assistant you must make the assumption that your employer will inform you at what level they will participate in the task.

We must honor and accommodate persons with language or cognitive disabilities by assuming that 1) they would choose to participate fully in task; and 2) assessing their desires based on past and present behavior, augmentative communication devices, language books, or however needs are communicated.

The principle of partial participation analyzes functional tasks for everyday living. The principle declares that if a person cannot perform any task fully, but is able to or chooses to use adaptations and/or varying levels of assistance, any person can partially participate in a task or activity. Partial participation affirms that:

1. Participation in community activities should be age appropriate.
2. Regardless of a person's level of need, the person should be encouraged to participate in a wide range of activities and environments.
3. The kinds of participation in the community may be increased through instruction and general exposure to different environments across the lifespan.
4. Participation should result in a person being perceived by others as a valuable and contributing member of society.

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[5] Baumgart, D., et al (1982). Principle Participation and Individualized Adaptations in Educational Programs for Severely Handicapped Students, *Journal of the Association for the Severely Handicapped, Vol. 7, No.* 2, 17-27.

5. Joint efforts must be initiated at a young age in order to prepare for participation across the life span.

How do You Adapt Tasks for Partial Participation? There is no one way a task is adapted. In fact, most personal assistants already adapt tasks by approaching the activities of daily living in some manner which better meets the needs of the persons they assist. Five types of individualized adaptations are described in articles by Brown, Branston-McClean, Baumgart, Vincent, Falvey, and Schroeder (1979)[6] and Wehman, Kregel, and Barcus (1980)[7]. Adaptations include:

1. Creating materials and devices such as wheelchairs, orthopedic braces, nonverbal communication systems, and adapted eating utensils.

2. Offering personal assistance in the form of verbal, gestural, and physical movement as provided by another person. An example of an adaptation may be plugging in an electrical cord before a person uses a computer speaking device, or cuing a verbal response.

3. Adapting skill sequences by using a different sequence of events to accomplish a task than non-disabled people.

4. Social/attitudinal adaptations referring to changes in assumptions,

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[6]. Brown, L., Branston-McClean, M. B., Baumgart, D., Vincent, L., Falvey, M., & Schroeder, J. (1979). Using the characteristics of current and subsequent least restrictive environments in the development of curricular content for severely handicapped students. *AAESPOO Review, 4*(4), 407-424.

[7]. Wehman, P., Kregel, J., & Barcus, J. M. (1985). School to Work: A vocational transition model for handicapped students. *Exceptional Children, 52*(1), 25-73.

judgements, and beliefs that allow or enhance community participation.

Remember to presume competence! Adaptations, much like personal assistance, help individuals perform an action or movement that was previously not possible without the aid of the adaptation.

Things to Consider When Increasing Participation in the Community for Persons with Cognitive Impairments.

- Is the activity one selected by your employer?
- Does the activity and participation of your employer increase the number of environments the person is gaining access to?
- Is the activity valuable and meaningful to your employer?
- Were adaptations and subsequent activities selected solely because they were available, convenient, and/or used with other persons in the same category, functioning level, city, etc.? (Make sure all adaptations are individualized).

It is important to remember that the level and form of assistance required is determined by the employer.

Suggestions Regarding Adaptations

1. Test adaptations in the environments where they will be used.
2. Select the adaptation your employer is most comfortable with, noting that a change in circumstances often requires a change in adaptations.
3. Adaptations should not be over used such as to make a person dependent on them. Over time the person might develop skills rendering the

adaptation unnecessary. Continuously re-evaluate by asking your employer what he/she desires.

4. Adaptations must be individualized (not all for one and one for all!)
5. Use adaptations which your employer chooses and allow for maximum participation. Select adaptations only after determining the activities desired by your employer. Don't select an activity just because an adaptation exists or is convenient.
6. Allow time for your employer to have several opportunities to use possible adaptations before one is selected.

Were tasks for partial participation and adaptations selected solely because they were available, convenient, and/or used with other persons in the same functioning level or category? Make sure all adaptations are individualized. Be creative and remember the person's age, interests, and behavioral objectives.

Partial participation in a practical way will mean different things for different individuals. It may be easier and more practical for you as a personal assistant to perform the task yourself. When in doubt, ask your employer what he/she would like.

For the following activities, respond to the ways you might adapt activities to your employer.

1. Fixing breakfast

2. Dressing

3. Eating

4. Talking on the phone

5. Making cookies

6. Changing a television channel

7. Cooking a microwave dinner

8. Cleaning the kitchen

9. Washing hair/taking a shower

By assisting your employers in participating as fully in their lives as they choose, you may empower them with feelings of accomplishment that are often taken for granted.

For a person to be fully empowered and engaged in maximum community participation he/she must have accurate knowledge of their basic human rights.

Basic Rights of Persons with Developmental Disabilities

The Right to an Education. Every person with a disability has a right to an education that is FREE, APPROPRIATE PUBLIC EDUCATION. In Michigan, education is provided to students up to the age of 26. The student should participate in as many typical activities as possible.

The Right to be Informed of Your Rights. Each agency that deals with persons with a developmental disability must inform them of their rights in a way that is fully understandable by the person and/or their family. For example, if an individual is Spanish speaking, then their rights must be delivered in the Spanish language. Or, if a person cannot read, then their rights must to be explained in a manner the individual can understand.

The Right to an Individual Program, Plan of Care or Education Plan. Each person must have a program plan that is observable, understandable, and tailor made to fit the strengths and desires of the person and their family.

The Right to Trained and Qualified Staff. Each person has the right to have qualified, certified and/or licensed teachers, job coaches and assistants. Staff should have proper training and experience to plan and implement programs for persons with developmental disabilities.

The Right of Access to Records. Each person has the right to complete and accurate records. All agencies must recognize the rights of parents and/or the individual to access to all public records.

The Right to Advocacy. Each person has the right to have legal, civil and human rights recognized.

The Right to Payment for Care. Each person has the right to affordable or reduced costs for all health care.

The Right to Access All Public Buildings. Each person has the right to access any buildings developed by public funds.

The Right to Appeal Decisions. All persons have the right to challenge decisions made by any public agency.

The Right to Freedom and Involuntary Servitude. If work is performed, each person shall be paid according to fair labor and wage legislation.

The Right to Accurate Assessment of Needs and Abilities. Each public agency must perform accurate assessments in a timely and regular manner.

The Right to Equal and Fair Housing. No person shall be denied housing on the sole basis of a disability.

The Right to Equal Opportunity in Employment. If one's disability does not affect work performance then it is discriminatory to deny employment.

Information taken from *Keys to the Future: A Handbook for Parents of Children with Disabilities*, Idaho State Council on Developmental Disabilities, 1990.

Specific Legal Rights

A number of laws affect services to and rights of citizens with disabilities. Federal legislation includes:

Section 504, Rehabilitation Act of 1973 (PL 93-122) requires any public or private building or service which uses public tax dollars to be accessible to citizens with disabilities. Service must be made available and physical barriers must be eliminated. All public transportation must provide for people with disabilities. Examples of accessible facilities include lowered telephones and water fountains, street and building ramps, braille and picture signs, convenient bus seating and wide entries to rest rooms. Covered under this act are any post secondary education, training and employment programs (including colleges and universities) that receive federal funds. Students cannot be excluded from programs because of physical barriers or the absence of auxiliary aids.

Education of All Handicapped Children Act (PL 94-142, and amendments, PL 99-457 and PL 98-199) establishes the right of <u>all</u> children to a free appropriate public education. It requires that education be provided with related services in the least restrictive environment appropriate for each child as specified in the child's individualized education plan (IEP), which must be written with the involvement and consent of parents. Due process rights are included in this law.

1986 Amendment (PL 99-457) Part B (Section 619) carries the guarantees under PL 94-142 down to children from ages three-five. As with 94-142, the State Department of Education and local school districts have authority for implementing this law.

The Developmental Disabilities Assistance and Bill of Rights Act (PL 100-146). This Act and its amendments define developmental disabilities and required services. Included is a requirement that every state have a council to plan and advocate for and to monitor the delivery of services to people with developmental disabilities (Council on Developmental Disabilities) and a protection and advocacy system. There are many problems which may be dealt with by such a system; employment discrimination, the right to education, transportation and building accessibility, guardianship, adult protective services, relocation of people from institutions, etc. Support and technical aid from both agencies is given to individuals and groups that work with people who are disabled. This Act includes a listing of rights, primarily dealing with treatment and services, of people with developmental disabilities.

The Americans with Disabilities Act (ADA) (PL 101-336). This new law prohibits discrimination against adults and children with disabilities in employment, public services, public accommodations and transportation, and provides for telecommunication relay services. The law requires that auxiliary aids and services be provided for individuals to have an equal opportunity to participate and that physical barriers must be removed or alternative access provided. In essence, this legislation opens all public buildings and programs to individuals with disabilities and promotes unlimited community integration opportunities. Private clubs and religious organizations are exempt from these requirements and there is language in the law to avoid "undue burdens" to businesses as they comply.

The ADA will be implemented on a staggered basis from January, 1992 to July, 1993.

The Fair Housing Act Amendments (FHAA) (PL 100-430) extends the scope of Section 504 to assure nondiscrimination in securing housing for people with disabilities.

Carl D. Perkins Vocational Education Act (PL 98-524) assures students with disabilities at the secondary, post secondary or adult level that 10% of the federal funds received by a state for vocational education will be allocated for services to them. Congress is currently proposing elimination of the 10% set aside and giving more flexibility to the states in those expenditures. The State Department of Education, Vocational Education Division, has responsibility for these funds, which are distributed to vocational-technical schools across Idaho.

The Civil Rights Restoration Act of 1987 (PL 100-259) makes clear that the intent of Congress in Section 504 of the Rehabilitation Act was to cover institutions receiving federal assistance, not merely programs.

Air Carrier Accessibility Act (PL 99-435) prohibits discrimination on the basis of physical disability for individuals traveling on commercial airlines. Regulations include provisions for priority storage space for equipment (such as wheelchairs), and free attendant travel if that attendant is required to enable the person with a disability to travel.

Voter Accessibility Act (42 USCS, 1973 ee) ensures that all polling places for elections that include federal candidates must be accessible.

In addition to these laws, there are rules and regulations and departmental and agency policies and procedures that further define what is established in law.

Reprinted from *Keys to the Future: A Handbook for Parents of Children with Disabilities*, Idaho State Council on Developmental Disabilities, 1990.

Match the description of the law in Column A to the law in Column B.

Column A

___ 1. All children have the right to a Free Appropriate Public Education.

___ 2. Defines developmental disabilities and requires states to have a plan and ways to monitor services.

___ 3. Public transportation must provide for persons with disabilities.

___ 4. Provides for priority storage space for equipment and free attendant travel on commercial airlines.

___ 5. This code provides rights and protection to Idahoans with developmental disabilities.

___ 6. All polling places must be accessible.

___ 7. 10% of funds must be used for services/education to persons with disabilities.

___ 8. Assures nondiscrimination in securing housing for persons.

___ 9. Private clubs and religious organizations are exempt from this law.

___ 10. Provides secondary education and transition services for youth ages 12-26 are a part of this law.

Column B

A. Sec. 504 Rehabilitation Act of 1973 (PL 93-122)

B. Air Carrier Accessibility Act (PL 99-435)

C. Education of Handicapped Children Act and Amendments (PL 94-142, PL 99-457, and PL98-199)

D. D.D. Assistance and Bill of Rights Act (PL 100-146)

E. Voter Accessibility Act (42 USCS, 1973ee)

F. Carl D. Perkins Vocational Education Act (PL 98-524)

G. Developmental Disabilities Act (Idaho Code 67-6701 et.al.)

H. American Disabilities Act (ADA) (PL 101-336)

I. Education of All Handicapped Children Act (PL 94-142, amendments, PL 99-457 and PL 98-199)

J. Fair Housing Act Amendments (FHAA) (PL 100-430)

Advocacy

A political movement has taken place in America in the last several years. Groups of persons with disabilities have united with the intent of speaking fo and about their rights, without the direction of non-disabled people. In many cases non-disabled persons support their efforts, but are not the ones making the decisions. This development is called self-help and self-advocacy.

The founders and members of self-advocacy groups are persons with disabilites who have the desire to improve the quality of life for themselves and others in similar situations. Self-advocacy groups meet and determine their own agendas. Some groups are very politically active; some meet for social reasons. As a personal assistant, you may be asked by your employer to attend meetings and support the disability movement through advocacy efforts. Self-advocacy challenges typical views of didabilities by helping all people claim a valued status for themselves. Paul Williams and Bonnie Shoultz (1982) say that "Self-advocacy means self-respect, respect by others, a new independence, assertiveness, and courage. I involves seriousness, political purpose and an understanding of rights, responsibilities and the democratic process."

If at all possible, assist your employer in their advocacy activities and when appropriate, make information available to them.

Following is a list of disability advocacy groups in Michigan.

ADAPT/ Michigan Regional Organizers

ADAPT/Michigan 2765 Adrienne Drive Ann Arbor, MI 48103	(313) 662-1256 Verna Spayth or Bob Liston

ADAPT
877 E. Fifth Ave.
Building D
Flint, MI 48503
(810) 239-7634
Michael Fosler

ADAPT-Oakland/Macomb
3765 E. Fifteen Mile
Sterling Heights, MI 48310
(810) 268-4160
Katrinka Gentile

ADAPT-Western Wayne
37601 Grantland
Livonia, MI 48150
(313) 462-2423
Scott Heinzman

ADAPT-Lansing Area
(517)337-8059
Bill Earl

ADAPT -Detroit Aea
2981 Lafayette #1B
Detroit MI 48207
(313) 832-3371
Marva Ways or
Donald Moore or
(313) 259-6817
Charles Johnson

ADAPT
11808 New Holland St.
Holland, MI 49424
(616) 786-0634
Paul Scalf

ADAPT-Washtenaw County
2115 Nature Cove Ct. #106
Ann Arbor, MI 48104
(313) 971-4659
Ward Squires

People First Advisors

ADS People First
Cecelia Antilla or
Karla Sorenson
206 Highlander Way
Howell, MI 48843

Glen Ashley
Comm. Mental Health
200 Orleans
Coldwater, MI 49036

Kathy Ellis
2660 W. John Beers Rd.
Stevensville, MI 49127

Sharon Brewer
700 S. Siver
Bad Axe, MI 48413

Vicki Halston
4595 W. 48th Street
Fremont, MI 49412

Jim Bolland
Life Consultation
319 Hubbard
Allegan, MI 49010

Keith Clement
P.O.Box 239
Caro, MI 48723

Joy Foco
People First
95 Dawson
Sandusky, MI 48471

Terri Hamilton
859 Holly Rd.
Cadillac, MI 49601

Susan Hoprick
361 Redwood Drive
Troy, MI 48083

Kim Hummerding
182 W. Van Buren
Battle Creek, MI 49017

Sarah Irvine
18778 Roseland Blvd.
Lathrup Village, MI 48076

Linda Kujat
4827 Grand Street
Muskegon, MI 49441

Kathy Malsom
1674 Gardner
Newago, MI 49337

John Messner
P.O.Box 128
Benzonia, MI 48616

Terry Morlock
124 Elm
Niles, MI 49120

Mary Lease
503 E. University
Rochester, MI 48307
Connie Ott
385 3rd Street
Manistee, MI 49660

Elaine Popovich
David Reece Fund
P.O.Box 2212
Midland, MI 48641

Steve Redmond
327 N. River
Holland, MI 49424

Ann Reynolds
45421 Hillcrest
Oscoda, MI 48750

Jana Ritter
P.O.Box 503
Centerville, MI 49032

Bea Russell
1033 26th Street
Port Huron, MI 48060

Kathy Sleziak
499 S. Range Rd.
Marysville, MI 48040

John Tobey
WCAR
35000 Van Born
Wayne, MI 48184

Virginia Urick
346 E. State Street
Grand Traverse, MI 49685

Ruth Weirma
920 Diana Street
Ludington, MI 49431

Joyce Veltman
Box 561, Rte 2
Mears, MI 49436

Tony Wiles
511 Griffen
West Branch, MI 48661

Carol Williams
2365 Jarco Drive
Lansing, MI 48842

Sherri Wilson
16708 Lamphere
Detroit, MI 48219

Self-Advocacy

A political movement has taken place in America in the last several years. Groups of persons with disabilities have united with the intent of speaking for and about their rights, without the help of non-disabled people. This development is called self-advocacy.

The founders and members of self-advocacy groups are persons with disabilities who have the desire to improve the quality of life for themselves and others. Self-advocacy groups meet and determine their own agendas. Some groups are very politically active; some meet for social reasons. As a personal assistant, you may be asked by your employer to attend meetings and support the self-advocacy movement. Self-advocacy challenges typical views of disabilities by helping all people claim a valued status for themselves. Paul Williams and Bonnie Shoultz (1982) say that "Self-advocacy means self-respect, respect by others, a new independence, assertiveness, and courage. It involves seriousness, political purpose and an understanding of rights, responsibilities and the democratic process."

If at all possible, make information regarding self-advocacy available to your employer.

Following is a list of self-advocacy groups in Michigan.

Group
Address
Phone #
Meeting dates & times
contact person

Read this article by Robert Perske. He identifies misconceptions and limitations caused by labels.

They Are People First

Not many years ago, we did not know very much about developmental disabilities, but we were outstanding in the way we labeled and classified people who had them. People were called

mentally retarded
cerebral palsied
epileptic
quadriplegic
deaf-blind
autistic.

Some even more esoteric and mysterious sounding classifications were

mongoloid
gargoyle
cretin
and many more terms that need not be listed.

Of course, diagnostic labels like these were created by professionals in order to identify the various types of handicaps. And in all fairness, it should be said that many of those professionals are laboring over another such process now. With a new sensitivity, many are trying to make sure diagnostic labels do not belittle or demean those who receive them. For example, some clinicians have developed a policy of using a label only as a noun referring to a condition *(e.g. a person with mental retardation).* Very infrequently do they allow a label to be used as a noun referring to a person *(e.g. the mentally retarded or the retardate),* or even as an adjective *(e.g. the mentally retarded person).*

But the worst effects of professionally created labeling are manifested in the conversation of ordinary citizens. You might hear a person on the street say, "What's the matter with that Johnson fellow?" And another would answer, "He's a mongoloid." Then the two would nod and give each other deep knowing looks *as if* *they knew everything* about the man--when in most cases, neither of them would even know what the word mongoloid means.

When ordinary citizens speak in that way about people with handicaps, it is as if they were pinning large badges on them. The diagnostic words on the badges draw so much attention that everyone around the poor labelees become blind to their attractive qualities. Such a practice is cruel, belittling, and unfair.

Today, it is the persons with handicaps themselves who are pleading most against insensate and unfair labeling practices. For example, a group of former residents of the Fairview State Hospital and Training Center in Salem, Oregon, had been struggling to choose a name for their innovative new self-advocacy organization. During the debate, a young woman rose to speak. She said, "We are tired of being seen as retarded. We want to be seen as people, first!" After this sincere, plaintive plea, the group was inspired to drop the other suggestions and name their organization People First. A most poetic choice. That young woman expressed the deepest longing of thousands of people with handicaps who lived even before she was born and who had hated being called retarded but could not do anything about it. Today, People First organizations are springing up throughout Canada and the United States, and that woman's plea will be repeated by thousands.[8]

The United States government responded to that plea, and on November 6, 1978, Public Law 95-602 was signed, *abandoning the use of categorical labels in defining persons with developmental disabilities.* It focused instead on the actual barriers that stand in the way of normal development. The law states that any person having substantial impairments in at least three of these seven precious functions of everyday living is in need of special understanding and help from the government.

1. self-care

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[8]. The forms of address suggested by some forward-thinking professionals and the plea of the woman from Salem have influenced me to construct the sentences of this book so that the words *persons, people, citizens, and human beings* appear first and the words for their *handicapping condition*, second.

2. receptive and expressive language
3. learning
4. mobility
5. self-direction
6. capacity for independent living
7. economic sufficiency

In this law, persons with developmental disabilities definitely are being seen as people first.

But the most hopeful result stems from the fact that many neighbors like you are viewing these people in that way, too. For example, Maggie Roggerio in Los Angeles was asked why she repeatedly held parties at her house for the men and women with handicaps who lived next door (these celebrations will be described in more detail later). She replied, "It's fun having parties with these people. . . . People--I guest that's the key. I see them as people before anything else."

So with what we now know, you have rich opportunities to look for beauty, value and talents in such persons, before focusing on their handicaps. In fact, you can become so good at this searching that if someone asked you, "What's the matter with that Johnson fellow?" you would not resort to the simple, mindless statement, "He's a mongoloid." Instead, it would be possible for you to respond with a sincere, thoughtful description of his attractive characteristics first, and later to tell of the barriers you have been watching him tackle in his struggle to grow and develop.

Reprinted from *New Life in the Neighborhood, How Persons with Retardation or Other Disabilities Can Help Make a Good Community Better* by Robert Perske, 1980.

The following article by Hale Zukas is an account of how a few University of California, Berkeley students with disabilities started the movement for independent living.

CIL HISTORY

The Center for Independent Living, Inc. (CIL), came into existence as a formal entity in March 1972, but its origins extend considerably further back in time and place; on occasion fortuitous circumstance has also played a role.

The roots of CIL can be traced to the Cowell Residence Program (CRP) at the University of California, Berkeley. In 1962, Ed Roberts, a post-polio respiratory quadriplegic, became one of the first severely disabled persons to be admitted to the University. Since he had to spend most of the time in an iron lung, it was decided that the only feasible living arrangement would be a room at the Student Health Service-Cowell Hospital on campus. By 1966, two traumatic quadriplegics had also moved into Cowell; three years later there were 12 severely disabled students in the Cowell Residence Program, which had by then been formally established and was being supported by the California Department of Education.

In 1969, the atmosphere at Cowell was a peculiar combination of disparate elements. On one hand, the CRP provided a quite sheltered living situation; indeed, in its hospital location (albeit in a separate wing) it bore some resemblance to the custodial institutions to which disabled people are so often relegated. The residents of the Cowell Program, for the most part, confined their movements to the campus as there was considerable apprehension about traveling out into the community. In part this was because the electric wheelchairs then available were unreliable or had very limited range. Even if their chairs had been adequate to the task, however, the surrounding community was largely inaccessible to them. There were no curb ramps in Berkeley, for example, until a four-block section of the main shopping street south of campus was reconstructed in 1969-70; ramps were incorporated in this project at the urging of the Cowell residents.

This insularity also had its positive aspects, however. In the Cowell Program, residents were in close, continuing contact with other people having similar problems and concerns. A sense of unity and self-confidence gradually developed, largely as a result of the free flow of communication and sharing of experience. The resident's' political consciousness grew as they became aware of the degree to which control over their lives had been taken over by medical and rehabilitation professionals. They thus came to realize that the concerns about self-determination raised by the black and student movements had considerable relevance to their own lives as disabled people. This consciousness-raising process was accelerated in 1969 when the rehabilitation counselor assigned to the Cowell Program tried, with the support of all but one of the professionals associated with the program, to have two of its residents evicted because she deemed their educational goals unfeasible and their life styles improper. United as never before, the Cowell residents defeated the counselor in this effort.

As time went on, the residents found the bureaucratic and *in loco parentis* restrictions under which they had to live at Cowell a source of increasing aggravation. Additionally, by 1969, some residents were nearing the end of their academic careers and consequently would have to leave Cowell. The need for some kind of alternative to the CRP was thus becoming more and more apparent. In order to address this need in a systematic manner, most of the Cowell residents in the Fall of 1969 organized their own class, called "Strategies of Independent Living," under the University's group studies program. Initially the major emphasis of the class was on developing a proposal for a communal living arrangement which would be similar in some respects to the Cowell Program but which would be controlled by residents themselves and open to non-students as well as students. After a few weeks of work on the proposal, however, it became apparent that establishing and operating such a facility would be very costly and that funding would be extremely difficult to find.

In the meantime, Ed Roberts had learned of the Special Services Program operating out of the federal Office of Education. Under this program various kinds of aid were available to disadvantaged students to enable them to successfully pursue college studies. In the establishing legislation Congress had expressed its intention that ten percent of the appropriation for the program be allocated to services for physically disabled students. It was reported that the Office of Education would be very receptive to a proposal for a program of services to disabled students on the Berkeley campus. Consequently, the students in the class put aside the establishment of a communal living arrangement and turned their attention to developing a program of supportive services which would enable severely disabled students to live independently and function more effectively as students.

Defining the services which should make up such a program was a relatively simple and straightforward process. The students drew on their own experience and figured out what services *they* would need in order to live independently in the community. They would need a pool of people available to help them in getting up, dressing, bowel and bladder care, preparing meals, and the many other activities of daily living that anyone leading an active life must perform. They would need fast, reliable wheelchair repair, for without a wheelchair in operating condition they were little better off than if they were bedridden. They would need assistance in obtaining the financial benefits and services to which they are entitled from other agencies, so they would have the resources needed to lead independent lives. Accordingly, an attendant referral service and provision for emergency attendant care, a wheelchair repair service, and an advocacy component were incorporated into the proposed program along with a component devoted to helping disabled students deal with University-related matters, such as pre-enrollment, getting classes moved to accessible locations, and making special arrangements for examinations when necessary.

The fact that the idea for a services program, on the one hand, came about largely for expedient reasons (namely, the exigencies of funding) and, on the other hand, was a logical outgrowth of the students' past experience might lead one to overlook its enormous significance for disabled people, not only in Berkeley but throughout the country. The approach envisioned in the proposed Physically Disabled Students' Program (PDSP) was a radical departure from past practice in the medical and rehabilitation fields. In contrast to the fragmentation which characterized the existing services, the PDSP would take a holistic, integrated approach by providing a comprehensive array of services in recognition of the fact that disabled people are likely to have a variety of needs, and functional independence will be hard to achieve unless *all* those needs are met. Self-evident though this may seem in hindsight, such an approach had, to our knowledge, never been tried before.

Over the years, the Cowell residents had evolved what might be called a philosophy of disability out of their collective experience. In the proposal for the PDSP, the guiding principles of this philosophy were clearly articulated for perhaps the first time. They were the following:

1. Those who know best the needs of disabled people and how to meet those needs are the disabled people themselves.
2. The needs of the disabled can be met most effectively by comprehensive programs which provide a variety of services.
3. Disabled people should be integrated as fully as possible into their community.

Most of those active in the development of the PDSP were spinal cord injured, and they were naturally, primarily concerned with services that would meet their own needs. But there was also an awareness on the part of some of those involved that broadening the program to serve people with a wide range of disabilities, including the blind, could be beneficial to all concerned. In addition, it was hoped that establishing a working relationship between disability groups which had traditionally had little to do with one another would lead to a coalition which could exert increased influence in the political arena. It was consequently decided that there would be blind representation on the PDSP staff.

Funded in July 1970, the PDSP began full operation two months later with a full- and part-time staff of nine, of whom five, including the director, were severely disabled or blind. During its first year, the PDSP provided a clear demonstration of the validity of the premises on which it had been founded. Disabled students began moving from Cowell out into the community; the drop-out rate was almost nil compared to that among disabled students at other institutions of higher learning; and there was a sharp reduction in medical problems. The effectiveness of different disability groups working together was also shown. Not only did the extent to which their problems and needs coincided become apparent, but services originally tailored to the needs of orthopedically disabled were adapted to the needs of the blind. For example, the attendant referral service was expanded to also provide readers for the blind.

That the PDSP was providing needed services unavailable anywhere else was indicated by the steadily growing volume of requests for assistance it received. At first, these requests came from students, but as word of its unique services spread through the surrounding community, more and more disabled non-students began to call upon the PDSP for help. The PDSP rarely if ever turned people away on the grounds that they were non-students. By the Spring of 1971, the time devoted to community people had begun to seriously affect the PDSP's ability to meet the needs of the students whom it was established to serve. Out of this dilemma arose the idea of establishing another program parallel to the PDSP to serve disabled and blind people in the surrounding community. Thus the seeds of the Center for Independent Living were planted.

At the instigation of the PDSP administration, a group of interested disabled people, including both students and non-students, met in May 1971 to begin discussing how to put together a community-based services program. Over the next year, this group put in many hours of work toward this end, meeting an average of once a week.

From the beginning there was a firm commitment not only to the three principles outlined above, but also to the principle that CIL would be an organization of and for all disability groups, more specifically, a coalition of the orthopedically disabled and the blind. These two groups had traditionally gone their separate ways, and in this pioneering attempt to work together, it was only to be expected that strains would occasionally develop in their relationship. By its very nature, a coalition is a gathering of groups with different interests which come together to pursue some larger objective. Making any true coalition work thus requires a conscious effort. Those involved in organizing the CIL made this effort the resultant benefits accruing to both the disabled and blind have shown that it was eminently worthwhile.

For example, wheelchair curb ramps in Berkeley have been placed so the blind will continue to have the detectable curbs they need in order to know when they are about to cross a street.

It was after the idea of a coalition between the disabled and blind spread beyond CIL to groups active in the political arena, however, that it produced its biggest dividends. For the first time the disabled came to be recognized as a force to be reckoned with in the California legislature. Their efforts were in no small part responsible for the fact that SSI benefit levels in California are just about the highest in the country.

The groundwork laid by the PDSP was of inestimable value in defining the general approach and methodology the CIL would follow. The task entailed in establishing the CIL, however, differed in several important respects from that which faced the founders of PDSP. For one thing, the populations to be served by the two programs were quite different. The disabled students at the University were a relatively small and homogeneous group, residing for the most part within a limited geographical area, and readily identifiable. The target population envisioned for the

CIL, on the other hand, was considerably larger and very heterogeneous, spread over a comparatively large area, and in large part very hard to identify, let alone reach. Those involved in the development of CIL were well aware that they were not representative of the disabled population of the community at large. They were thus very conscious of the need for community input into the design of services and, once those services were in operation, into their evaluation.

Secondly, obtaining funding for the CIL was more difficult than for the PDSP; other than the in-kind support provided by the PDSP, its only resources during this period were occasional contributions from some of those active in the organization, proceeds from a few benefit poker games, and a $250 donation from the local Rotary Club.

In July 1972, three months after its incorporation, the CIL received a one-year $50,000 grant from the federal Rehabilitation Services Administration to enable it to get on its feet organizationally and to do a systematic job of research and planning for a comprehensive community-based services program for the disabled and blind. During most of the grant period, the major emphasis of the CIL was on developing a proposal for such a program costing, in its various forms, from $250,000 to $400,000 per year. As the expiration of the grant drew near and prospects of new funding continued to prove fruitless, the CIL staff lowered its sights considerably, and the prime objective became, not expansion, but simple survival. In the last week of June 1973, the CIL was informed that a renewal of the planning grant, its last hope, would not be forthcoming. At this point the CIL was in serious danger of going under. In an attempt to avert this eventuality, a few CIL staff members, along with Ed Roberts and John Hessler, Director of the PDSP, met with University Vice-Chancellor Robert Kerley to ask for his help. Through Kerley's personal intercession $15,000 was made available through the University's Community Projects Office to keep the CIL afloat for another four months. In August the City of Berkeley allocated $15,000 to the CIL to cover a year's overhead costs, principally rent and utilities. Even though these two grants by no means assured the CIL's future, there was a strong feeling among the staff that there had been enough of planning and it was time to get down to the business at hand and start delivering direct services, without regard to what the future might hold. In September 1972, the CIL established its own attendant referral service, giving limited help with locating housing, and providing transportation with a donated Volkswagen van.

The University money stopped in mid-November 1973, and the CIL became essentially dormant. Understandably, demoralization among the staff was widespread. In late December, however, word was received with great rejoicing, that the San Francisco Foundation had approved the CIL's application for $30,000. Regular operations were resumed with the start of the new year. In March 1974, the long search for a facility to replace the two-bedroom South campus apartment which had been the CIL's base of operations since August 1972, culminated in a move to a much larger and more centrally located quarters in the downtown area. At about the same time, the CIL was allocated approximately $35,000 on a six-month basis from Alameda County revenue-sharing funds. With the reasonable expectation that teach of the current grants would be renewed, a relatively firm base of financial support had been established which assured that CIL would be able to maintain at least a modest level of activity over the next several years.

While it would have been desirable to obtain funding for the CIL in one comprehensive package, experience had thus shown that the only feasible strategy was to fund CIL on a piecemeal basis through an accumulation of relatively small grants. The CIL has continued to pursue such a funding strategy in the intervening period with considerable success, and several new programs have been established as funding has become available. The multiplicity of funding sources and the accompanying rapid expansion makes it difficult to chart, except in very general terms, the direction CIL should take in its future development. One thing has not changed, however: the CIL's overall objective is still eminently well described by its name.

CIL History: A History of the Center for Independent Living by Hale Zukas, World Institute on Disability, Berkeley, CA, 94703 (1987).

Module Two

Overview of Developmental Disabilities and Family Needs

In this module we will review the federal definition of developmental disability and definitions of several conditions which fall under this federal definition. We will also discuss how these definitions and labels negatively and positively influence society and people with disabilities and their families.

Definitions, like rules and regulations, are created not for the sake of labeling people, but rather for determining who will receive services and who will not. Governments generally have a limited amount of resources or money and therefore have the difficult task of determining service distribution. Definitions help them more consistently identify those persons who are eligible. Eligibility requirements under any comprehensive federal personal assistance (PAS) should be simple and straightforward.

Any adult or child should be eligible for PAS who:

(a) has a permanent or temporary physical, sensory, cognitive, or mental impairment;

(b) has an impairment which substantially limits one or more major life activities; and

(c) requires personal assistance services as defined in the law.

The term "major life activities" should be defined to include everyday tasks such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, remembering, concentrating, reasoning, information and stimulus, processing and working.

State government definitions of developmental disability generally are paraphrased from the definition provided by the federal government in the recently amended Public Law 95-602. The reason for the similarity is because the federal government allocates money for developmental disability services only to states which comply with the federal definition. This is the federal government's method of controlling how money is spent. State governments need money to operate developmental disability services and therefore have defined "developmental disability" using the federal guidelines. If a state is in compliance with the federal definition they may receive federal funds.

It is important, when defining a disability, that we do not confine the person with a disability by our biases and expectations. Various characteristics of disabilities are the barriers that personal assistants will strive to overcome for their employers.

As a personal assistant, you must learn about the nature of disabilities so barriers will not hold a person back from participating in their family and community to their full potential. Personal assistants are to work for and with their employers in overcoming the barriers that the disability may cause.

What is a Developmental Disability?

Federal Definition of Developmental Disabilities

Definition stated in Comprehensive Services and Developmental Disabilities Amendment of 1978, & P.L. 95-602: *developmental disability* is a severe, chronic disability of a person that:

1. is a mental and/or physical impairment;
2. is manifested before the age of 22;
3. is likely to continue throughout life;
4. substantially limits functioning in three or more of the areas:
    - self-care,
    - receptive and expressive language,
    - learning,
    - mobility,
    - self-direction,
    - capacity for independent living, and
    - economic self sufficiency; and
5. results in a need for individualized, interdisciplinary services of extended duration.

Selected Definitions of Specific Disabilities Which Are Often Developmental Disabilities

Mental Retardation

The most widely accepted definition of mental retardation comes from the American Association on Mental Retardation (AAMR)[1]. The major components of the AAMR definition include:

1. Significant subaverage general intellectual functioning (defined as a score which is two standard deviations below the mean on an individual test of intelligence);

2. Adaptive behavior deficits that are defined as significant limitations on a person's ability to meet standards of maturation, learning, personal independence, and social responsibility; and

3. A time interval specifying that the disability must occur during the period from birth to 22 years-of-age.

Persons with mental retardation vary in their abilities, just as the general population does. It is more important to focus on what the person can do than focus on his/her limitations. Remember, persons with mental retardation should define their personal assistance and make their own decisions including the hiring, firing, and management of their personal assistants.

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[1]. American Association on Mental Retardation.

The American Association on Mental Deficiency (AAMD) further defines areas where deficits in adaptive behavior can be found within different age groups. Deficits in adaptive behavior during infancy and early childhood include:

sensory-motor skills,
communication skills (speech and language),
self-help skills,
socialization skills (interacting and getting along with others).

Defects in adaptive behavior during childhood and early adolescence include:

application of basic academic skills in daily life activities,
application of appropriate reasoning and judgement in mastery of the environment, and
social skills (participation in group activities and interpersonal relationships).

Defects in adaptive behavior during late adolescence and adulthood include vocational and social responsibility and performance.

There are many known causes of moderate, severe, and profound mental retardation. These have been categorized by the AAMD as:

1. infections and intoxication (e.g., rubella, syphilis, encephalitis, meningitis),
2. trauma and physical agent (e.g., accidents before, during, and after birth; anoxia),
3. metabolism and nutrition (e.g., phenylketonuria or PKU),

4. gross brain disease (such as tumors),
5. prenatal influence (e.g., hydrocephalus, microcephalus),
6. chromosomal abnormality (such as Down's syndrome), and
7. gestational disorders (premature births).

Users of personal assistants may need initial support but should train their own assistant. Each person is unique and should direct their personal assistants, as opposed to agency training, which may stereotype persons with cognitive impairments. Specific issues of health and safety should be adhered to specific to each individual. Remember, a person communicates through their behavior. If a personal assistant user does not like the people they are with or the situation they are in, then it is up to the personal assistant to interpret and listen to that behavior. For example, if a person is not happy with people they are with, they may try to "escape" from the situation. This "escape" may take the form of running away, hitting, biting, or any other number of behaviors considered inappropriate. When any of these behaviors occur, it is up to you, the personal assistant, to ask yourself "what is my employer trying to communicate to me through this behavior?" "Is he/she mad, sad, unhappy or frightened?" Based on how these questions are answered, changes should be made immediately. If we presume all users of personal assistance to be competent, then errors in judgement will occur less frequently.

Racino (1991) believes that the option needs to be available for each employer to have choices in managing their own personal assistants or to share management with a selected person or agency, this way safeguards are adhered to as well as assistance/support in hiring and firing their own personal assistants.

Cerebral Palsy

Cruickshank (1976)[2] defines cerebral palsy as a neurological syndrome evidenced by motor problems, general physical weakness, lack of coordination, and physical dysfunction. The syndrome is not contagious, progressive or remittent. Its seriousness and overall impact can range from mild to severe. A variety of classification schemes have been used to describe the different types of cerebral palsy, but the two major schemes for classification focus on the motor and topographical characteristics of the syndrome. The motor scheme emphasizes the type and nature of physiological involvement or impairment. The topographical scheme focuses on the various body parts or limbs affected.

Several categories of motor involvement have been identified, each recognizing the nature and extent of brain damage involved. They are:

1. *Spasticity*. An individual with spastic cerebral palsy experiences great difficulty in using muscles for movement. Involuntary contractions of the muscles occur when the individual attempts to use various muscle groups. Spasticity prevents the person from performing controlled or voluntary motion.

2. *Athetosis*. An individual with athetosis is characterized by constant contorted twisting motions, particularly in the wrists and fingers. Facial contortions are also common. The continual movement and contraction of successive muscle groups prevent well-controlled muscular motion.

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[2]. Cruickshank, W. M. (1976). The problem and its scope. In W. M. Cruickshank (Ed.) *Cerebral Palsy: A developmental disability* (3rd ed.) Syracuse, NY: Syracuse University Press.

3. *Ataxia.* An individual with ataxia experiences extreme difficulties controlling both gross and fine motor movements. Problems related to balance, position in space, and directionality make coordinated movement extremely difficult, if not impossible.

4. *Rigidity.* An individual with rigidity has one of the most severe and rare types of cerebral palsy. This condition is characterized by continuous and diffuse tension as the limbs are extended. Walking or movement of any type is extremely difficult.

5. *Tremor.* An individual with tremors manifest motions that are constant, involuntary, and uncontrollable. The motions are of a rhythmic, alternating, or pendular pattern. They are a result of continual muscle contractions.

6. *Atonia.* An individual with atonia has little if any muscle tone. The muscles fail to respond to any stimulation. This condition is extremely rare in its true form.

7. *Mixed.* An individual with mixed cerebral palsy may manifest parts and combinations of all the conditions described above.

The topographical classification approach refers not only to designations given to individuals with cerebral palsy, but also to those who have paralytic conditions from accidents or neurological diseases such as polio. The topographical classification system includes seven categories.

1. *Monoplegia*, involves one limb.
2. *Paraplegia*, involves the legs only.
3. *Hemiplegia*, involves one side of the body in a lateral fashion.
4. *Triplegia*, involves three appendages or limbs, usually both legs and one arm.
5. *Quadriplegia*, involves all four limbs or extremities.
6. *Diplegia*, refers to a condition in which the legs are more involved than the arms.
7. *Double hemiplegia*, affects both halves of the body, with one side more involved that the other.

Because cerebral palsy affects movement, coordination and speech, it often gives a person the appearance of being more disabled than he/she actually is.

Autism

Autism is a complex combination of biological symptoms manifested before 30 months of age and includes disturbances of:

developmental rates;
responses to sensory stimuli;
speech, language, and cognitive capacities; and
capacities to relate to people, events and objects.

Lovaas (1977)[3] described six common characteristics of persons with autism. They include:

1. Apparent sensory deficit. (The person might not respond to loud noises or might not seem to see things. However, there is great variability in this response to stimulation. For example, the person might not react to a loud noise but might orient to the crinkle of a candy wrapper or be fearful of a distant siren).

2. Severe affect isolation. (Often there is a profound lack of interest in showing or accepting affection or being with others).

3. Self-stimulation. (Often, they do very repetitive acts such as rocking their bodies when sitting, twirling around, flapping hands at the wrists, or humming a set of three or four notes over and over again. Lights, spinning objects, closing doors, etc. also may hold their attention for long periods of time).

4. Tantrums and self-mutilatory behavior. (The persons might sometimes bite themselves, hit themselves in the face, or attempt to scratch, bite or hit others).

5. Echolalic speech. (Many of these persons are non-verbal, make simple sounds, or utter single words. The speech of those who do

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[3]. Lovaas, O. I. (1977). The Autistic Child: Language development through behavior modification. Halsted Press, Vol. 8, 246.

talk may simply echo the speech of other people. For example, when asked "What is your name?" the person might simply repeat "What is your name?" At other times, the echolalia might be delayed; the person might seemingly out of the blue repeat something they heard earlier, including items from TV commercials, etc.).

6. Behavior deficiencies. (Behavior development might be delayed and they might not show understanding of common dangers).

Autism is perhaps the most puzzling of all developmental disabilities because of the untapped potential of the individuals who are autistic. Persons with autism may appear to have sensory or cognitive impairments but, in reality, their senses may be so sharp that they focus on some everyday activities but not others. Patience and astute observational skills are the most important qualities necessary to assist a person with autism. Also needed is the assumption that with appropriate methods of communication and support, all persons can direct their own personal assistance.

Epilepsy - Seizure Disorders

The term seizure disorders or epilepsy is used to describe a variety of disorders of brain function characterized by recurrent seizures. *Seizures* are clusters of behaviors that occur in response to abnormal neurochemical activity in the brain. They typically have the effect of altering the individual's level of consciousness while simultaneously resulting in certain characteristic motor problems. Between seizures, the brain functions normally. Seizures largely may be controlled with medications and stress management. Sometimes such large doses of medication are needed that learning and behavior are adversely affected. Some medications cause drowsiness, nausea, weight gain, or thickening of the gums. There are three common types of epileptic seizures.

1. *Tonic Clonic.* This seizure is the most obvious and serious when it occurs. It may also be known as a grand mal seizure. Muscles stiffen and the person loses consciousness resulting in a fall to the floor if standing. There is violent shaking of the whole body as muscles contract and relax. Saliva may be forced from the mouth and bladder and bowels may be emptied. After a few minutes, the contractions cease and the person goes to sleep or is conscious in a confused or drowsy state. The Epilepsy Foundation of America recommends the following procedures but always ask your employer what specific strategies are most effective:

    a) Ease the person to the floor and loosen snug clothing. Do not attempt to restrain the person. The seizure cannot be stopped so don't try.
    b) Remove hard, sharp, or hot objects from the area to protect the person from injuries.
    c) Do not force anything between the person's teeth. If the mouth is already open, place a soft object between the side teeth. Do not get your fingers between the teeth.
    d) Turn the head to one side for release of saliva. Place something soft under the person's head.

e) Let the person rest when he/she becomes conscious.

f) If the seizure is longer than a few minutes or if the person passes from one seizure to another without regaining consciousness, call for medical help. This is very rare but requires immediate attention. If your employer tends to have seizures of this nature, ask in advance what you should do.

2. *Absence.* These are much less severe than grand mal seizures but occur more often and are sometimes known as petit mal seizures. The person loses consciousness, generally for less than 30 seconds. Indications of the seizure might include a blank stare, a pale color, the drop of something held in the hand, the appearance of "daydreaming," or some such related response. These seizures might occur as many as 100 times each day for some persons. There are no violent shaking movements of the body and no special first aid is required.

3. *Complex Partial.* This type of seizure might appear as a brief period of inappropriate or purposeless activity such as lip smacking, aimless walking, or shouting, and may be known as a psychomotor seizure. The person appears conscious, but is not aware that he/she is even behaving this way. Usually these last only a few minutes, but have been known to go on for several hours. Dangerous objects should be kept out of the person's way, but physical restraint is not recommended unless imminent danger to the person exists. Some people might actually respond to spoken directions during this type of seizure.

Absence and complex partial seizures might go unnoticed or unrecognized for quite some time. Observant persons with knowledge regarding the different types of seizures might recognize behaviors indicative of such seizure activity. With proper attention and medication prescribed by a physician, much seizure activity can be reduced or even eliminated. It is important to observe and record information about the seizures. Their frequency and topography is critical for personal assistants to observe and recognize, if a clinical record is to be kept. Information regarding seizures, medication and their reaction is to be shared with the appropriate medical personnel but ask your employer who he/she would like for you to share this information with.

Muscular Dystrophy

This is a group of non-contagious diseases of the muscles which are progressive (meaning that they gradually become worse over time). At birth there are no apparent problems, but by the age of 4 or 5 there is a slowness or "clumsiness" in walking. Gradually, the child loses the ability to walk. Smaller muscles in the hands and fingers are the last to be affected. There is presently no known cure for MD and the disease is often fatal.

People with MD may have difficulty getting to their feet after laying down or falling. Independence can be maintained for the longest period of time through regular physical therapy, exercise, and adaptive devices. Children with muscular dystrophy should not be lifted by their arms because limbs are easily dislocated due to the weakness of muscles which normally support the joints. Emotionally, it may be difficult to cope with the gradual loss of physical abilities and the possibility of death related to the disease. It is not the role of the personal assistant to comment regarding the process or progress of their employer's health.

Spina Bifida

Also known as "cleft spine," is a congenital (existing at birth) defect in the formation of the spinal cord and the overlying bones of the vertebrae. A section of the spinal cord and nerves which control muscles and sensations in the lower portion of the body fail to develop normally. Spina Bifida can range from mild, where there is no serious physical consequence, to severe, where the spinal cord and nerves protrude through an opening in the child's back. In its severe form the child is at high risk of paralysis and infection. A person with spina bifida might have complete control of the upper body, but have little or no control of bowel and bladder control due to lack of feeling and muscle strength in the lower body. It depends largely on the individual, their overall health, lifestyle, and attitude towards their own condition.

Surgical techniques enable the spinal cord and nerves to be tucked back into the spinal column preferably within 24 hours of birth. Thus, persons with spina bifida are usually quite independent. Some walk with the aid of braces, crutches, or walkers and may use wheelchairs for long distances. Special help may be needed with dressing and toileting for some. Often, persons with spina bifida need to use a catheter, but can learn to regulate their own bowel movements. Presume competence in your employer.

Communication Disorders

There are numerous types of communication disorders and many possible causes. Some causes are *organic*, related to a physical problem such as cleft palate, absence of teeth, paralysis of muscles related to speech, enlarged adenoids, etc. These often occur along with other disabilities for example, cerebral palsy, hearing impairment, and mental retardation. It is important that all behavior is communication and should be considered as important as one's ability to communicate verbally.

Speech Impairments. A person is considered to have a speech impairment if his/her speech deviates so greatly from accepted speaking patterns of other people that it:

draws unfavorable attention,
interferes with communication, or
causes the speaker to have difficulty in social relationships.

Speech impairments include: *articulation disorders* which result in the omission, substitution, distortion, or addition of speech sounds; *voice disorders* which affect the quality, loudness, or pitch of the voice; and *fluency disorders* which interrupt the smooth flow of speech with inappropriate pauses, hesitations, or repetitions; and *delayed speech*, when a person speaks like someone much younger. Delayed speech is a deficit in communication ability and is often associated with other maturational delays.

Language Disorders. Language disorders are classified as "receptive" or "expressive" disorders. A *receptive disorder* interferes with the understanding of language, an *expressive disorder* interferes with the production of language (such as a limited vocabulary for the age of the person, confusion about the order of sounds or words, or incorrect use of tenses and plurals). A person may have one or both of these types of language disorders. Several factors might contribute to language disorders:

cognitive limitations or retardation,
environmental deprivation,
hearing impairments,
emotional impairments or behavior disorders, and
structural abnormalities of the speech mechanism.

Some severe language disorders may be caused by brain damage. One example is *aphasia*, the inability to formulate or retrieve and decode arbitrary symbols of language. Aphasia may be congenital (from birth) or occur as a result of a head injury or stroke.

Hearing Disorders. A hearing disorder may be defined according to the degree of hearing loss. The degree of hearing loss is determined by assessing a person's sensitivity to sound intensity and sound frequency. *Sound intensity* (loudness) is measured in decibel units. *Sound frequency* (pitch) is measured in hertz units.

Deafness and hard-of-hearing are commonly used terms to define hearing disorders. A person who is *deaf* typically has profound or total loss of auditory sensitivity and little, if any, auditory perception. The primary information input is through vision; speech is not understood through the ear. A person who is *hard-of-hearing* (partial hearing) generally has residual hearing through the use of a hearing aid that sufficiently processes language through the ear.

A hearing disorder may be congenital or acquired during a person's life. Age of onset is critical in determining the type and extent of intervention necessary to minimize the effect of the hearing disorder. *Prelingual* disorders are identified as occurring prior to the age of two years, or about the time of speech development. A hearing loss that occurs before language has developed is more problematic, especially in the areas of communication and social adaptation. *Postlingual* disorders occur at any age following speech development.

The anatomical site of loss is a critical factor in defining a hearing disorder. *Conductive hearing losses* result from poor conduction of sound along passages leading to the inner ear. The effect of a conductive hearing loss is the reduction or loss of loudness. A conductive loss can be offset by amplification (hearing aids) and medical intervention. *Sensorineural hearing losses* are the result of an abnormal sense or a damaged auditory nerve. Sound is distorted with a sensory hearing loss, thus affecting the clarity of human speech. Sensorineural losses cannot be treated adequately through medical intervention. A sensorineural loss is generally more severe than a conductive loss, and it is permanent. *Mixed hearing loses* are a combination of conductive and sensorineural problems.

Visual Disorders. There is a distinction between medical-legal and educational definitions of blindness. *Medical-legal* definitions are primarily concerned with the loss of visual acuity and the central field of vision. Visual acuity is indicated by the use of an index that refers to the distance at which an object can be recognized. A person is considered blind whose visual acuity does not exceed 20/200 in the better eye fitted with corrective lenses. A person is considered to be blind if the central field of vision is limited at its widest angle to 20 degrees.

Educational definitions of blindness focus primarily on the individual's ability to use vision as an avenue for learning. Children who are unable to use their sight and rely on other senses, such as hearing and touch, are described as educationally blind.

There is a distinction between individuals who are blind and those who are partially sighted. A person who is partially sighted can still use vision as a primary source for learning. This person has a visual acuity greater than 20/200, but not greater than 20/70 in the better eye after correction.

The field of education distinguishes between blind and partially sighted to determine the level and extent of support services required by a student. Partially sighted students are able to use vision as a primary source of learning. These students are encouraged to make maximal use of residual vision.

The following descriptors have been proposed to refine the terminology and group various levels of visual problems. A *profound visual disability* is a disorder in which the performance of the most gross visual tasks may be difficult, and vision is not used for detailed tasks. A *severe visual disability* is one in which additional time and energy are needed to perform visual tasks. The performance level may be less accurate. A *moderate visual disability* is a disorder in which visual tasks may be performed with the use of special aids and lighting.

Severe Emotional Disturbance

Severe emotional disturbance is a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree. This condition adversely affects community acceptance and/or performance. For example, a severe emotional disturbance results in:

1. an inability to learn unexplained by intellectual, sensory, or health factors;
2. an inability to build or maintain satisfactory relationships with peers and/or teachers;
3. inappropriate types of behavior or feelings under normal circumstances;
4. a general and pervasive mood of unhappiness or depression; and
5. a tendency to develop physical symptoms or fears associated with personal or community problems.

The judgement of professionals carries a lot of weight when determining if someone is seriously emotionally disturbed. Regardless of the definition, most agree that the person's behavior must differ extremely over time (chronically) from current social or cultural norms to be considered as severe emotional disturbance. It takes a great deal of patience to assist persons with severe emotional disorders. It is imperative that personal assistants learn to separate the emotional disturbance from the personality of the individual, deal with the behaviors--not the personality, and be objective. With this classification, it is critical to presume competency with your employer.

Learning Disabilities

Specific learning disability is a disorder in one or more of the basic psychological processes involved in understanding or using language, spoken or written, that manifests itself in an imperfect ability to listen, think, speak, read, write, spell, or mathematical calculations. The term includes such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include children who have learning problems which are primarily the result of visual, hearing or motor handicaps; mental retardation; or environmental, cultural, or economic disadvantages (from section 5(b)(4) of P.L. 94-142:).

This term is not meant to be used for those who are having minor or temporary difficulties in learning. It is reserved for those who have a severe discrepancy between ability (overall intelligence) and achievement. These are often measured with standardized tests (IQ & achievement tests) as well as other methods. A variety of assessments must be included in any recommendation for special services. The exact definition of a "severe discrepancy" is still argued. Lack of a specific definition of severe discrepancy from the federal level has forced state and local educators to find some means of objectively identifying those who are to receive special services in education.

Learning disabilities are most relevant for school-age people but continue on throughout adulthood. The term is used only so those persons having prolonged difficulty in learning can get specialized help. After the school years, it may only be relevant for others to know the person may need to take special approaches in learning things. Others do not need to know the person was previously labeled learning disabled. Special approaches for learning might include:

1. precise definitions of the behavior to be taught,
2. task analysis to break skills down into smaller units or subskills so the learner has to master only one part at a time,
3. direct teaching methods that require the new skill to be practiced many times, and

4. direct daily measurement to monitor progress and evaluate the instruction.

Many believe that the reference to dyslexia, minimal brain dysfunction, perceptual handicaps, and developmental aphasia, which have historically been difficult to define, only add confusion to the definition of learning disabilities.

Within the federal and state definitions of "developmental disability" remain a certain amount of flexibility in determining who will receive services. The judgement of what constitutes a "substantial limit" of functioning for an individual, for example, is usually based on various assessments and the professional opinions of persons connected with the field of developmental disabilities. As long as a disability becomes evident before a person turns 22 years of age, and that person can be shown to have substantial limits in three of the seven areas outlined in the definitions, and the condition is not temporary, then it is likely the person will receive services. The more disabilities a person has the more intensive the services.

We should not be quick to label individuals as developmentally disabled, retarded, etc. because, as you have seen, these are merely titles for definitions used to determine which group of people are eligible for services allocated by government entities. These titles do not describe individual characteristics. Often they create a limited view of a person's worth and abilities, and negatively affect their human dignity. Remember, they are people <u>first</u>.

Give an example of a daily task in each of the following areas.

1. Self-care

2. Receptive language (hearing and understanding)

3. Expressive language (talking/communicating)

4. Learning

5. Mobility

6. Self-direction

7. Capacity for independent living

8. Economic self-sufficiency

The following article written by Robert Perske illustrates the limits and misconceptions associated with definitions and labels. Too often misconceptions lead to clinging to labels and not seeing people first.

Becoming More Intelligent About Intelligence

An eighty-three-year-old woman in Omaha gave me an interesting explanation of mental retardation. When she was casually asked how she felt about her new neighbors, she said, "I get along very well with the fellows. We speak to each other as we pass on the sidewalk, and I think it's great the way those young workers train the men the way they do. . . . But isn't it sad? After all, you and I know there wouldn't be any mental retardation in people if it wasn't for loose women."

Today, it is possible to laugh at such a belief. But when that woman in Omaha was a teenager, nobody laughed. Many leading psychologists and sociologists of that day viewed as a scientific fact the theory that persons having "good blood" were virtuous and pure in heart, while the lineage of "bad blood" was laced with trollops--and that anybody with that heritage simply had to be feebleminded, too.

Here is how it came about. In the early 1900's, Alfred Binet developed a series of puzzles and stunts, which he tried out on two hundred school children in Paris, France, in an attempt to define intelligence. He died, however, before coming to any final conclusions. Then around 1910, Lewis Terman, a professor at Stanford University, tried Binet's puzzles on some children in California. American children didn't do well on French stunts, so Terman rewrote the series, using puzzles that middle-class California students could understand, and called it the Stanford-Binet Intelligence Test. Terman and a number of the nation's leading researchers coupled the Stanford-Binet with Mendel's data on the breeding of pea plants, and they began a push to develop a pure race of people. Their movement contained some powerful thrusts that strongly conditioned the thinking of people living at that time, such as the neighbor in Omaha.

- In 1912, a best-selling book entitled *The Kallikak Family* (New York: The Macmillan Co.) was written by Henry Goddard, the director of the research laboratory at the Training School for Feebleminded Girls and Boys in Vineland, New Jersey. Goddard, applying the Stanford-Binet test and the pea-plant data, told the story of Martin Kallikak, Sr., a noble Revolutionary soldier of "good English blood" who, at a tavern frequented by the militia during the war, met and slept with a "feebleminded woman." By this woman, he became the father of a feebleminded son. Although Martin, Sr., was far away at the time of the birth, the woman, in a not-so-feebleminded way, named her son Martin Kallikak, Jr. Goddard described how Martin, Sr., this "scion," this noble soldier, "in an unguarded moment, steps aside from the paths of rectitude and with the help of a feebleminded girl, starts a lone of mental defectives that is truly appalling." Goddard claimed to have identified four hundred eighty descendants, of whom many were feebleminded, as well as illegitimate, sexually immoral, and alcoholic. There were prostitutes, epileptics, criminals, paupers, perverts, welfare clients, whorehouse madams, horse thieves, and one was even "of the Mongolian type." After a list like that, one has to admit that Goddard was capable of delivering one powerful sermon against sowing wild oats. But that was only half his study. He continued,

> *"Martin, Sr., on leaving the Revolutionary Army, straightened up and married a respectable girl of good family, and through that union has come another line of descendants of radically different character. There now number 496 in direct descent. All of them are normal people. . . . All of the legitimate children of Martin, Sr. married into the best families of their states, the descendants of colonial governors, signers of the Declaration of Independence, soldiers and even the founders of a great university. Indeed, in this family and its collateral branches, we find nothing but good representative citizenship. There are doctors, lawyers, judges, educators, traders, landholders; in short, respectable citizens, men and women prominent in their communities wherever they have gone."*

After this book and a few others like it were published, the good blood/bad blood theory became extremely popular. It set off what came to be known as the "eugenic scare," which spread rapidly throughout the land.

- In 1912, Goddard was invited by the United States Public Health Service to test newly arriving immigrants at Ellis Island. By 1912, his report, "based on a mass of average immigrants," showed that 80 percent of the Hungarians, 79 percent of the Italians, and 87 percent of the Russians were feebleminded. He stated that the polish, in the ninetieth percentile, were the most feebleminded of all the immigrants (which may explain the quality and prevalence of Polish jokes). On the other hand, immigrants from England, Holland, Denmark, Scotland, and Germany were found by Goddard to be the most intelligent.[4] According to this data, if you want to be a high-grade, bright individual, you shouldn't let yourself be born in any country east of Germany.

- During World War I, when Robert Yerkes of Harvard University conducted the mass testing program for two million draftees, he made his discovery that over half the United States troops were subnormal. According to his tests, the average soldier had a mental age of fourteen.[5] These results, however, were not published until 1921, so the country never knew until the war was over that better than half its troops were not fit for battle.

- Lothrop Stoddard, in *The Revolt Against Civilization* (New York: The MacMillan Co., 1922), carefully distilled all the intelligence scores from across the nation--including the army test scores-- and he claimed, also, that the average mental age of Americans was

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[4]. Leon J. Kamin, "Heredity, Intelligence, Politics and Psychology: II," in *The I.Q. Controversy.*

[5]. *Psychological Examining in the United States Army, Vol. 15.*

below average. (His average boiled down to the fourteen-year-old mind, as well.) Walter Lippmann, writing *The New Republic* in 1922, stated that Stoddard's conclusion "is precisely as silly as if he had written that the average mile was three-quarters of a mile long."

- Later, Yerkes and his colleagues admitted that the army tests were geared not only for discovering feeblemindedness, but also were carefully timed so that 4.5 percent would receive an A. That was the number of men from the masses that the army needed to send to officer's training school. When Lippmann learned of this, he wondered what would have happened to the timing--and to the rest of the men taking the test--if the army had needed only half as many officers.

- *If we don't stop them, they will out breed us*--this became the ultimate myth. It was felt that the good blood of the "meritocracy" must never become defiled by the bad blood of the feebleminded masses. So in the 1920's we tested within the country for feeblemindedness, and we filled institutions with those the test rated in that category. At Ellis Island, we tested newly arrived immigrants, and those who were found to be "feebleminded" were denied entry into the country. This was easily done because, in 1924, Congress passed an immigration law assigning "national origin quotas," utilizing recommendations and reports prepared by Goddard, Terman, Yerkes, and their colleagues. Soon afterward, the Stanford-Binet was radically modified into a more abbreviated test. Alistair Cooke, in *America* (New York: Alfred A. Knopf, 1975), described how it was used at Ellis Island:

> *"The newcomers crowded into the main building and the first thing they heard over the general bedlam were the clarion voices of inspectors bellowing out numbers in Italian, German, Polish, Hungarian, Russian and Yiddish. According to assigned numbers they were herded into groups of thirty and led through long tiled corridors up a wide staircase into the biggest hall most of them had ever seen.... Once they were assembled there in their thousands, the clearance procedure began....*
>
> *They moved in single file through a stockyard maze of passageways and under the eye of a doctor in a blue uniform who had in his hand a piece of chalk. He was a tough instant diagnostician. He would look at the hands, the hair, the faces and rap out a few questions. He might spot a panting old man with purple lips, and he would chalk on his back a capital "H" for suspected heart disease. Any facial blotches, a hint of gross eczema brought forth a chalked "F" for facial rash. Children in arms were made to stand down to see if they rated an "L" for the limp of rickets or some other deficiency disease.* ***There was only one chalk mark that every family dreaded, for it guaranteed certain deportation.***

> ***It was a circle with a cross in the middle, and it indicated "feebleminded."***

Civilization has come a long way since then. The testing and culling craze of the early 1900's has given way to intelligence researchers who have begun to focus on every aspect of hereditary and environmentally influence. And not one of them has come up with easy, dualistic, good-guy-versus-bad-guy theories. On the contrary, they see a richness, a complexity, and a deepness in each person that earlier testers never even dreamed existed. For example, *Psychology Today,* in September, 1979, developed a special issue on intelligence testing. A new breed of researchers described the present situation, and almost all the writers honestly admitted that, with what is now known about the human mind, *they do not know what intelligence is.* And if one can't define it, how can one test for it?

Make no mistake--those researchers did not make such statements because of a lack of knowledge, but from an additional appreciation of the great complexity and potential of each human mind. The editor of the magazine summarized it this way.

> Now, the brave new world of intelligence research is beginning to come up with some answers. At universities and research centers across the country psychologists are coming to believe that *intelligence may not be just one thing*: it may be many different things--some of them ignored by IQ tests. Ironically, intelligence in real life may truly be a multiple-choice proposition.

This knowledge is good news for you and me--and for our neighbors with handicaps. It means that our society no longer needs to view people as if they were so many pebbles on a beach that need to be labeled "above average" or "below average" and classified along a single, monotonous line. The penchant for testing and culling people is over.

From New Life in the Neighborhood

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Reading Assignment "Becoming More Intelligent About Intelligence"

1. What does intelligence have to do with behavior?

2. What do you think influences behavior?

3. Pick a person and describe a situation where they acted out. This person could be disabled or not.

4. Looking back at the situation, why did he/she behave in that manner?

The Ethics of Feeding and Positioning

A person may require assistance in being both fed and positioned. It is important to remember the following in regards to feeding and positioning:

1. It is the job of the personal assistant to feed/position/toilet, etc. to the wishes of their employer.

2. Do not force anyone to eat or drink anything that you would not eat or drink!

3. Do not move anyone in a way that you would not want to be moved!

If you honor these ethics you will be treating the person with the respect and dignity they deserve. Ethics reach further than feeding and positioning techniques, however. Ethics apply to everything you do to and with the person receiving your assistance.

Family Dynamics

There is no typical family in America today. Children with disabilities are born into families all over the world. Yet, we forget that the major role of any family is to nurture their children. The majority of families who have a child with a disability not only nurture their children but they grow strong from the experiences encountered with their children who have a disability. Some of the strengths result from the parents' adaptation to the event of having a child with a disability.

There are three steps that families take in the process of adapting to a child with a disability (Taylor, 1983)[6]. They are:

1. Search for Meaning. Families ask themselves "Why me!" They attempt to attribute the disability to something they did or that someone else did. Typically, they change the priorities in their life. Money may take a back seat to the care and safety of their loved ones.

2. Gaining a Sense of Mastery. Families gain control over the event through information, education and/or treatment and rehabilitation.

3. Self-Enhancement. Families realize that they have the power to make themselves feel good about their situation. They may begin to compare themselves to someone worse off then they are. This is

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[6]. Taylor, S. (1983). Adjustment to Threatening Events: A theory of cognitive adaptations. *American Psychologist, 38,* 1161-1173.

called social comparison and can be a positive means to their enhancement.

Turnbull and Behr (1986)[7] believe families have strengths in specific areas. Examples of family strengths include:

Being happy
Giving and receiving love
Having strong family ties
Religious faith
Making friends
Child's accomplishments
Being tolerant and sensitive
Learning about disabilities
Not taking things for granted
Being patient
Personal growth
Assuming control over their life
Family life, and
Having energy.

It is important to believe all families have strengths. If we make this assumption we will assist them in providing the love and energy necessary to be a successful family.

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[7]. Turnbull, A. P. & Behr, S. (1986). Family Strengths Assessment Scale - Draft Version. Kansas University Affiliated Program.

Module Three

Positive Supports For The Entire Person

In this module we will discuss ways to promote community integration, specifically for persons with cognitive disabilities. Just as we participate in the community, all individuals need the opportunity to participate too. Therefore, your goals as a personal assistant include: developing the highest quality of life potential to all persons with a developmental disability; and assisting persons with developmental disabilities so they may be as independent as possible and participate in the community to their full extent[1]. Community inclusion begins when all persons, regardless of their level of need, live independent and productive lives.

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[1]. Code of Ethics for Direct Care Providers, Idaho Center on Developmental Disabilities.

How Does a Person With a Developmental Disability Learn to Participate in the Community?

Community Living Skills

Community living skills (CLS) are the tools necessary for becoming part of a community. The teaching and development of CLS make the process of supported living and community inclusion active. In other words, community inclusion is not just physical placement in the community--it is PARTICIPATION in the community.

All people should have the opportunity to take risks, make mistakes, and sometimes fail. This is our privilege - not our problem. Through community based training, supported living, and community living skills it is possible for an individual with cognitive disabilities to achieve goals involving community integration.

As personal assistants we don't actually have problems with given situations and the person we work for, we have "opportunities to cope." Each of these opportunities is a teachable moment. It is our job to use these moments for building an individual's repertoire of skills. In this way, the possibility of future success both in and out of the community is increased.

Community Based Training

Community based training is training conducted in the community environment. It is important to teach people in the setting the skills will be performed so they can correct the activity and the environment. The goal is to increase the person's ability to function in various community settings.

Imagine the problems encountered if a personal assistant spent all of their time training someone to grocery shop in an isolated environment. Imitating the community setting **cannot** and **does not** include similar details and cues as the actual environment. When the individual with disabilities finally practices the new skills in the environment, the surroundings may be overwhelming, may not include similar cues, and the learning setting may place the individual in an awkward situation for which he/she is not prepared. Of course no one can plan for every detail, but if the individual is exposed and trained in the community, one may come to expect disruptions and inconsistences in the environment. What are some of the problems we might encounter when we venture out to a real supermarket after experiencing in-home training?

Supported Living

Supported living is an active process by which people with disabilities are supported in making their own choices about where they want to live, with whom they want to live, and the kind of lifestyle they wish to lead. The term *support* is where Community Living Skills (CLS) instruction enters the picture.[2]

Choosing What to Instruct

Arriving at a decision about what to teach an individual is not a random process. Careful planning is important because the decision will affect the level and quality of the person's participation and independence within their community. Several sources of information must be consulted before instructional decisions are made. These include the individual, parents, family

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[2]. Adapted from a definition developed at the University of Connecticut, University Affiliated Program by Orv Karan, James Granfield, & Debra Suiter.

members, and others who interact and assist the person, such as personal assistant, employer, or teacher. Considering the preferences, priorities, and suggestions offered by such a group helps assure the individual's needs and desires are met.

The following pages include sample forms to record information about your employer, their level of need in various settings, and participation in activities. With this information it is then possible to determine which skills to instruct and the priority of instruction. The person's interests are the launching point for inclusion in the community and for setting future behavioral objectives and goals.

Personal Inventory

Name ______________________________ Date ________

1. List activities you participate in at home.

2. List activities you would like or need to learn to participate in at home.

3. List activities you participate in the neighborhood and community.

4. List activities you would like to participate in the neighborhood and community.

5. What are your expectations regarding community participation?

6. What are your concerns regarding community participation?

7. What are your educational priorities and goals?

8. What are your vocational goals?

9. What types of support do you feel you need in order to accomplish these goals?

Personal Inventories

1. What do you see as your strengths?

2. What do you see as areas needing improvement?

3. Summarize your long-term goals(s) for yourself:

4. List the places that you typically have contact with, e.g., school, grocery store, shopping center, work, etc.

5. For each area below, list typical activities that you currently do, e.g., video games, making the bed, making a purchase, etc.

   A. Domestic (activities around the home)

      What domestic activities would you like to participate in which you currently do not?

   B. Community (activities in public):

      In what community activities would you like to participate?

C. Vocational (activities that are considered as jobs or work):

D. Recreation/Leisure (activities that your employer enjoys or would like to do):

6. What type of living arrangement do you want in the future?

7. Below, circle the other types of assistance you need:

   a. medical assistance
   b. financial support
   c. transportation services
   d. other ____________
   e. daily living skills training
   f. social skills training
   g. vocational training

8. What barriers do you perceive, as a personal assistant, to letting your employer making their own choices?

9. What health care skills does your employer have?
   A. Hands and body washing?

   B. Teeth brushing?

   C. Proper toileting skills?

10. As a personal assistant, what are your skills in recognizing illness?
   A. If a person becomes ill, what steps would you take to get assistance/or treatment?

   B. Do you know the common signs of illness?

   C. What phone numbers would you call in case emergency care is needed?

   D. Do you wear gloves when handling body fluids, e.g. urine, feces, mouth care, mucus membrane?

11. What are signs and symptoms of abuse and neglect?

12. What are steps that you should take if your employer is being abused and neglected?

(Consult with local Health and Welfare protection agencies to help in answering these questions)

Signs and Symptoms that Indicate Illness and/or Injury
(unusual for this person)

List of Signs
(What assistants can observe)

hot, dry skin
fever - elevated temperature
rapid pulse
skin rashes
skin bruises, cuts, abrasions
unusual behavior
unsteady gait (not usually present)
memory losses
vomiting
coughing
red eyes, tearful ego
swollen body parts
discolored (dark) toes, fingers
pulling at ears
difficulty speaking & swallowing
sleeping too much, too little
sluggish mannerisms and speech
frequent falls
unexpected seizures

List of Symptoms
(What person with DD complains of)

nausea
pain
headaches
difficult with breathing
short of breath
unusually tired
loss of appetite
weakness of limbs

Barriers to Personal Choice

Personal choice is often denied to those with developmental disabilities because others perceive that they are incapable of having and expressing preferences. Have you ever been told not to pursue something because it was too difficult for you? Imagine a lifetime of people making these types of decisions for you. Decisions are often made for rather than by an individual with a disability. The result is that the individual never experiences making a choice nor the consequences (good or bad) which follow. Making choices is key to independence and self esteem, and it should be encouraged for all people regardless of their level of need. For example, knowing resources, cost information, background of person, amount of time available, patience, lack of equipment.

What barriers might you encounter as a personal assistant when letting the person you provide for make choices?

How might you overcome these barriers?

Making Connections in the Community

One mistake often made when working with persons with developmental disabilities in facilities such as group homes, schools, and anywhere else that persons tend to be "grouped," is we do just that, group them. Personal Assistance is defined by the Consortium for Citizens with Disabilities as "assisting another person with tasks which that individual would typically do if they did not have a disability". This includes making social connections.

How many times have you seen groups of people with disabilities at the local mall, McDonald's, the bowling alley, or elsewhere? It is not necessarily wrong, doing activities in groups is natural - just not all the time. Certainly the practice should not be perpetuated just because it is easier to do an activity as a group. There are appropriate activities for groups and appropriate activities for individuals. It is natural to desire time for both.

What are some advantages to participating in the community as individual?

List ways to assist your employer in making community connections.

The principle of participating in community life through the development of community living skills implies two concepts:

1. Supported community living does not just mean placement in the community. It means a meaningful involvement. All people want to be recognized and to have presence in their community.

2. Personal Assistance must provide the employer with functional skills, those which all people typically do.

Eating: If an individual can't hold a spoon in either hand or eat independently, a personal assistant may hold the spoon and physically assist by moving employer's hand from the plate to mouth. Always ask your employer what their choice is!

Transfers: If your employer is unable to move body from chair to the toilet, a personal assistant may help me stand, turn then sit on the toilet by verbally prompting their employer to set the breaks on chair and grab the hand rail on the wall, and physically prompting by helping to stand and pivot, aligning my body with the toilet. It is the choice of your employer how best to transfer.

When functional skills are performed through personal assistance, your employer is on an equal footing with persons without disabilities.

Community Living Skills

Everyday, whether it be at home, on your way to work, on the job, at a weekend sporting event, at the grocery store, or just walking down the street, you exercise an incredible number of community living skills. These skills are tools that help you participate in the community. They include social skills such as waiting your turn in line at the bank, or greeting the teller. They include finding groceries at the store that are listed on your shopping list. They also include survival skills such as appropriately and safely crossing the street. Therefore, the term *community living skills* represents a broad variety of skills.

It is probably safe to say that no two people have exactly the same community living skill requirements. The types of skills a person needs depends upon individual preferences and lifestyles. Each person participates in the community differently and therefore skill requirements are generally not exactly alike.

Steps for Assisting Your Employer in Community Living Skills

1. Always consider the personal choice of your employer when embarking on community activities.
2. Conduct an Ecological Inventory to examine the places and activities which require adaptations or modifications.
3. Conduct a Discrepancy Analysis to determine how your employer presently performs the skills necessary for their chosen activities.
4. Develop adaptations or assist your employer where necessary.

Ecological Inventory Process

The ecological inventory process is an effective, individualized approach that can be used for any activity that your employer chooses.

The Ecological Inventory Process is a sound method for teaching functional community living skills because it:

> breaks activities into their component parts,
> determines which parts require individual instruction,
> provides a method of instruction, and monitors progress toward the instructional objective.

What is the purpose of an ecological inventory?

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Ecological Inventory Process

Why are we doing all of this?!!! Can't we skip it ?

Answer: This process helps break everything down into manageable pieces. We begin to see areas of potential functioning previously unnoticed. Through this process we can assist our employer in participating in the activities of their choice.

The following steps are all components of the ecological inventory process. These steps are an avenue for adapting community living activities. Remember independence and dignity are the ultimate goals of the process.

Step One - Domains

Help an individual develop and improve skills in a well rounded manner by looking at all aspects of their lives. A *domain* is any aspect of a persons life, for example domestic, community, recreation, leisure or work. We should avoid focusing our attention on deficits in each area and instead build on existing strengths, and the choices that our employer has made.

Step Two - Environments

List the environments that your employer wants to access. Provide at least three examples of environments within each of the domains listed earlier.

Step Three - Sub-environments

List the sub-environment within the environments identified in step two. A sub-environment is a specific place within the environment.

Examples of Environments Within Different Domains

Domestic

Natural homes
Shared apartments or homes with non-disabled adults
Apartments or homes with 1-2 disabled persons

Work

Store: grocery, clothing, general merchandise, sports, music, hardware, pharmaceutical, pet
Industries
Libraries
Courthouses
Employment agency buildings
Public health buildings
Mental health buildings
United Way offices
American Red Cross facilities
Service organization facilities (e.g., Lions, Rotary Club)
Parks and Recreation facilities
Fire and police departments
Universities and colleges
Hospitals
Churches and synagogues
Laundromats
Housekeeping services

General Community Environments

Transportation systems (bus, subway, taxi)
Intersections (controlled, uncontrolled)
Restaurants (fast food, sit down order, cafeteria)
Grocery stores (supermarkets, small convenience stores)
Merchandise stores (clothing, general merchandise, sports, hardware, pet, pharmaceutical)
Service locations (doctor, dentist,hairstylist, post office, bank)

Community Recreational/Leisure

Arcades
Nature centers and trails
Arts and crafts classes
Libraries
Cultural centers
Shopping centers
Parks
Movie theaters
Bowling alleys
Fishing ponds
Boating areas
Horseback riding stables
Beaches
Swimming pools
Skating rinks
Spectator sports arenas

Accessing Community Settings. Consider the following factors when generating a list of possible environments:

Physical accessibility
Transportation requirements
Presence of persons without disabilities
Number and type of activities/jobs available
Individual preferences for activities, tasks, task structure (sitting/standing, repetitive/changing), and environmental arrangements (indoor/outdoor,quiet/noisy)

Step Four - Activities

Select a sub-environment identified in the previous step and list activities which typically occur in that sub-environment. Prioritize the activities with emphasis on the personal choice of the individual and/or the choices of parents/guardians.

Step Five - Skills

Provide a detailed list of the specific skills needed in order to participate in the chosen activity. Observe one or two persons without cognitive disabilities as they participate in the activity. Record each action and movement used while they participated in the activity.

Step Six - Discrepancy Analysis

Observe the person with a disability as he/she participates in an activity. Record his/her level of ability to complete the skill steps identified in step five.

This is like an assessment in that it gives us an idea about which skills must be adapted or performed by the personal assistant. Also begin to determine possible adaptations to establish or improve performance of a skill. After discrepancy analysis one of the following events take place.

Adapt chosen activity
Provide or arrange for assistance.
Develop an adaptation the person can use, while participating in the activity.

The purpose of personal assistance is to provide for whatever a person needs to live fully within the community. Assistance should be given that demonstrates self-determination, respect, and full participation for all persons (Racino, 1991).

Teaching A Skill

It is the choice of your employer whether or not he/she would like to "learn" a skill. If they want to "learn" a skill then the following should be observed.

The primary reason for teaching a skill is to move the person with cognitive disabilities closer to independence. As personal assistants, we will honor and accommodate activities and tasks, both in their home and in the community. If it is the choice of the employer, then it may be the assistant's job to teach skills. The most effective method to use when teaching a skill is the *prompt hierarchy*. When using this method the personal assistant may present prompts to show the individual what needs to be done to perform a skill. Prompts are presented in order from least obtrusive to most obtrusive. Keep in mind the initial reason for teaching a skill is to give the person more independence, so present most independent prompts first and only use prompts that allow less independence when necessary. After the skill is almost learned, reduce prompt use until the person performs the skill automatically. Remember, it is always the choice of your employer to perform the task or not, but an individual must be exposed to varieties of activities before a decision is final. As a personal assistant, it may be appropriate for you to "cajole" your employer into trying a new activity, i.e., swimming, cooking. But "behavior is communication" if it is clear that they do not want to participate, then their request must be honored. Presume competence in your employer at all times.

The Prompt Hierarchy (from least obtrusive to most obtrusive)

G - Gesture (such as pointing to an object to indicate "pick it up")

V - Verbal (telling the person to pick up the object)
M - Model (showing the person how to pick up the object)
P - Physical (assisting them)
    partial - guide the person's hand to the object
    full - actually manipulate the person's hand by closing his/her fingers around the object

<--------------Physical----------Model----------Verbal----------Gesture-------------->

Most obtrusive Least obtrusive

The prompt hierarchy sequence is flexible. For example, it is often desirable to use a gesture and a verbal sequence at the same time, or combine other prompts. It is more effective to fade to least obtrusive prompts and then, if possible, no prompts. When combining prompts, fading is possible by dropping the more obtrusive prompt when performance reaches a certain predetermined level. You must determine when to fade to the next least obtrusive prompt based on your employer's behavior. This is why collecting data may be important. You can see improvement and make decisions when the time is right as shown by recorded data.

Remember when using the prompt hierarchy, reinforce the person regardless of the level of prompts used. For more information about reinforcement see Module 4.

Do I Teach One Skill at a Time or Can I Work on More?

Concurrent Sequence (total task presentation). This method teaches more than one skill. In other words, we don't require someone to master skill "A" in a cluster of skills making up an activity before they learn skill "B." In a cluster of skills, each remains in context while using this approach. The result is maximum participation from the start.

Backward Chaining. This method produces connections between completion of a task and reinforcement, that is a result of completion. Instruction begins with the last skill step and moves backward a step each time the person masters a skill. For example, teaching a person to make the bed by beginning with the last step. After the last step has been mastered and the person has been reinforced, the step prior to that is taught and so on until the person is performing the entire task.

Cues and Correction Procedures

Cues are information gathered in the environment, and can be persons, - places or things. A cue exists in the environment and is not presented; it is observed. Cues are one of the reasons why activities should occur in the community as opposed to an artificial setting, e.g., making change. Many cues used in the community cannot be observed in a home setting. Cues and prompts are similar only because they both are sources of information. However, a prompt is given by the personal assistant to the person being assisted. It is related to the skill or environment and planned in its presentation. Prompts are controlled assistance, cues are not.

Natural Cue Example:

> John wants to cross a street at a corner where crosswalk lights are present, he waits when it says "Don't Walk" and crosses when it says "Walk".

Assistant's Response:

Personal assistant announces walk when it is safe to cross the street.

Cue Examples:

Debbie wants to enter a store with automatically opening doors which open when stepping on the door mat. She steps on the mat in front of one door and the door does not open. She steps off the mat and observes someone else entering the store through the next door, the door with "IN" printed on it. She then enters through the correct door.

Personal Assistant Response:

Debbie's assistant watches her step on the wrong door mat and then verbally instructs her to step back and look for the door which says "IN". Debbie does so and enters through the correct door.

Sometimes it is necessary to correct the person while in the community setting. Use discretion. Remember, community participation is a way to promote the person's independence. In all situations, treat the person in the same manner you would want to be treated if in the same situation. Respect this individual's rights as a person and as your employer.

Personal assistants will exercise objective judgement and will place themselves in the shoes of those persons they assist before making decisions (or taking actions) which will affect that person.[3] When in doubt, ask your employer.

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[3]. Direct Care Provider Code of Ethics: Idaho Center on Developmental Disabilities.

Cue and Correction Activity

Give an example of a cue and correction you and the person you work with have encountered.

Cue Example:

Correction Procedure:

Personal Assistant Response:

Examples of Natural Cues and Natural Correction Procedures

Domain: Vocational

Environment: Grocery Store

Sub-Environment: Checkout stand and store parking lot

Activity: Helping customers with their grocery bag

Natural Cue:	**Required Action:**
Customer is finished paying	Bagger asks if the customer wants help carrying the groceries.

Natural Correction Procedures if the Action is Not Performed:

The checker asks the customer if help is desired. OR The customer requests help when none is offered.

****

Natural Cue:	**Required Action:**
Customer says "No" to offer of help.	The bagger remains at the checkout stand.

Natural Correction Procedure if the Action is Not Performed:

The customer restates that help is not necessary.

****

Natural Cue:	**Required Action:**
Customer says "Yes" to offer of help.	The bagger follows the customer to his/her vehicle with the groceries.

Natural Correction Procedures if the Action is Not Performed:

The customer says, "My car is this way." OR The customer says or gestures "Follow me." OR The checker tells the bagger to carry the groceries out to the customer's car.

****

Natural Cue:	**Required Action:**
There is just one bag.	The bagger carries it by hand.

Natural Correction Procedures if the Action is Not Performed:

Checker says, "You probably don't need a cart." OR The supervisor might suggest carrying the single bag.

****

Natural Cue:	**Required Action:**
There is more than one bag.	The bagger loads the bags into the cart.

Natural Correction Procedures if the Action is Not Performed:

The bagger realizes that the bags are too heavy or awkward to carry. OR The checker recognizes the situation and suggests the use of a cart.

****

Natural Cue:	**Required Action:**
The customer indicates where to place the groceries once at the vehicle.	The bagger loads the bags as requested.

Natural Correction Procedure if the Action is Not Performed:

If the bags are placed wrong in the vehicle the customer may request that they be moved.

****

Natural Cue:	**Required Action:**
The groceries are loaded.	The bagger says, "Thank you," returns the cart to its proper place and returns to the checkout stand.

Natural Correction Procedure if the Action is Not Performed:

The bagger might be called back to the checkout stand on the intercom by the checker or may be corrected by the supervisor.

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Generalization of Learned Behavior

Generalization exists when a learned skill is remembered and used in different settings to achieve other means. For example, if you teach someone to use a telephone at home (which is a push button phone) and he/she uses other identical push button phones elsewhere as a result, then generalization has taken place. However, let's say that there is a push button phone at work that has push buttons in the receiver handle, or the phone has a dial instead of push buttons, or is a pay phone, and as a result, the person doesn't know to operate it, then his/her phone operation skills don't generalize to other phone types. To fully participate in the community the person needs to generalize the skills learned to adjust in a variety of situations.

Ways to Promote Generalization.

1. Train the skill in various settings and conditions, for example, learning to shop in a grocery store and market.
2. Aim for natural contingencies of reinforcement, for example, if an individual puts $.50 in a pop machine they expect a pop in return.
3. Use intermittent schedules of reinforcement, continue to reinforce but don't every time a behavior occurs.
4. Teach self-management techniques and acceptance of the responsibility for actions taken.
5. Use cues available in the community setting when training the person for independent functioning.

Give an example of a skill your employer has learned and has generalized.

What is Assistive Technology?

A critical component of living independently is knowledge and use of assistive technology. Assistive technology are those devices and services which allow disabled individuals to lead more independent lives.

The Technology Related Assistance for Individuals with Disabilities Act of 1988 (P.L. 100-407) offers the following definitions for Assistive Technology Devices and Assistive Technology Services.

Assistive Technology Device is any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain or improve functional capabilities of individuals with disabilities.

Assistive Technology Service is any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device. Service may include:

a) the evaluation of the needs of an individual with a disability;
b) purchasing, leasing, or otherwise providing for the acquisition of assistive technology devices;
c) selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing, or replacing of assistive technology devices;
d) coordinating and using other therapies, interventions, or services with assistive technology devices;
e) training or technical assistance for an individual with disabilities,

or, where appropriate, the family of and individual with disabilities; and

f) training or technical assistance for professionals, employers, or other individuals who provide or are otherwise substantially involved in the major life functions of individuals with disabilities.

Characteristics of Assistive Technology

1) Assistive Technology works successfully in many settings.
2) Assistive Technology includes both high and low tech solutions.
3) Assistive Technology is an interdisciplinary activity.
4) Assistive Technology addresses a specific problem (not general).
5) Assistive Technology must be robust.

Taxonomy of Assistive Devices

The Idaho Center on Developmental Disabilities has identified six major areas of assistive devices. Those areas and some examples of devices in each area are listed below:

1) *Computer Accessibility* - adaptive software and hardware, alternative input devices.
2) *Mobility* - wheelchair, canes and walkers.
3) *Augmentative Communication* - voice synthesizer.
4) *Environmental Controls and Home Equipment* - remote control switches, and grab bars.
5) *Recreational and Sports Technology* - adaptive swim aids.
6) *Barrier Free Environments* - ramps to home, adaptive building designs.

How do I best use Assistive Technology?

Whether considering the purchase of a $15,000 wheelchair or a $2.50 switch at Radio Shack, these assistive devices are nothing more then glorified tools. Devices created to accomplish a job. As such, acquiring a new assistive device requires five basic steps which are listed below. We believe that these five steps provide a useful paradigm or framework that will ensure the use of best practices when utilizing assistive technology. We hope that you will apply this framework to all your encounters with assistive devices.

Step 1. Choose the right tool for the job to be done.

Sounds so easy. However, in practice you may find it difficult to accurately assess the technology related needs of your employer. One reason is the specific nature (as opposed to general nature) of each assistive technology solutions. No one solution will be similar to another. Also, you still face the task of locating the appropriate technology to assist you in providing a solution for each problem. For these reasons, careful planning at this stage of the process is critical.

Step 2. Learn how to use the assistive device.

This can include a wide range of training options. Generally, you must first provide training to the individual who is to use the device. Additionally, parents and anyone who works with that individual such as school aides, in-home personal assistants, or others, may need training with the device.

Step 3. Plan for the maintenance and repairs of the device.

The reliability of the device, the availability of parts, and the frequency of visits by repair personnel in your local area is of critical importance in the selection of assistive devices.

Step 4. Anticipate the replacement of the assistive device.

No machine lasts forever. An electric wheelchair, which may cost in excess of $5,000.00, has only a five-year lifespan. It is important to develop long range goals which anticipate the role technology will play in meeting the needs of a disabled individual in the future.

Step 5. How to pay for assistive technology.

The last step hangs like a dark cloud over the previous four steps. In many instances, public funding for technology is difficult to acquire and is, in essence, a competitive process in which only the strong survive.

Funding Sources

These are very general guidelines. Contact the listed agency for specific eligibility requirements and coverage.

Medicaid

A federal and state program intended to meet basic health care needs of person with low incomes.

Eligibility:

- children under 18, persons over 65, or people with disabilities of any age with low income and resources
- children, persons over 65, or people with disabilities with limited assets, with income over limit, but excessive medical bills
- those who receive SSI (Supplemental Security Income) or Aid to Families with Dependent Children (AFDC).

Coverage:

- provides basic services
- follows Medicare guidelines for Durable Medical Equipment, need physicians prescription, medically necessary
- usually requires prior authorization

Contact:

- local Assistance Payments Office or Community

Medicare

A federal program responsible for purchasing medically necessary products and services for eligible beneficiaries.

Eligibility:

- all persons over 65 years of age
- persons under 65 who are eligible for Social Security Disability Income (SSDI) (based on past work record, income and disability - unable to perform substantial, gainful activity and last 12 months or longer
- persons under 65 with a disability who have not worked enough hours to qualify for SSDI, may still qualify for SSI

Coverage:

- Part A - covers all, primarily inpatient medical care
- Part B - must enroll, pay monthly premium, satisfy deductible and coinsurance requirements - covers wider array of services including **Durable Medical Equipment** (can withstand repeated use, medical purpose, appropriate for use in the home, & not useful in absence of illness or injury)

Contact:

- Social Security Administration under United States Government 1-800-333-6667

Vocational Rehabilitation

A federal and state program that provides vocational, independent living, supported employment services for citizens with disabilities.

Eligibility:

- 16 or older with disability that interferes with ability to work

Coverage:

- device or service must be vocationally enabling or promote independent living, individual determination

Contact:

Special Education

A federal law requiring all children with disabilities to receive free appropriate education. Special education services are available on the basis of need.

Eligibility:

- disabled, ages 0 to 26, served by local school district

Coverage:

- device/service must be educationally relevant i.e. improve functioning in school setting and must be included in IEP.

Contact:

- Special Education teacher or local school district

Private Insurance Companies

Health insurance, liability insurance, long-term disability insurance, no-fault automobile insurance.

Eligibility:

- covered individuals

Coverage:

- most standard health insurance companies fund durable medical equipment, other types of insurance vary

Contact:

- insurance agent

Workers Compensation

Employers insurance required by law to cover employee injuries or accidents.

Eligibility:

- job related injury or disability

Coverage:

- covers all approved medical expenses prescribed by treating physician

Contact:

- Employers insurance company that handles workers compensation

Veterans Administration

A federal agency which provides medical assistance to service men and women.

Eligibility:

- veterans

Coverage:

- medical equipment, wheelchairs, hearing aids, prosthetic devices, speech devices, and hand controls

Contact:

- Veterans Administration under United States Government 1-800-662-9163

Independent Living Centers

A non-profit organization which provides support, evaluation, services, and devices.

Eligibility:

- any person with disability can participate in center activities, eligibility for some services based on economic need, however most programs available to all people with disabilities regardless of income

Coverage:

- free evaluation, sliding fee scale on assistive devices & services

Division of Services to the Handicapped

A state agency which provides primarily residential support services, training programs.

Eligibility:

- primarily adults, persons, with severe chronic disability likely to continue indefinitely that require special individualized treatment

Coverage:

- residential group homes, supported apartment living, family support services, day training programs some assessments, occasionally may provide one time devices

Contact:

Easter Seal Society

A charitable organization that provides services to all disabilities, all ages, statewide.

Eligibility:

- children or adults with disabilities

Coverage:

- technology and equipment services, support groups, disability awareness, information and referral

Contact:

March of Dimes

A charitable organization which assists adults and children with polio and birth defects.

Eligibility:

- children or adults with polio or birth defects

Coverage:

- varies, depends on local agency, usually what is not covered by anything else

Contact:

- local chapter

Cerebral Palsy

Non-profit organization provides services to persons with cerebral palsy.

Eligibility:

- children or adults with cerebral palsy

Coverage:

- determined through assistive technology funding request form. Limited funds, based on ability to pay, and insurance coverage

Contact:

Service Clubs

Local civic organizations such as Lions, Kiwanis & Rotary Clubs.

Eligibility:

- varies, usually prefer to assist local individuals

Coverage:

- varies, usually a last resort

Contact:

- Current local organization president

Summary and Overview of the Community-Based Training Process

Steps for Conducting Ecological Inventories

1. Consider all <u>domains</u>: domestic, vocational, recreational and community; when listing possible areas for participation.

2. List all <u>environments</u> within each domain that are available to same-age peers without disabilities.

3. List the <u>sub-environments</u> within each environment.

4. List the <u>activities</u> that occur within each sub-environment.

5. List the <u>skills</u> performed for each activity by looking at a peer who does not have a disability and noting the skills used as he/she participates in the activity.

** Don't forget to consider personal choice every step along the way! **

Steps for Conducting a Discrepancy Analysis

1. Observe and record whether the person with a disability is able to perform the skills required for a particular activity (see step 5 above).

2. Determine the specific aspects of a skill where the person has difficulty. Note these aspects and possible teaching strategies or adaptations which might help this person participate in their chosen activity.

3. Use one of the following four options:
    a. Teach the person to perform the skill.
    b. Develop an adaptation to assist the person when performing the skill; then teach the skill with the adaptation.
    c. Teach the person a different but related skill that has the same outcome.
    d. Provide full assistance to the person while he/she performs the skill.

Overview of the Community-Based Training Process

1. Identify community settings in each of four domains which your employer wants to access: domestic (residential living), work, recreational/leisure, and general community use areas such as stores, restaurants, transportation systems, and health care services.

2. Ask your employer to select specific current and future environment in which a person might participate (e.g., Corner Market, Lockett's Grocery).

3. Conduct ecological inventories of the current and future environments for the purpose of delineating sub-environments (e.g., kitchen sub-environment of the home), and identify activities that typically occur in the sub-environments (e.g., washing dishes in the kitchen).

4. Establish priorities among the activities and select the highest ranked ones for instruction. The activities selected will constitute the goals of the training program.

5. For each activity selected, list the sequence of skills that non-disabled persons typically use, in order, when performing the activity.

6. Conduct a discrepancy analysis for each activity to identify how the individual's present skills compare to the skills that non-disabled persons use when completing the activity.

7. Develop individualized adaptations for those skills the person lacks and is unlikely to learn.

8. For each activity, develop an instructional objective taking into consideration the results of the discrepancy analysis and the individualized adaptations.

9. Address implementation issues such as scheduling, staffing, transportation, and locating monetary resources.

Five Schools of Thought Which Unnecessarily Limit Learning by Persons With Cognitive Disabilities

1. *Developmental Age Hypothesis* often results in adolescent and adult persons with severe disabilities receiving instruction in environments, engaging in activities and using materials designed for much younger persons.

2. *All-or-Nothing Hypothesis* instruction is not initiated until there are assurances that the person can acquire all the skills. This often excludes people from taking part in chronologically age appropriate activities and fosters dependence.

3. *Independent Performance Hypothesis* before instruction on a skill sequence, it must be determined whether the person will be capable of performing the whole sequence without assistance or supervision. This approach shelters the person and does not allow your employer to participate in an environment of their choice.

4. *Prerequisite Skill Hypothesis* refers to the idea that certain skills must be acquired before access to other environments is allowed so that unnecessary failure and frustration will not occur. A sufficient number of these skills is rarely attained and the person is excluded.

5. *Artificial Approximation Hypothesizes* that a person is first taught the skill in an environment other than the natural one. For example, teaching someone to ride a bus using a cardboard model of a bus instead of a real bus. The natural environment is much different than the one in which training was given. Therefore, it is less likely the skills will be performed properly in the natural environment.

The following article written by Joseph P. Shapiro is one mans testimony of his nursing home and home care experiences.

Forcing the Young Into Nursing Homes

Jeff Gunderson's voice is choked with worry. He is about to reenter the place he calls "the concentration camp." It is a nursing home, one of two where Gunderson, who has cerebral palsy, was sent from the time he was 18 until he turned 27.

"I always said if I had to come back here, I'd rather be six feet under." Gunderson says nervously as his attendant tugs him from the car parked outside the nursing home and lifts him into his wheelchair. Nine years have passed since he lived here. He has returned to this brown-brick building of his nightmares because he wants to introduce a reporter to his former roommate, another man with cerebral palsy who, he says, is anxious to get out.

Gunderson wound up at this Beloit, Wisconsin, nursing home--where he says he was abused and forgotten--after his mother and father divorced. His mother could not lift her large son out of bed and care for him. Hiring an attendant to come into the Gunderson home was not covered by private or public insurance and was prohibitively expensive for the woman who worked on a canning factory assembly line. But Medicaid does pay for all of the costs of a nursing home. So Gunderson's mother--as many other parents of severely disabled sons and daughters--had little choice: She put her teenage son into a nursing home.

Now back at the nursing home, Gunderson sees an ambulance that has pulled to the front door. It is a bad omen, he thinks, making him remember how death was a constant here. The two nursing homes where Gunderson lived were set up to care for the elderly, not for the young. Gunderson was required to follow the same regimen as the generally sickly, elderly people around him. This made it easier for the nursing home staff. He went to bed at 7 p.m., the same time as his first roommate, a man in his 80's. His food was bland, unseasoned, often a form of gruel made for older residents who could not eat solid food. Gunderson admits he rebelled: "I'd have fits."

At both nursing homes, Gunderson says, the staff tried to break him. Sometimes aides tied him to his bed. They would drag him into cold showers as punishment. To make him use the bathroom, on a schedule convenient for the nurses, they would put ice cubes down his pants. It was a form of torture for Gunderson, since the cold set off his spastic muscles. On several occasions, Gunderson says he was given a suppository before sleep, and, since he could not move by himself, he would spend the night lying in his own feces. (Officials at both homes say they are unaware of the incidents and that such practices would have been against their policies.) Until his last years in this second home, days were spent in bed watching soap operas. "Many times I wanted to kill myself," he says. "I planned it, too."

Inside the nursing home, the antiseptic hospital smell is strong and the hallways lights are bright. Gunderson is panicky. He greets staffers with a cheery, "Remember me?" But he ignores the severely disabled young people, who now live on a separate wing, some of whom are excited to see him. Loud music, from a radio, comes from one darkened room where a man lies curled up in a hospital bed. Gunderson, wheeled down the hall by his attendant, cannot find George, his former roommate. George is gone, he announces, perhaps he no longer lives here.

Quickly outside again, Gunderson relaxes at a nearby restaurant with a hamburger. An elderly man enters, wearing a white cap, white pants and an emerald-green sweater. It is George's father. He comes to the nursing home every day to feed his son. George, it turns out, had been there and Gunderson had spotted him. He was the man with the radio. But Gunderson had not been able to face him. His reasons are vague. "George probably would have thought I would stay there with him," he explains.

Later, on the telephone, George's father, a friendly retired restaurant owner, explains that his son "got hurt at birth." George's mother takes the receiver. Would they like to see their son out of the nursing home, like Gunderson, in his own apartment with an attendant? It is not possible, says the mother. Her son is "absolutely, completely helpless, he has no communication, he needs to be dressed." The staff at the nursing home is very caring, she says. Only she and a few of the aides know George well enough to understand him when he speaks. One nurse has recently devised a board with pictures. George points to a picture of "water" when he wants to drink or "radio" when he wants his music. A therapist has begun working with him, softly throwing a ball to George and giving him colored blocks to stack.

The mother notes, "They have a program with the children." George is 49.

Gunderson, now 36, lives in a subsidized, two-bedroom apartment. He shares it with his attendant, Shaun Boyd, who helps him dress, bathe, toilet, cook, eat, do housework and get around town. Gunderson works three days a week at a sheltered workshop, where he is paid a piece rate to help pack boxes of chili that go to grocery stores. He runs up his phone bill, talking long hours to friends. Bowling trophies--he is in two leagues--are scattered around his large living room. His neighbor comes over to watch football. Boyd has become his closest friend. The two eat out together, take rides in Boyd's second-hand car, or stay up late watching rented movies.

Younger people like Gunderson, between 18 and 64 years old, make up 10 percent of the population of U.S. nursing homes. There they lose "the basic rights that the rest of us take for granted, like choosing where they live, who they live with, what they eat, when to eat, who their friends are or if they are going to have sex," argues Tom Hlavacek of United Cerebral Palsy of Southeastern Wisconsin. "If it happened to us, we would scream holy hell and go to the highest court in the land. We do it to people with disabilities all the time and we feel justified by the fact that they have a disability."

Most disabled people in nursing homes have developmental disabilities, such as mental retardation and cerebral palsy. Others have muscular dystrophy and similar illnesses. But a new class of residents includes young people with spinal cord and head injuries, who likely would have died from their accidents before medical technology of the last two decades. There have been several recent cases, like that of 34-year old Georgia quadriplegic Larry McAffee, of young people going to court for the "right to die" when they face lifetimes in nursing homes.

In the 1970's, states started closing large institutions after lawsuits and newspaper exposes attacked the hellish conditions at many of these facilities. Often residents were removed from one institution only to be dumped into another--a nursing home--that was equally regimented, inappropriate and sometimes abusive. The number of people with developmental disabilities in state institutions dropped from 195,000 in 1971 to 88,000 today. But the total of developmentally disabled younger people--from 18 to 64 years old--in nursing homes grew by a third in that same period, according to K. Charlie

Lakin of the University of Minnesota.

Some 148,000 people under 64, of various disabilities, lived in nursing homes in 1987, according to the U.S. Department of Health and Human Services. Some are there because they or their parents prefer it. But most want to live on their own, says Nancy Hansen-Bennett of United Cerebral Palsy of South Central Wisconsin, the group that helped Gunderson move into his own apartment. Even the most severely disabled person can manage outside of a nursing home with attendant care and other support, she says. Power wheelchairs, computer with voice synthesizers and innovative group homes and work programs allow unexpected independence. And living in the community is always less expensive, Hansen-Bennett says, since nursing homes employ costly nurses and doctors, which are not needed by someone who has a disability but is in good health.

Gunderson is one of the first users, and biggest success stories, of Wisconsin's Community Options Program. It gets disabled and elderly people out of nursing homes and into their own apartments and group homes. Some 1800 disabled people are served by Wisconsin's various community programs, but there are another 5800 on waiting lists, who either live in institutions or with family members.

Visits to Gunderson and others in Wisconsin--where there are 4600 people between 18 and 64 in nursing homes, according to the Wisconsin Council on Developmental Disabilities--make it clear that who stays in a nursing home and who gets out is often quirky business. It may be a matter of not having a friend or family member to be a strong advocate with the bureaucracy, as in the case of James Lee, an articulate 37-year old man with cerebral palsy who wakes up at dawn, but often waits until noon for the nurses at this understaffed skilled nursing facility to get him out of bed.

Or it may be a matter of running into cold-hearted bureaucratic rules, as in the case of Pamela Erickson who has no hope of leaving her nursing home until she can get a proper wheelchair. Erickson, 42, with cerebral palsy, is lively and verbal. But her body is so twisted by scoliosis that she needs a customized wheelchair to keep her sitting upright. The special chair would cost about $4,000. Wisconsin Medicaid, however, will not reimburse for a nursing home resident's customized wheelchair, unless it can be proven to help them work or live on their own. No one can give Erickson money for the chair since, as a Medicaid recipient, she is not allowed to have more than $2,000.

So Erickson has spent 15 of the last 16 years in the home lying on a padded wooden cart with large wheels. It is her prison. Recently, at her Milwaukee nursing home, Erickson's cabana cart was left in front of a television set. Most of her friends were visiting a botanical garden. But Erickson's cart is too big to fit in a van. Once, five years ago, someone hired an ambulance, her only means of transportation, to take her to a Milwaukee Brewers game. Her only other trips out of the home have been to a hospital. Because she spends day after day without sitting up, Erickson develops intestinal blockages. Medicaid, which denies her the chair she needs, has paid for four costly hospitalizations to correct her resulting health problems.

In November, a state hearing examiner ordered Medicaid to pay for Erickson's wheelchair. The decision, according to her attorney, Roy Froemming of the Wisconsin Coalition for Advocacy, gives Erickson "the right to leave the place she lives. She wants to go to church, to go to the store. It's an essential right to a meaningful life."

Few children go into nursing homes and institutions now. But more and more working-age disabled people who live with their families face institutionalization as their parents age. Virginia Helmin, who recently fought cancer, worries about what will happen to her son, Richard Helmin, after she dies.

Her fear is not exaggerated. Consider the case of Jackie, a high school graduate, with mental retardation, who reads, writes, can cook and take buses around Milwaukee. When her mother died nine years ago, she was thrown into a grim and crowded nursing home solely for people with developmental disabilities. She is not allowed to leave the facility because the surrounding neighborhood is considered unsafe. Fearful of retaliation from staff, she asks that her last name not be printed. Jackie has been on and off a waiting list for a group home for 10 years.

To get people like Jackie out of nursing homes may require more money, or at least a redistribution of existing funds. Most federal funding is directed to institutions and nursing homes and that discourages states from setting up community programs, complains Dennis Harkins of Wisconsin's developmental disabilities office. In Wisconsin, two-thirds of such money serves 5500 residents of nursing homes and institutions, while a third pays for 25,000 people in community programs, he says. Proposed legislation by Senator John Chafee (R-RI) would freeze funding at current levels to institutions with more than 15 beds, in effect forcing states to spend more on smaller homes. But after seven years, Chafee's bill is perhaps irreversibly stalled in Congress. Forceful opposition has come from unions, which fear job losses at institutions, and vocal parents with children in state facilities who distrust the state's ability to provide safe community-based programs.

Recent federal nursing home reform laws, however, are aimed at ending "warehousing" of residents. Facilities are required to focus on rehabilitation, a tenet of the disability field that is now being applied to better the lives of both disabled and elderly residents of nursing homes.

Even with changes, one nursing home official says that such facilities can never really meet the needs of young people. "How many of us live with 107 other people?" she asks. "We try to make it comfortable, but it's still an institution."

Joseph P. Shapiro, an associate editor of U. S. News and World Report, is examining the disability rights movement. Currently, he's working on a book about disability rights scheduled to be published in the fall of 1992. This article first appeared in the Alicia Patterson Foundation Reporter.

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Thoughts About the Article

Many young people with developmental disabilities today live in nursing homes. Not all are as bad as the ones Jeff describes, but they still place tremendous limitations on a person's lifestyle and personal choice.

The number of people with developmental disabilities living in state institutions dropped from 195,000 in 1971 to 80,000 today. But the total of persons with developmental disabilities from ages 18 to 64 living in nursing homes grew by 33% in that same period.

"Even the most severely disabled person can manage outside of a nursing home with attendant care and other support"

Why do some people with developmental disabilities often end up living in nursing homes?

List some rights these people might lose as nursing home residents.

How does this article affect you as a personal assistant?

A HOME OF THEIR OWN

The nightmare of Willowbrook is over.

Today these mentally retarded adults live in group homes filled with love.

By Joseph L. McCarthy

The names of the residents have been changed.

This year, Christmas Eve at 48 AB Executive Way will be much the same as Christmas Eve anywhere else. A pile of gifts tied with colored ribbons and bows will be placed beneath a seven-foot tree trimmed with powder-blue doves, twinkling lights and yards of silver garland. Stockings will be hung above a brick fireplace in the living room, and upstairs, household members will rest fitfully, awaiting the moment when they can rush down and tear the wrapping from their holiday prizes.

But this is no ordinary household. The six women who live here are all mentally retarded. And four of them once lived in the Willowbrook State School, an institution for the retarded in Staten Island, New York, that was known as "America's concentration camp."

Jean, now 47, came to Willowbrook in 1955. Her mother had died, and as is the case with many of Willowbrook's residents, her surviving family was no longer able to care for her. Often, in anger, she would attack those around her or violently smash her head against the wall. After several years at the school, she was moved to building number two, where heavy sedation, straitjackets and solitary confinement were commonplace.

Mary entered Willowbrook in 1960 at the age of seven. She was diagnosed as severely retarded, hyperactive, and epileptic. One day, after ripping an attendant's uniform, she was transferred to a ward that housed 60 other highly disturbed, violent patients. "My little girl came out of that building blind in one eye, with a broken nose and scars all over her body," says Mary's mother.

Jean and Mary still live at Willowbrook, but now that once-dreaded names stands only for a quiet Staten Island neighborhood--not the for human warehouse that used to be there. In 1986 New York State closed the institution and opened 12 residential apartments for the mentally retarded on the outskirts of its former 382-acre site; 48 AB Executive Way is one of them. The women who moved there, however, have more than new addresses. They have new lives.

Nowadays Jean and her friends go dancing, attend special schools in their community and enjoy boat trips and hayrides in the country. With help from the staffers who work at their home, they clean house and shop for their own clothing and groceries.

All told, 11 staffers work at 48 AB Executive Way in three shifts, along with a recreation therapist, social worker, dietitian, psychologist, nurse and speech therapist, who are also responsible for other residences.

"The minute these women came here, they began to get better. Their turnabout has been almost miraculous," says Marie Ortiz, a former Willowbrook employee who is now the apartment's manager and a part-time surrogate mother to the women who live there, "In Willowbrook they were treated like animals. Now they're a family."

Not everyone in the family came from Willowbrook. Susan, at 27 the family's junior member, came to Executive Way from her mother's Staten Island apartment. And not all of the women were born mentally retarded. At age four, Rose came down with scarlet fever, then contracted encephalitis, an inflammation of the brain that left her with a progressive form of mental retardation.

This Christmas season the women will travel to see the giant tree at Rockefeller Center--a shimmering emblem of the New York holiday season. They'll dine by candlelight on roast turkey, cranberry sauce and hot biscuits. And they'll attend their annual Christmas disco/pageant, where they'll sit on Santa Claus' lap and ask him for gifts.

But this Christmas, along with the packages they'll receive from Santa, their families and the apartment's staff, there will be other gifts. Jean and Mary seldom lash out anymore. Sixty-nine-year-old Marcia, who had been ripping out her hair by the handful when she moved into her new home, has grown back a gorgeous head of snow-white hair. Sally, age 40, who used to be "hell on wheels," according to a former staffer at the institution, now does her wheeling around on the dance floor. And the greatest gift of all just might be the apartment itself--and the kinship it has engendered.

"They found each other," says Ortiz, "and that has made all the difference."

Willowbrook had been conceived amid great expectations: It was to be the first state institution for the mentally retarded to admit children under five years of age. But almost immediately after Willowbrook opened in 1947, its population began to soar. By 1956 the institution, built to accommodate about 3100 residents, held 3900. By 1962, after an expansion program that increased Willowbrook's capacity by 1200 beds, the school's population had swelled to 6200. Under such conditions, individual attention was virtually impossible, says Katy Tucker, a staffer at 48 AB Executive Way who started working at Willowbrook in 1958. Resident-staff ratios often exceeded 100 to 1. Children were herded to meals "in packs, like cattle," she recalls, and they often went weeks without a shower or change of clothes. Because of the filth and overcrowding, intestinal diseases, such as shigella, swept through the population. In May of 1965, a ten-year-old boy was scalded to death on a shower, partly because of the school's archaic plumbing. A month later a 12-year-old suffocated to death when a restraining apparatus loosened and became wound around his neck.

Such was the Willowbrook that Jean found upon her admission there. Responding to the squalor and neglect, she lost an eye through self-abuse, staffers acknowledge.

In 1972, amid steadily deteriorating conditions, Mary's mother and scores of other Willowbrook parents finally revolted. Aided by the American Civil Liberties Union, they filed suit against New York State. At about the same time, more than a dozen other states--including Illinois, Pennsylvania, and Texas--became involved in similar litigation. As these cases were settled, plans were laid to close or trim many institutions and to place their residents in community-based group foster homes. In the early 1970's there were no more than a handful of group homes; now group homes serve an estimated 114,000 clients. Some homes, like those on Executive Way, have been built on the ground of dismantled institutions, but most are in regular communities. Because of the group-home movement, the institutional count of retarded people fell from 194,650 in 1967 to 94,696 in 1987. According to the most recent survey by the Association for Retarded Citizens of the United States, at least 64,000 people are on waiting lists to enter community-based facilities. And what began as an experiment in social services has emerged as a dramatic success.

It's daybreak at Willowbrook. In the eerie half-light, one can see that the windows of the empty, low-slung ward buildings are sealed shut with heavy sheets of plywood or tin. Marie Ortiz used to work in one of those buildings. But today she drives past the abandoned complex and parks in front of a two-story, brick garden apartment, its front neatly appointed with evergreen hedges.

Inside, the dwelling radiates an easy charm. In the dining room, two rock-maple dining tables are set with cornflower-blue tablecloths and magenta silk flowers. The living room is furnished with a couch, a pair of soft easy chairs, an exercise bicycle and a 25-inch console color television. Scattered about is an assortment of toys and games: building blocks, a checkerboard, a jigsaw puzzle and a fuzzy white unicorn with a pink horn.

Jean pads downstairs and bids everyone a cheery good morning. Assisted by Charlotte Young, the house's director, Jean sits and softly hums a tune. "She know the melody to 50 or 60 songs by heart," says Jean's sister-in-law. Jean never sang at Willowbrook.

Other family members filter down to the breakfast table. "Who's going to say grace?" Young asks. "Me!" Jean volunteers. The family digs into a breakfast of scrambled eggs, hot cereal, toast and coffee.

When she finishes her coffee, Mary bangs the table with her fist, points to her cup and shouts at staffer Katy Tucker, who prepared their meals, "Want!"

"*I* want," Tucker reminds her charge.

"I want," Mary replies.

"You want what?"

"Coffee."

"You want coffee, what?" Tucker coaxes.

"Coffee, please," Mary finally responds. With a heartfelt laugh, she bounds from her chair and wraps Tucker in a steep-trap bear hug.

The severely and profoundly retarded, whose I.Q.'s are less than 40, were once thought to be uncontrollable and ineducable. "Many of them may never learn to read or write," says Dr. Mary Howell, assistant clinical professor in pediatrics and geriatrics at Harvard Medical School and a Joseph P. Kennedy, Jr., Scholar in Geriatrics and Mental Retardation. "But through consistency and repetition they can be taught to feed, dress and groom themselves and to clean house--activities that increase their independence and self-esteem."

For the more mildly retarded, Dr. Howell says, mastery over such tasks might facilitate their admission into a job-training program, or even a move to an apartment of their own. But for Jean and her housemates, learning these skills might simply mean "graduating" to a group home with a more independent environment. Because of the shortage of group homes and the painstaking process of teaching the retarded necessary skills, moves are relatively infrequent, says Harris Rimshnick, who administers several Executive Way units.

Still, when moves are proposed, they're often cause for celebration. "One of our residents was moved to a less restrictive house last week," Rimshnick says. "It was practically next door, but he couldn't stop bragging to his housemates: 'I'm going up the road.'"

Breakfast is finished. Marcia totes her dishes to the kitchen; Sally grabs a dustpan and begins to sweep the dining room floor. Rose, assigned to report to the family on the day's weather forecast, has become enraptured by Jane Pauley on the *Today* show. Jean trundles out the door to take the bus to a special-education program in a nearby neighborhood. Seeing her out, Ortiz smiles.

"Her brother never thought she'd make it in a group home," Ortiz says. "It's really incredible, isn't it?"

Almost as incredible is that the idea of group homes for the mentally retarded caught on at all. At first, even many who were appalled at institutional conditions opposed them. "In effect, group homes second-guessed a parent's decision" to put away a family member, points out attorney Chris Hansen, who helped to press the Willowbrook case against New York State and is now associate director of the American Civil Liberties Union's Children's Rights Project. "After all, if they could live in homes, the question became, Why didn't the family keep them in the first place?"

Perhaps the most formidable obstacle to group homes, though, has been resistance from the neighborhoods and townships in which they've been located. According to Ellen Ashton of the New York State Office of Mental Retardation/Developmental Disabilities, four facilities in the New York area were set on fire when they were under construction or renovation: In Queens in 1987, in Northport in 1981, in Shirley/Mastic in 1980 and in Huntington in 1978. In 1985, neighbors in Russell Gardens, a Long Island community, tried less violent tactics: They chipped in and bought a house to keep it from becoming a group home.

Elsewhere, municipalities have passed laws designed to exclude the mentally handicapped. In 1980, citing a regulation barring "hospitals for the feeble-minded," the city council of Cleburne, Texas, denied a zoning permit for a group home. In 1985 the U.S. Supreme Court unanimously agreed that the permit was unconstitutionally denied; subsequently, 13 retarded men and women moved into the house.

A flyer taped to the wall of a downstairs bathroom at 48 AB Executive Way reads, "*Being mentally retarded never prevented anyone from being a good neighbor.*" But given the terror that group homes have generated, how many neighborhoods really have given the mentally retarded that chance?

The Russell Gardens episode ended on a happy note. On appeal, a New York State Supreme Court justice ruled that the residents' purchase of the prospective group home was illegal. The state eventually purchased the house, and 12 mentally retarded men and women moved in. The new arrivals then threw a coming-out party for their neighbors, serving them bagels and cream cheese, cakes, cookies and hot coffee.

Staten Island also has had its share of success stories. "One group home in my neighborhood caused a lot of flak," says Lisa Piper, a Staten Islander and a recreation therapist who used to work with the women of 48 AB. "The neighbors didn't like it, but eventually they began to talk to the residents and get to know them." The happy climax came two Christmases ago. "A couple of people brought over a huge gingerbread house and a fruit basket," she says. "The residents here were delighted."

Tonight what's on tap at 48 AB is a combination Christmas-New Year's celebration with the men from 47 Executive Way--the apartment next door. In one room some of the residents, including Sally, Rose and Susan, gather to fashion sparkling papier-mache ornaments out of Styrofoam balls and red and green foil. Marcia shuttles back and forth between the craft room and the refreshment table, toting chocolate-chip cookies, cups of vanilla ice cream and steaming flasks of hot cocoa. Mary alternates between urging some of the shyer residents onto the dance floor and clamoring for a counselor to play

Michael Jackson on the stereo. Jean claps her hands in time to the pounding disco beat.

Christmas at the old Willowbrook wasn't terrible, recalls Katy Tucker. The buildings were decorated, and there was a tree in each one. The tragedy, she says, was that the makeover was only cosmetic, and once Christmas was over, Willowbrook reverted to form. "I stopped by one of the Willowbrook buildings the other day," says Marie Ortiz, "and you know, it might sound crazy, but I can still hear the kids crying out. When I worked there, I used to cry too."

Ortiz isn't crying anymore. Nor are her "kids." "This home is filled with peace and love," she declares.

Come to think of it, kind of like Christmas itself.

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Questions about "A Home of Their Own"

1. What makes the New Willowbrook a successful group home?

2. How did the home overcome conflict from their neighbors?

3. List an example of partial participation, community integration and reinforcement from the article.

Module Four

Strategies For Increasing Positive Behavior

This module will provide you with information so that you may assist your employer to live in the community. Life which includes choices, respect, and community presence will help your employer to be respected community members. When we do not honor our employer with choice, respect, and community presence, then very often, he/she may respond in disruptive or challenging ways. Whenever behavior threatens community participation we must ask "why is this person behaving this way?" "What is this person trying to tell us?" Do not make the decision that the challenging behavior is the fault of the person or their disability. There may be a variety of reasons for challenging behavior, i.e., living arrangements (group homes, segregated settings); lack of choice in life; lack of self-determination in life; lack of meaningful activities in life; lack of natural social supports; associations primarily with paid professionals (job coach, personal assistants).

It is the personal assistant's job to find possible reasons for the behavior and work to change the circumstances enhancing the problem behavior. Often we don't need to "intervene" directly with the individual because the problem is in the environment. "Behavior is Communication" because it tells us whether or not something needs to be changed. We must train ourselves to "listen" as others "speak" through their actions. Perhaps the old saying is true: "Actions speak louder than words."

Keep track of your progress during the day; then review and answer these eight objectives upon completion of this module.

1. Define behavior and describe a challenging behavior.

2. Define functional assessment, its purpose, and two methods for performing an assessment.

3. Define aversive and explain why using aversive events to change behavior is not effective.

4. List three or more components of a non-aversive approach to behavioral support.

5. Know the difference between reinforcement and punishment and identify examples through short descriptions of a person's behavior.

6. Describe the three main schedules of reinforcement.

7. Define satiation and describe three ways of reducing its risk.

8. Given a scenario, apply non-aversive methods for behavioral support and list strategies for increasing positive behavior.

Reading Assignment

The following article, "A Tale About Lifestyle Changes: Comments on Toward a Technology of 'Non-aversive' Behavioral Support" written by Ann P. Turnbull and H. Ruthford Turnbull, II illustrates how behavior modification changed one person's life. After reading the article answer the questions below.

1. How has behavioral programming changed Jay's life?

2. List other techniques and considerations other than behavior modification you have learned through the training programs that are discussed in this article.

3. How could you apply this information to better assist the person you provide direct services to?

4. Does this article motivate you to learn more and seek information you've learned in the program?

Jay's Story

This is a tale about two different lives lived by the same person, a story of two different worlds--one mass-produced and mass-marketed, and the other tailor-made to the specifications of the individual. It is also a tale of different behaviors--one that consisted of frequent and serious self-injury and aggression, and another that has reduced that behavior to almost nil. We tell this tale so that the reader may know that we have traveled both roads and, with our son Jay, have detoured from one and chosen the other. We have rejected the road that tolerates aversives and is characterized by restrictiveness, and we have chosen the road that combines positive behavioral programs with fundamental lifestyle changes reflecting integration, relationships, choices, communication, problem solving, and social skills.

Picture the person. The diagnosis: low moderate mental retardation, mild autism, and intermittent bipolar emotional states. The underlying traits: wavers between relational and aloof, usually characterized by a gentle disposition; expects to be liked and accepted; tends not to initiate; determined to have his own way; manipulative in response to undesired demands; far more capable of understanding others than expressing himself; accustomed to pleasant and normal environments and interactions with others; and values individual attention from committed and caring individuals. In this tale, the person, the diagnosis, and the traits do not change: Jay is and always has been the same person.

Understand his worlds. Four years ago, his world was typical for many people with his disabilities. He was employed by a sheltered workshop, worked on the premises, was given manual work to do, had no choice about the nature or location of his work, had coworkers who all had disabilities, including the other "residents" in his group home, and had little individual instruction in developing work-related skills. He said he wanted to work where he could wear a coat and tie. Of course, he was required to work elsewhere.

He lived in a group home with eight other people with disabilities; until he moved into that house, he did not know any of them. Nor did he know previously any of the many "houseparents" who came to work on varying shifts. His "free time" consisted of being shuttled from the house to work, back to the house, then to some recreation (usually bowling) and always with the same "herd" of people with disabilities, always in the same "handicap van," and almost always in disregard of what he wanted to do and with whom he wanted to be. Except when his family and their friends would enter his life, his relationships were always with people with disabilities or the staff. Finally, he was the "client" of an organization that rejected value-based and state-of-the-art approaches to its work, and this was explicitly and even proudly acknowledged by the chairman of the organization's board of directors.

Conjure up his behaviors and the agency's responses. He became self-injurious (head-banging on walls and floors), destructive (ripping curtains off of walls, breaking pictures, tearing up mattresses), and aggressive (choking a co-resident every time he saw him and pulling the hair of others). The agency responded by throwing water in his face to get him to comply with its requests, such as getting up in the morning; it demoted him from job to job until he "flunked" the lowest level of sheltered workshop employment; it moved him to more restrictive and controlled houses; it required us to pay for a "bodyguard" who verbally abused him and physically controlled him--control that was acknowledged and considered "appropriate" at the workshop and group home. (Some might say that this program used behavioral programming inappropriately and that the use of aversive procedures should only be evaluated when they are employed under expert and monitored procedures. That response ignores the reality that people with mental retardation cannot *hypothetically* deal with the issue. Our grave concern is that the agency that "served" Jay may be typical of agencies across this country in the implementation of aversive approaches. In fact, this particular agency has been the recipient of a number of state and national awards for meritorious programming).

Now, hear a new tale, told 4 years later. Picture the same person: there is no change in his diagnosis or traits. However, his world and his behavior are different, for a radical change has occurred. For nearly 2 years, Jay has worked in competitive employment and makes more in a month of half-time work than he would have made in a year of full-time work at the workshop. He has a job coach who, of course, attends to Jay's job skills. Because job skills are the easy part, however, the coach gives far more attention to communication, social interactions, environmental adaptations, and predictability in how Jay and others in his life relate at work, at home, and in the community.

For a year, Jay has lived in his own home. His net monthly wage is enough to meet the monthly payments of principal, interest, taxes, and insurance on a home that he and his family own. Using only his present wage, he will pay off the mortgage in 27 years. He shares the cost of living with his housemates and his parents. He has chosen two non-disabled housemates because he likes them and because they like him; they have a relationship based on care, concern, commitment, and competence.

In addition to being an honorary member of the Sigma Alpha Epsilon fraternity at The University of Kansas, he has a large and enjoyable circle of friends with whom he shares interests and hobbies. He receives the benefits of a behavioral program based on positive, non-aversive approaches that is devised by members of his circle and carried out in all of his interactions at home, work, and in the community.

By his own choice his social interactions are primarily with non-disabled people, but he also greatly enjoys dating his girlfriend, who has a disability. He understands and accepts both the positive and negative consequences of his choices. If, for example, he chooses to stay in bed in the mornings, he gives up activities and relationships that he values, both during and after work. His self-injurious and destructive behaviors are nil; they simply do not occur. His aggression is minimal and occurs only when his family and friends have failed to make environmental accommodations to extinguish its antecedents.

Through communication and problem-solving supported by his family and friends, he is learning to choose the who, what, where, when, why, and how of his life. He is making progress, but he still has miles to go. His bipolar moods are becoming more predictable and less intense. Through ongoing functional analysis and manipulation of ecological events, Jay's circle of friends is making significant and rewarding progress in creating a lifestyle that responds to and minimizes mood shifts.

These are two different tales. Remarkably, the person, his diagnosis, and his traits remained much the same. What changed radically was his world and his and our roles in it. In a nutshell, fundamental lifestyle changes pervasively incorporating positive behavioral programming made the big difference. Verbally and through his behavior, Jay was demanding changes. And all of us involved in his life acceded to his great expectations, acknowledging and responding to his choices and helping him to make choices, communicate, solve problems, refine his social skills, and understand consequences. At no time have any aversive interventions even been considered. The result: no change in Jay's diagnosis (that is, in the nature or extent of disability), but a big change in Jay and his quality of life.

It is an awesome responsibility--requiring huge amounts of talent, time, and money--to create, implement, and evaluate fundamental lifestyle changes. We created a non-profit agency, Full Citizenship, Inc., to develop demonstrations and research-supported living options. It has taken us and the agency 4 years to make this much progress, and much more needs to be done.

A key to success in Jay's lifestyle changes is his circle of friends. It consists of people with sophisticated behavioral programming skills who are also deeply committed to Jay as friends, coworkers, housemates, family, and "ordinary" community citizens. Each makes a unique and necessary contribution, and all have worked and played together, demonstrating creative problem-solving, cooperation, optimism, determination, joy, pain, and pride in accomplishments. The circle has generated intellectual and emotional power.

The same time and effort that Jay requires is necessary for the other seven people also supported by Full Citizenship, Inc. Supported living that is *individually and personally crafted* for individuals with challenging behavior cannot be mass-produced. We speculate that it is more demanding of resources on the front end but likely more resource-efficient over time.

Is Jay's experience in the restrictive program shared by others with severe disabilities? Yes. Although space does not permit a thorough review of the literature, there is ample documentation that people with severe disabilities experience pervasive restrictions in jobs, housing, recreation, social relationships, transportation, self-determination, and behavioral programming. Therefore, why focus attention narrowly on the reduction of inappropriate behavior? Such a narrow focus simply rearranges the chairs on the deck of the Titanic. It merely tinkers with a service delivery system that is destined to produce and maintain inappropriate behavior.

We wholeheartedly endorse and want to amplify the point of Horner et al. that positive behavioral programming requires an *emphasis on lifestyle changes*. In fact, Horner et al. listed nine themes concerning the technology of positive programming. We speculate that the first theme, an emphasis on lifestyle change, is the key condition and that the remaining eight themes identify components that must characterize lifestyle customization (functional analysis, multi-component interventions, manipulation of ecological and setting events, emphasis on antecedent manipulations, teaching adaptive behavior, building environments with effective consequences, minimizing the use of punishers, and distinguishing emergency procedures from proactive programming). The crucial point here is that we must holistically combine effective procedures into daily and weekly activities, relationships, and schedules that characterize how people live, work, recreate, and socialize. Also, control of the process must be assumed by the people with disabilities, their families, and advocates. Professionals' roles are to collaborate in carrying out the preferences. This approach will reconceptualize positive behavioral programming from management procedures superimposed on one's living condition to the building blocks of custom-designed lifestyles characterized by personal control, independence, integration, and productivity.

In order to move in this direction, we believe that research and demonstration projects for the 1990's should focus on developing and refining procedures to accomplish the following: (a) provide information to people with challenging behavior and their families on state-of-the-art options for housing, jobs, recreation, and social relationships; (b) identify the general lifestyle preferences of the person and family for housing, jobs, recreation, and social relationships; (c) identify the specific needs, strengths, and preferences of the person and family for custom designing each aspect of the preferred lifestyle; (d) create, implement, and evaluate each aspect of the preferred lifestyle (e.g., housing, jobs, recreation, social relationships), incorporating the positive programming technology principles as suggested by Horner et al.; and (e) disseminate information to individuals with disabilities, families, service providers, researchers, policy makers, and the general public to create new societal expectations for lifestyle options for people with challenging behavior.

Research on lifestyle customization will be incomplete without rigorous and comprehensive investigation of bio-behavioral states, such as the work presently being conducted by Doug Guess and colleagues, and of psychopharmacological interventions, such as the work of Tom Gualteri and Steve Schroeder. Ensuring independence, integration, and productivity can likely best be accomplished through combining state-of-the-art technology in behavioral and biomedical areas. The nexus of these two areas of science and intervention is one of the leading challenges of the decade in creating preferred lifestyles.

We applaud the work of Horner, Dunlap, Koegel, Carr, Sailor, Anderson, Albin, and O'Neill and look forward to their future contributions.

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Challenging Behaviors

Part of being a personal assistant is enabling the person who employs you to enjoy a higher quality of life. Meeting other people, going places in the community and functioning independently are activities people enjoy. But in the past, perhaps your employer hasn't participated in activities because of their behavior. Keeping in mind that behavior is communication, read the following considerations regarding challenging behaviors.

1. Understand that people often respond in a disruptive, dangerous manner because they are not receiving supports and services that meet their needs.

2. Recognize that helping another person change his/her behavior requires a comprehensive plan that deals with all major aspects of the person's life, such as choice, self-determination, and lack of social supports.

3. Assist your employer to access new environments with choice and respect as opposed to rewards or punishments.

4. Remember there are many causes for challenging behaviors.

5. Distinguish between managing a person's behavior and supporting a person in learning to change behavior through listening, negotiation and effective positive teaching strategies.

Have you ever displayed challenging behavior? Think of a time when the person you provide for displayed a challenging behavior. What was the situation and what was the person communicating?

What is behavior?

Based on your definition, what is a challenging behavior?

Behavior Change: Basic Principles

There are two basic kinds of behavior, respondent and operant. A *respondent behavior* is a response to something that happened earlier. This type of behavior is involuntary. Examples of respondent behavior include fear of high places, becoming nauseated before a test at school, shaking when having to speak in front of a group, and feeling pleasure when wearing a favorite shirt or blouse. All of these behaviors are learned from an earlier event. For example, you may feel good when wearing your favorite shirt or blouse because someone once said you looked great when you had it on.

An *operant behavior* operates on (or changes) the environment, thus changes created by the behavior are either reinforcing or punishing. This type of behavior is voluntary. In other words, the behavior is performed (or not performed) based on what the person expects will happen afterward. Before, we mentioned an automatic feeling of pleasure when wearing a certain shirt or blouse -- that was a response. If, however, that same person wears the item hoping that someone will compliment them, the behavior of putting on the item is an operant behavior. It's not a reflex, it is an action made to get a certain end result.

Most often, operant behavior is what needs to be changed. As a personal assistant, your job is to assist your employer by altering the response and subsequent consequence of the behavior. In return, the consequences of the behavior will create new expectations for the person acting out.

Reinforcement

A *reinforcer* is any event that increases the strength of the behavior it follows. The only way to determine whether or not a given consequence is a reinforcer is to observe its effects on the behaviors it follows. Reinforcement must immediately follow the desired behavior in order to have maximum effect. Remember consequences that are reinforcing for some people may not be effective as reinforcers for other people. The more quickly reinforcement follows a target behavior, the more effective it will be. The assistant who makes encouraging and complimentary remarks as appropriate behaviors are observed is delivering much more effective reinforcement than the assistant who waits until the end of the day to express herself about the day's activities.

Extinction - Planned ignoring

The process of removing reinforcement until behavior returns to low levels is called *extinction*. Behavior that has been followed by reinforcement will decrease in rate if reinforcement is withdrawn. Extinction can be thought of as a planned way of ignoring behavior a person exhibits. Extinction of undesired behaviors can be accomplished while reinforcing another more appropriate behavior. Reinforcing a competing behavior weakens the behavior to be extinguished.

Primary Reinforcers

A *primary reinforcer* does not depend upon previous conditioning for its reinforcing power. Research has established that consequences which satisfy certain biological needs are reinforcing to all forms of animal life. Thus, food is reinforcing to a hungry animal and drink is reinforcing to a thirsty animal. These are primary or unconditioned reinforcers.

Secondary Reinforcers

Events that are reinforcing and not directly related to biological needs are *secondary or conditional reinforcers*. Attention, praise, and money are frequently used as reinforcements. Events which have been repeatedly paired with primary reinforcers can come to have reinforcing properties themselves. Thus, if proximity to a mother or to a mother's attention and a mother's voice are paired with food, comfort and warmth, the mother's presence comes to be a secondary reinforcer.

The events which are reinforcing for a given person depend upon his/her life, preferences, and overall self-determination. What may be reinforcing to one person may not be for his neighbor. Generally, however, certain environmental events act as reinforcers for most people and can be used to motivate them. Among these are consequences that provide attention, and opportunities to engage in a real and meaningful life.

Procedures for Reinforcing Behavior

Adding Something Good	Taking Away Something Bad
1. Present food to a laboratory animal.	1. Stop shocking a laboratory animal.
2. A baby giving a smile when picked up by a parent.	2. A baby ceasing crying when picked up by a parent.
3. A teacher giving praise to her class for quiet study behavior.	3. A teacher scolding her class until them become quiet.
4. A child thanking a parent for candy and helping carry groceries into house.	4. A child throwing a tantrum in a store until a parent buys him candy.
5. A father paying his son a bonus for helping around the house.	5. A father who discontinues his son's allowance until he helps around the house.
Adding something good results in the person and/or the situation becoming a secondary reinforcer and further results in approach behavior	Taking away something bad results in the person or situation becoming a punisher and often results in escape or avoidance behavior.

Functional Assessment of Challenging Behavior

This section presents ways to look at behavior. It is important to assess the behavior performed by the person who receives your services. This assessment provides clues for you to find strategies for modifying and directing behavior through other domains interesting to the person.

Functional Assessment is the process of looking at events which happen immediately before a behavior (antecedent events) and those which happen immediately after a behavior (consequences) to determine the events effect upon the behavior. Look at the whole situation; the life and opportunities for inclusion are critical components. Knowledge of these antecedents and consequences help develop methods for changing such behavior. Before attempting to change a person's behavior:

1. Presume competence in all people.
2. Identify your employer's choices and preferences that reinforce the challenging behavior.
3. Identify antecedents causing the challenging behavior, such as people, places, and events.
4. Find more outlets for your employer in the community which will bring about new choices and subsequent positive experiences and behaviors.

Types of Functional Assessment

Informant Assessment

Behavioral Interviews. Interview more than one person and include people from different environments in which the behavior might occur. Include questions regarding antecedent and consequent events, intensity of the behavior, and rate of the behavior, and suggestions that might help determine what is maintaining the challenging behavior. Always seek to strengthen the information gained in an interview by using other techniques such as direct observation and self monitoring in addition to other techniques that will be presented later in the module. Interviews are limited because they are an <u>indirect</u> way to gather behavioral information. Therefore, they may include information that is not completely accurate. Interviews are a starting point for collecting information to use with other methods.

Behavioral Rating Scales, Checklists, & Questionnaires. These are generally more structured than interviews in that they provide a limited number of ways to respond, such as multiple choice or a limited number of items in a checklist. This method is limited because it is an indirect way to collect information.

Direct Observation Assessment

Scatterplot Assessment. This is a graph which shows whether or not there is a pattern that indicates the behavior's time of occurrences and frequency. This tells us when a behavior is most probable and thus we know to do other direct observation assessments at that time, such as the A-B-C assessment described next.

A-B-C Assessment - Antecedent, Behavior, Consequence. This is where we objectively record what happens before, during, and after a challenging behavior. Although no conclusions as to cause and effect can be made, we might come up with some ideas to try when planning a behavior change program. This method is limited because it depends entirely on the accuracy and objectivity of the observer. When performing an ABC assessment:

1. Use abbreviations for speed and accuracy.

2. Record only those events seen or heard (do not interpret).

3. Record events occurring immediately before and after the behavior of interest.

4. Record the duration of each event (how long did it last?).

5. Observe on several occasions.

6. Remain as unobtrusive as possible (you are only observing).

7. Record the information on a form or data sheet specifically designed for the individual behavior and/or situation.

Remember, behaviors can be affected by events that happen at times not immediately before and after the behavior.

The above was adapted from an article by David Lennox and Raymond Miltenberger entitled "Conducting a Functional Assessment of Problem Behaviors in an Applied Setting" JASH, vol.14, no.4, 1989.

Functional (A-B-C) Assessment
(Antecedent, Behavior, Consequence)

Behavior Information Sheet

Behaviors: (be specific)

1. ____________________
2. ____________________
3. ____________________
4. ____________________

Name: ________________________________

Directions: Please fill in all blanks completely

Date	Time	Location	Prompting Event: What Happened Before Incident?	Behavior Observed (number)	Outcome of the Behavior

Challenging Behavior is Communication

Our first questions should always be: **"What message is the person communicating with the behavior observed?"** Resist falling into the trap of focusing all attention on the behavior itself. Look deeper for the message contained in that behavior.

As with most things in this world, there is an exception to the idea that behavior is communication. Some behaviors are neurologically driven self-stimulatory actions. Therefore, there might not be a message connected with such an action because the cause is purely biological.

The best way to observe behavior and derive change methods is to look at what happens immediately before a behavior and what happens immediately after the behavior (ABC analysis), so a pattern can be identified. ABC analysis often doesn't yield a pattern, however, because behavior can be affected by events occurring at other times. For example:

> You get up in the morning and there is no hot water left to take a shower, and when getting dressed for work you can't find your shoes. On the way to work you run out of gas, then your boss chews you out for being late. At lunch you get a parking ticket. Upon returning to work a customer yells at you for something you didn't do. On the way home your windshield get hit by a rock and cracks. Then to top it all off, you get home only to realize that the house key is safely locked in the house. Once you get into the

house through an unlocked window, your cat comes over to greet you by rubbing up against your leg. You promptly kick the cat, field-goal style, over the couch.

Antecedent = cat rubs your leg
Behavior = you kick the cat
Consequence = cat makes a satisfying arc over the couch

A simple ABC analysis will not reveal the build-up of events leading to the flying cat. Initially it appears that you are very sensitive to cats touching your legs. In order to see the message contained in the behavior, we must look at the big picture, not just the events happening immediately before or after the behavior. Very individualized analyses are necessary.

Changing Challenging Behaviors and Maintaining Positive Behaviors

What is an Aversive Event?

An *aversive event* is anything that, when presented to a person, causes the person to want to escape or avoid the event. Some events are mildly aversive, some are extremely aversive. Some things which are aversive to one person might not be to another (eating hot peppers for example)!

What are some events which you find aversive?

Non-aversive Behavioral Events

Non-aversive events are opposite of aversive events. To distinguish between aversive and non-aversive events and how to change behaviors observe the following:

1. Use the functional analysis approach (look at Antecedents, Behaviors, and Consequences).

2. Focus on a person's lifestyle (methods should provide for increasing community participation).

3. Teach adaptive behaviors (alternative ways of obtaining the outcomes they currently get through challenging behaviors).

4. Consider other events which might be affecting behavior (diet,

eating schedule, exercise options, sleep patterns, rapport, noise levels, nature of living arrangements, predictability of daily events).

5. Use reinforcements which are positive and are determined to work for the individual.

Use of procedures that deliver pain (shock, pinching, slapping), result in harm (bruises, cuts, broken bones), and are disrespectful or dehumanizing (spraying water in face, shaving cream in mouth, foul smells) are absolutely no longer acceptable.

Adapted from Horner, et al., JASH Vol.15, No.3, 1990

Reviewing Definitions

Define Reinforcement.

Give an example of reinforcement.

What reinforces your behavior.

Define punishment. *Punishment* is anything - anything - that decreases behavior.

Give an example of punishment.

What punishes you?

What is the difference Between Reinforcement and Punishment?

YOU MAKE THE CALL...

Check the appropriate column to identify each of the following as an example of reinforcement (R) or punishment (P).

R	P

Russ often gets too close to other people,makes loud noises, and flaps his hands close to the person's face. Each time he does this, his assistant makes him sit down and fold his hands on his lap for five minutes. Russ' challenging behavior increases.

Another Possible Approach:

____

____

____

R	P

Claudia earns points if she doesn't wander off while shopping at the grocery store. She can exchange these points for things she wants (such as renting a movie, a new pair of earrings, etc.). Claudia stays with her personal attendant a lot more now during shopping.

Another Possible Approach:

____

____

____

R	P

Her personal assistant is trying to help Sally remember to wipe her mouth more often so the drooling will not be the focus of attention when out in the community. Sally can do it, but doesn't wipe her mouth often enough. The assistant praises her each time she wipes her own mouth and tells her how nice she looks. However, Sally's independent mouth wiping has been decreasing since praise was introduced.

<u>Another Possible Approach</u>:

____

____

____

R	P

Dave seemed to enjoy swearing at people for no apparent reason so his personal assistant decided to take away his bicycle privileges for a day if he swore. Dave's swearing gradually decreased and completely stopped.

<u>Another Possible Approach</u>:

____

____

____

Reinforcers

Picking strong and durable reinforcers is an important part of changing a person's behavior. If the reinforcement does not affect the person the behavior will continue. Find out what the person likes through interviews, observations, and increased opportunities in the community. Then ask yourself if what you are seeing is actually a reinforcer for this individual. Remember, even things which seem reinforcing to you might not be for another person.

Find out, through functional analysis, what presently reinforces the inappropriate behavior. This same reinforcer might also reinforce the appropriate behavior. Use a schedule of reinforcement that will help reduce the chance of satiation (overuse).

Reinforce the behavior in more than one setting for purposes of consistent behavior change and generalization which promotes durability of change. Use a variety of reinforcers to prevent boredom and satiation. If it seems that a limited number of reinforcers exist for a person, make several potentially reinforcing events available and always be on the lookout for additional reinforcement ideas.

Schedules of Reinforcement

Not only is choice of reinforcers important, but also how often they are presented. There are three basic schedules of reinforcement.

Continuous Reinforcement. This means a person is reinforced every time a particular behavior occurs. This is the best schedule for strengthening and supporting a new behavior.

Intermittent Reinforcement. This means that not every instance of a behavior is reinforced. For example, every second or third time a behavior is observed a reinforcer is given. This is used for maintaining behavior once higher occurrence rates have been established.

Extinction. No occurrence of the behavior is reinforced. Over time the behavior will stop (become extinct). If someone is used to getting reinforced on a continuous schedule and reinforcement suddenly ends, extinction will likely happen fast. On an intermittent schedule, extinction will happen more slowly.

Schedules of Reinforcement

Please provide examples from your own experience of the three schedules of reinforcement:

Continuous Reinforcement:

Intermittent Reinforcement:

Extinction:

YOU MAKE THE CALL...
Schedules of Reinforcement

Circle the word which describes the schedule of reinforcement being used.

1. Lou's boss is trying to increase the number of times per week that Lou arrives at work on time. His boss waits by the time clock and praises Lou whenever he arrives on time.

   Continuous Intermittent Extinction

2. Lou's boss has successfully increased Lou's on-time behavior and praises him every third working day for being on time.

   Continuous Intermittent Extinction

3. Lou's boss occasionally sees Lou at the time clock - it could be once a week or so but it varies - and he praises Lou for being on time. Lou keeps coming to work on time.

   Continuous Intermittent Extinction

4. Lou has been coming to work on time every day and his boss never says a word any more. Lou decides that the boss doesn't care and gradually slips back into his old way of being late almost every day.

   Continuous Intermittent Extinction

Satiation. Reinforcement at a high rate (such as under a continuous schedule) and with the same consequences may cause the reinforcer to lose power. For example, the same praise heard repeatedly for arriving to class on time might become boring and ineffective. This is satiation. There are ways to reduce the risk of satiation:

1. Vary the type of reinforcement.

2. Move to an intermittent schedule of reinforcement.

3. Fade to natural reinforcers (those available naturally in the environment where the person is functioning).

Methods of Positive Reinforcement: Differential Reinforcement of Behaviors

Other Behavior (DRO). Reinforcement is delivered when an inappropriate behavior does not happen for a specific time. Be careful, wait too long and the person might behave inappropriately again, wait too little and so much reinforcement will occur that it loses power.

Low Rates of Behavior (DRL) or High Rates (DRH). Reinforcement is delivered when the rate of behavior reaches a certain level (low or high depending on the behavior.

Alternative Behavior (DRA). Reinforcement for performing a specific behavior taking the place of the inappropriate behavior, but the two could happen at once. Appropriate and inappropriate behavior could occur simultaneously.

Incompatible Behavior (DRI). Reinforcement of a behavior which can't possibly happen at the same time as the inappropriate behavior.

What Would You Do?

Keep the non-aversive, positive approach in mind when considering what to do in the scenarios below.

1. Terryl spends a lot of time in the confines of her home. Her personal assistant comes over three times a day to help her with her needs. Terryl rocks her body constantly as she sits, not just small movements, but very noticeable large motions. How might you help Terryl change this behavior?

2. Wayne has a bad habit of constantly picking his nose all the time. This really turns people off and it is a problem at work too. How might you help Wayne change this behavior?

3. Lets face it, Evan is a grump - at least that's what others at the group home say about him. When visitors come he has nothing good to say. When he is out in the community he grumps at store owners, scowls at people on the street, and generally looks "G-R-U-M-P-Y"! How might you help Evan change this behavior?

4. Wendy likes people - often a little too much. Her real problem is that she always walks up to total strangers and hugs them. She is a strong person and often doesn't let go right away. What will you do to help her change this behavior?

Why Record Behavioral Information?

Recording behavioral information is important because it increases our knowledge about the person, their behavior and possible solutions for changing the behavior. This behavioral information is connected to the person's skill learning and quest for independence, integration and dignity. Therefore, record all information relating to the person's behavior. Behavioral information:

1. Helps the personal assistant determine the best way (reinforcements and other activities) to change the behavior.

2. Gives the personal assistant specific information to determine if the present approaches to change the behavior are effective.

3. Provides information for developing new strategies to change inappropriate behavior, if we have record of those behaviors.

4. Assures person's individual rights through documentation.

5. Allows the personal assistant to summarize progress and provide a clearer picture of what the behavior is like over time and in different circumstances.

The more community opportunities, choices, and self-respect an individual has, the more likely challenging behavior will dissipate!

The following story is an illustration of behavior modifications through reinforcement. When reading this, consider everything discussed in the module then note how you would handle the situation.

Kathy's Story

Reprinted with permission from "Exercise for Kathy's Story," in *Positive Learning: An Alternative to Behavior Management* by Wade Hitzing. St. Paul: Minnesota Governor's Planning Council, 1990.

Kathy's Story - Success is in the Eye of the Beholder

Kathy was 9 years old and labeled profoundly retarded. She has been living at a state institution for persons with mental retardation for the last nine months. Each morning one of the aides walked Kathy across the grounds to her school program. She was scheduled to stay at school until the early afternoon.

Kathy had lots of difficulty adjusting to the school program. During the first few months she often cried and tried to run out of the room. Her teacher, Mr. Richards, handled these situations by ignoring her crying, as much as possible, and gently redirecting her back to her desk is she attempted to run from the classroom. These procedures worked to reduce the crying and running away. During her sixth month at school she had only three tantrums and attempted to run away only once. However, Mr. Richards became concerned about a new behavior that presented even more serious problems. During her seventh month at the Center, Kathy began to vomit while at school. At first it only occurred infrequently but it gradually increased until she was throwing up every day.

Some of the members of her team felt that she might be overly anxious about school and recommended that the physician prescribe a mild tranquilizer. The doctor agreed with the request but the change in medication did nothing to decrease the vomiting behavior. The team then decided to suspend her from school for a month. This of course worked perfectly to decrease vomiting behavior at school. She couldn't throw up at school unless she was actually there! However, when Kathy returned to school she immediately returned to the vomiting behavior.

Hoping to get a new perspective on the situation, the teacher asked the Center's behavior specialist, Roberta Fox, to visit the classroom and see if she might be able to help. The first day Roberta visited the classroom Mr. Richards described what had been happening, about the results of the change in medication and the school suspension. As she was finishing the description they heard a sound, looked up and saw Kathy throwing up at her desk. She and the student who sat in front of her were a mess.

Mr. Richards immediately called for an aide to escort Kathy back to her cottage to be cleaned up and get a change of clothes. Ms. Fox asked the teacher if what she had just seen was typical of most days. Mr. Richards said yes, that almost every time Kathy threw up she had to be returned to her cottage and that often she did not return to school until the next day. Ms. Fox returned the next day with the following plan for decreasing Kathy's vomiting behavior.

At first it looked as though the plan might not work. Kathy threw up repeatedly during the first few days. In fact, on the third day she threw up, or at least tried to throw up 23 times. However, after the third day things began to improve. As the graph shows the frequency of the vomiting steadily decreased over the next 27 days and by the 30th day of the new procedures she went the entire day without vomiting. The graph below shows the frequency of vomiting over the 30 day period. She never threw up in class again.

Mr. Richards and Roberta Fox had accomplished their objective. Kathy never threw up at school again. Do you consider this a success story? Let's look at the "SUCCESS" of the behavior plan from the point of view of all the people concerned.

Mr. Richards: "It certainly was a success. The room smells nicer. Kathy looks better. Now maybe we can get on to school work."

Ms. Fox: "I was more than happy to help Mr. Richards. We eliminated the target behavior faster than I thought we would. Maybe I can publish this as a research study."

WHAT ABOUT KATHY??

Kathy cannot talk, but pretend for a minute that she could. How do you think she would answer the success question? Suppose we were to interview her on the 30th day of the new behavior plan, the first time she went the whole day without throwing up--what is she going to say?

"I JUST LOVE IT HERE!"

"MY SCHOOL WORK IS VERY INTERESTING AND I AM LEARNING A LOT."

OR

"I STILL HATE IT HERE. I'D STILL RATHER LEAVE. I JUST DON'T TELL ANYONE ABOUT IT ANYMORE..."

Kathy is not likely to answer that the "BEHAVIOR INTERVENTION PLAN" was a success because nothing was done to help her with her "PROBLEM."

HER "PROBLEM" WAS THAT EITHER:

1. She disliked/was afraid of the classroom setting.

2. Nothing at school was more interesting or engaging than being back in the day room of her ward. The Behavior Plan did nothing to change these "PROBLEMS." The Behavior Plan was just that - a behavior plan.

The teacher and Ms. Fox implemented a plan that was successful in making an improvement in Kathy's behavior but did nothing to help the basic reasons behind the problem behavior. Let's look at the situation more closely.

MS. FOX'S ANALYSIS OF THE SITUATION WAS IN A SENSE CORRECT. SHE SAW THAT:

- Kathy either did not like the classroom or wanted to be back on her ward.
- Mr. Richards had "accidentally" reinforced the vomiting behavior by letting her leave (escape) the classroom.
- Over a period of weeks Kathy learned to vomit to leave the classroom.

- Ignoring the vomiting (not allowing Kathy to leave) would eliminate the "ACCIDENTAL" reward.

OVER A THIRTY DAY PERIOD KATHY GAVE UP. SHE STOPPED VOMITING.

There is no doubt that if people are placed in situations that they find unacceptable they will try to find a way to leave. They will often do whatever works - tantrums, aggression, even vomiting. There is also no doubt that if you are bigger than they are, if you are in control - you can make sure that nothing works. That's what they did to Kathy. At first Kathy was successful in running from the classroom, but then the teacher learned to beat her to the door. Later she had tantrums and sometimes was sent back to the ward to "CALM DOWN." The teacher was then instructed to ignore the tantrums.

One day while she was having a tantrum she choked and threw up. The teacher immediately said, "Take her back to the ward, clean her up. No more school today, she is too upset."

Kathy didn't understand much of what the teacher said but she did learn a new sign:

VOMITING = "I WANT TO LEAVE THE CLASS IMMEDIATELY."

It wasn't at all clear to Kathy why the teacher required such an unusual sign, why he hadn't understood what Kathy meant by running away and crying both of which seemed to be more obvious to her. But she was happy for small favors and each day followed the teacher's "INSTRUCTIONS" by throwing up when she wanted to leave class.

Now of course I don't think that Kathy actually thought all these things out so logically and rationally but at the same time it is an accurate description of the important events and also makes it clear where the focus of our attention should be. We should be most concerned with answering the question - Why does Kathy want to leave the class?

There is no arguing with the fact that vomiting behavior is "INAPPROPRIATE," that Kathy would be better off if she stopped doing it. In fact, if we really wanted to stop the vomiting quickly it would probably have been more efficient to teach her to exchange a token to leave the class. Each day we could give her a blue poker chip. If she hands the chip to the teacher she is immediately allowed to leave the class - no questions asked. In far less than 30 days she would probably have learned the "exchange" value of the token and use it to leave class rather than resorting to vomiting.

MANY OF YOU ARE PROBABLY THINKING:

"Wait just a minute. Kathy may not be throwing up anymore, but now we have a different 'problem.' She spends very little time in school. Most days she hands in the token after only a few minutes and leaves school."

Right! Now we have the "REAL" problem. The one we should have been most concerned with all along, that is - the school setting either frightens/disturbs her or offers her nothing more interesting/fun and engaging than the day room back on the ward. Ms. Fox should have helped Kathy's teacher figure out what was frightening Kathy or how to interest her in at least some activities in the class. That would not have been an easy task. It was difficult to understand Kathy's likes and dislikes, except for the vomiting, and because of her limited experiences and profound disabilities her interests were fairly limited. But the fact is they made only minimal efforts in this direction - they were too focused on eliminating the vomiting behavior.

Module Four

Daily Monitoring Activity

1. **Define Behavior.**

2. **What is reinforcement?**

3. **What is punishment?**

4. **How would you increase positive behavior in the person you work with?**