

Universal Enhancement: Raising the Bar

by Thomas E. Pomeranz, Ed.D.





The Whole Future Catalog

BY JOHN R. WOODWARD

You can't find them in real catalogs yet, but science may one day make these dreams a reality.

Jargon Genie

It happens all the time: you ask a simple question and your rehab worker begins speaking in tonques. Now you can cut through the Rehab Babble with Jargon Genie! Powerful dedicated microprocessors translate professionalese into everyday English in real time, or use the special half-speed instant playback. Optional Federal Government Enhancement Pack enables Jargon Genie

to interpret regulations of the IRS and Social Security Administration.

Portable Handicapped Parking Space ®

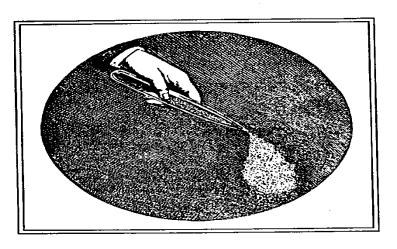
No traveler should be without one! Unrolls to create a 10x15 foot parking space with blue access logo and room to operate a lift.

Works on concrete, asphalt, dirt and gravel in any weather. For temporary use only — not intended to replace permanent designated parking spaces.

Stall Widener®

Tiny portable hydraulic jack applies 6,000 pounds of pressure to widen those cramped bathroom stalls.

Special reverse feature compresses them back again. Requires 6 "D" cell batteries (not included).



Portable Curb Cut®

This handy device stores neatly in purse or backpack, and is rugged enough to use on the highest barriers.

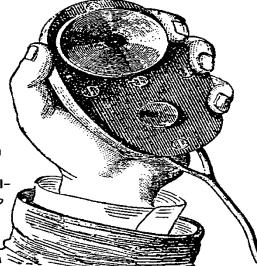
Comes with a lifetime warranty and an attractive slipcase.

Door-Be-Gone®

Turnstiles and heavy fire doors holding you back? Not any more!

Amazing new electronic device de-materializes person and chair, re-materializes them up to ten feet away.

You'll laugh at barriers that used to stop you cold! (Not recommended for use by children under sixteen.)



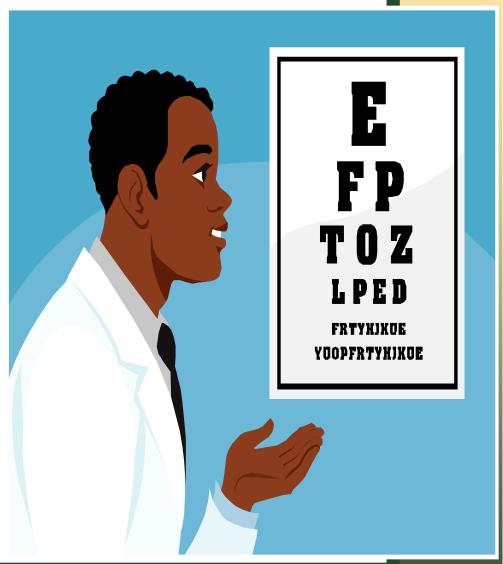
Disability vs. Handicap

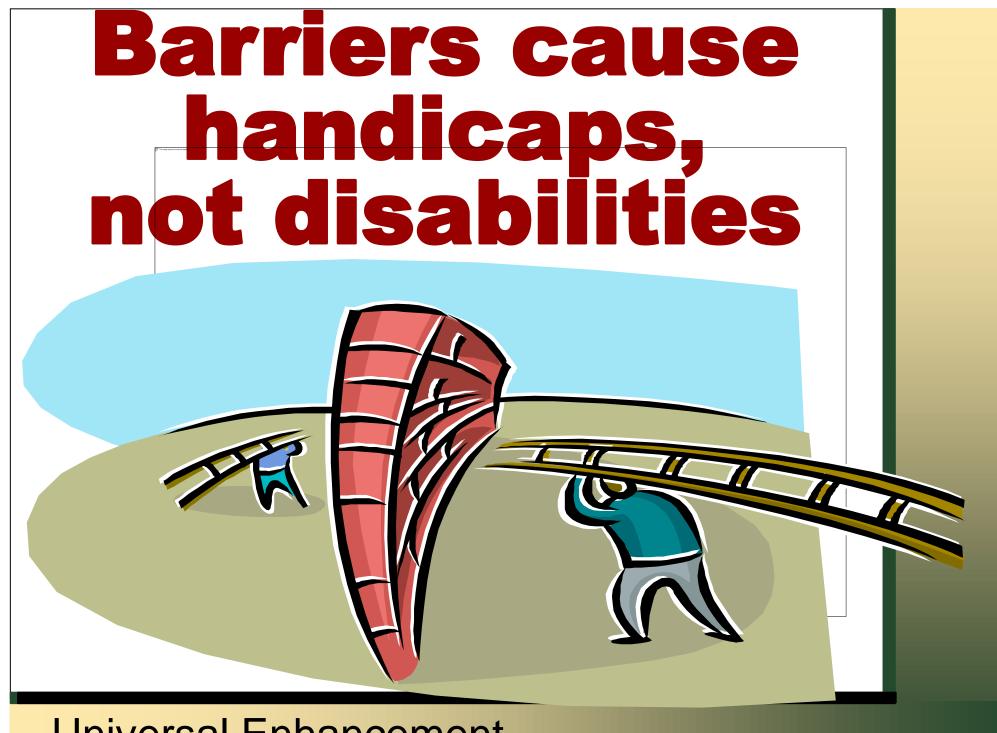
A disability – is a pathology of the individual:

- Cataract
- Muscular dystrophy
- Cerebral palsy
- Asperger's

A handicap – is a resulting impairment in performance and functioning:

- Impaired vision
- Impaired mobility
- Impaired speech
- Impaired social skills





Emancipation

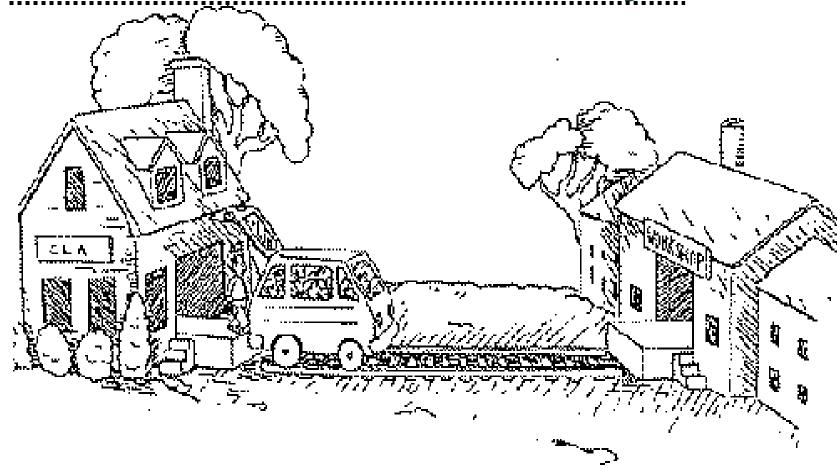
Will the day ever come when all people with disabilities can celebrate being free from unnecessary dependence and control?





Back Wards Of The Community A community characterized by: Loneliness despondency Fear anxiety Segregation poverty degradation despair intimidation prejudice

Life In The Community



Would you like to trade Places? Reprinted from The Arc of Berks County Newsletter (June 1998)

Danish culture holds that "no person is better than another." If our culture held this value, would we continue to segregate people with disabilities in housing, employment and leisure?



Call It What You Will People may be segregated for many different reasons: Type of Segregation **Factor** □ Native American Reservation Ethnic □Low Income HUD Housing **Poverty**

□ Japanese Internment Camp

□ Inner City Ghetto

□ Leper Colony

□Nursing Home

□Latino Barrio

□ Developmental Center

Nationality

Race

Disease

Age and Infirmity

Cultural background

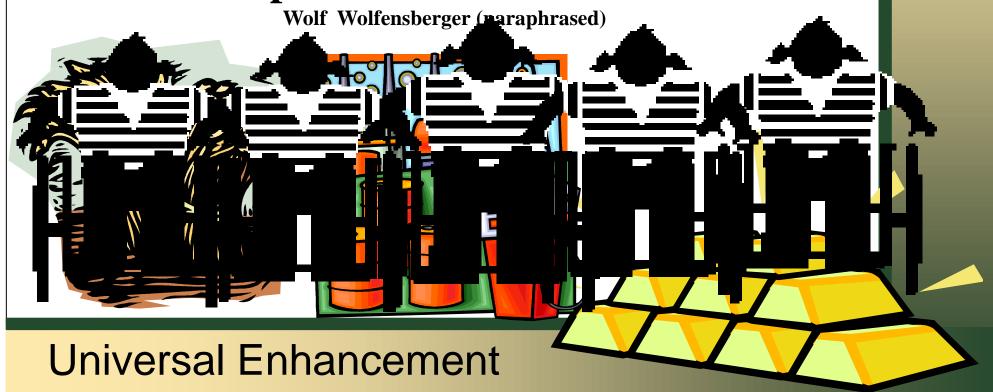
Intellectual disability

Check the box where you wish to live.

The Consumed

Co modification of the treatment of afflictions is a process wherein the "consumer" becomes the "consumed" as part of the human services economy.

Under such conditions the number of people served represents a function of merit!



There Is...

...no separate but equal!



Segregated Bathrooms

It is legal in all states to segregate restrooms on the basis of intelligence:



Fresh scents & décor Stalls for privacy Paper towels



Barren
No stalls
No paper towels

Separate-Never Equal



Neither Federal nor State **Courts have** prohibited the establishment of segregated bathrooms based upon disability.

Separate but equal has never been demonstrated as a workable concept.

Keep Them Together

In juxtaposing and congregating different devalued groups, we have taught the public very well to disregard people with disabilities. Don't Damn Them! (the public)

Bone County Social Services	
Directory	Room #
Women's Shelter	320
Alcohol Treatment	518
Mental Health Outpt.	227
Parole Office	110
Alzheimer's Services	210
Day Habilitation for	
The DD	212-219
AIDS Clinic	318
Food Stamp Office	419
Juvenile Court Service	s 120
WIC	307

Wolf Wolfensberger (paraphrased)

Segregation Can Work

Some people prefer to be with "their own kind":

Wealthy people

Geniuses

Attorneys

Nuns

Military Personnel

Male College Students

Body Builders

Gym This works because they

Country Club

Mensa

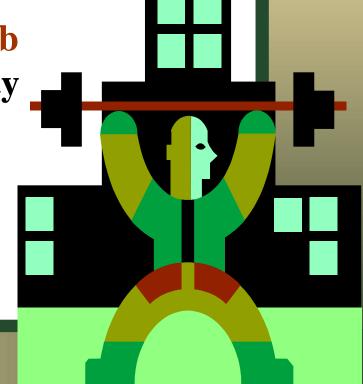
American Bar Assoc

Convent

USO Club

Fraternity





Tardi-Gras

A costumed celebration of limited religious significance, held before Easter in the early spring, in which participants from group homes, developmental centers, day activity programs and workshops parade through the streets riding on motorized floats, tossing **Special Olympic-type** coins to the bystanders.



Disenfranchised...

...to deprive (a person) of any right, privilege or power; the act of taking a right away from an individual



Diaspora...

...refers to any people or ethnic population forced or induced to leave their traditional ethnic homelands; being dispersed throughout other parts of their environments and world, and the ensuing developments in their dispersal and culture. The Acadian diaspora — the Great **Expulsion occurred when the British** expelled about 10,000 Acadians (over 3/4 of the Acadian Population of Nova Scotia)

Diaspora (cont'd)

Assyrian diaspora – a pre-Arab Semitic Christian population of the Middle East. In the 20th century, millions of **Assyrians left the Middle East from** ongoing ethnic, political and religious persecution Bosnian diaspora – appeared after four years of planned ethnic cleansing in **Bosnia** Chechen diaspora – fled Chechnya during the 1990's insurrection against Russia

Diaspora (cont'd)

Afghan diaspora – fled their country throughout the 20th century and the long civil wars especially to nearby Pakistan, India, and Iran Armenian diaspora — living in their ancient homeland, which had been controlled by the Ottoman Empire for centuries, fled persecution and massacres during several periods of forced emigration The African diaspora – native Sub-Saharan Africans and their descendants, taken from Africa into slavery

Diaspora (cont'd)

People with Developmental Disabilities — People challenged by physical and intellectual disabilities have been removed from the larger community and their homes starting in the mid 1800's. These individuals are "placed" in segregated residences,

work and day service environments with their peers. A strategy of inclusion is often used as appeasement



Shame On Us

Should we not at least consider apologizing to people with intellectual disabilities for:

 Institutionalization - in the name of "treatment"?



Admission

Admission AS Treatment vs. Admission FOR Treatment

It is not one's presence in the

therapeutic setting that has therapeutic value; rather it is the services and supports one receives in that environment that

Universal Enhancement

have value.

Disability Gulags...

...are state-created institutions where people with disabilities disappear one by one. The disappearance is often called voluntary placement. ...characterize isolation and control as care and protection.

Those who die there are replaced by new arrivals.

Hariett McBryde Johnson



It's a Matter of Perspective

Crime — Disability

Evidence — Data, tests

Suspect — Provisional diagnosis

Interrogation ——— Interview

Investigation ——— Evaluation, assessment

Trial ———— Placement meeting

It's A Matter Of Perspective (cont'd) Jury Placement committee

Convicted — Diagnosed

Conviction — Misdiagnosed overturned

Multiple Multiply
Convictions handicapped

Awaiting ——— Waiting list

Sentenced —— Placed

It's a Matter Of Perspective (cont'd)

Prison ——— Residential facility

Prisoner — Consumer

Punishment ——Programs

Guard — Staff

Warden — Residential director

Paroled Trial visit, therapeutic leave

It's A Matter Of Perspective (cont'd) ____ AWOL, Leave **Escape** without permission **Prison** Day activity **Yard** room Solitary Time out room **Parole** Discharge **Board** committee **Parole** Case manager Officer

It's A Matter Of Perspective (cont'd) Service Penal **System** system **Day activity** Work Release program Resident Inmate **State Big House** Institution Cell **Bedroom** Nurses Guard Station **Tower**

It's a Matter of Perspective (cont'd) Exonerated ——— No Diagnosis Hall, Suite, **Cell Block Unit, Wing Mobile Work Chain Gang** Crew Industrial **Hard Time** therapy Release Discharge Will the day ever come when the "victims" of the service system are

emancipated and given a reprieve?

Clinical Services

Clinical services are a necessary response to prevent and correct the harm caused by "institutional environments."



PT Range of motion exercises to correct contractures resulting from benign neglect

OT Sensory stimulation to reverse the effects of sensory deprivation

SW Facilitating relationships with family members estranged as a result of being "placed" distant from home

Clinical Services (cont'd)

PSY Interventions to "extinguish" behaviors resulting from anomie RN Health services to treat decubitus, hepatitis, URI's and other nosocomial disorders

RT Integrated recreation to teach social skills never learned in a segregated setting How does the role and function

of clinical services change when people are emancipated from an institutional life?

Shame On Us (cont'd)

Should we not at least consider apologizing to people with intellectual disabilities for:

- Institutionalization in the name of "treatment"?
- Industrial therapy in the name of "work"?
- Eugenics (involuntary sterilization) in the name of "birth control"?

THE WASHINGTON POST

LYNCHBURG, Va. - Rose Nuckols was 16 when she was raped by a married man at a truck stop. Nine months later in January 1958, she gave birth to twin boys. She held them exactly once before the nurse explained that they were headed to foster care in

Rose objected. But, as an unwed, illiterate teen-ager, she understood that she had few choices. What she did not know was that these were the first and last children she

Two months after giving birth, Rose was ordered before a judge and was involuntarily committed by her grandmother to the Virginia Colony for Epileptics and the Feebleminded in Lynchburg to be sterilized.

Hers was a fate shared by more than 8,000 men and women between 1927 and 1979 under Virginia's eugenics law, a statute upheld by the Supreme Court and aimed at preventing those considered ge-netically unfit from passing on

The law targeted a wide range of peg

state g Eugenics meaning v only to fo but to socia at keeping groups seg Indiana

first steril were the r

over seven decades.

appendectomies."
California led the nation, re-

cording 20,000 involuntary sterilizations. Virginia followed with 8,000, most done before World War II.

Historians say the U.S.

Forced sterilizations aimed for genetic purity

Rose Brooks, shown with husband Cecil, was involuntarily

1907....resulting in the

sterilization of more than

60,000 people nationwide

committed in 1958 and later sterilized under Virginia's

on eugenics in

first sterilization law based she said tutor her.

d photos is one taken when she was 8. She

Indiana passed the nation's bernard the result of the state of the sta

The judge said, 'Rose, you ain't fit to have kids, and you need to have this operation done.' They said it was the best thing for my health."

work bathing and feeding the many genuinely disabled pa-tients living there. The state paid her \$2 a month.

"Often, people who were the most capable were used as caretakers for others who capable," said Paul Lombardo, a eugenics expert at the University of Virginia's enter for Biomedical Ethics. They didn't necessarily get discharged (after being sterilized), depending upon the in-stitution's needs and their

Brooks said she told those at the institution that she wanted to leave.

"I said, 'I don't want to be here.' But it was happening to

She would not get out until she was in her late 20s. Her busing tables at a Howard Johnson's restaurant, and she worked there for more than five years. Similar jobs followed, as well as a marriage to vorced when he stopped workner meager pay, she said.

Nine years ago, she met Cecil Brooks, now 65, a retired custodian. They attended the same church, but it wasn't until they bumped into each other on the street a few times that; he asked her out. Two

Historians say the **United States** church cer

Pursuit of genetic purity became a cal mother

who long blueprint for Hitler ever since

in the Nazi effort to

create a master race.

to the mor the government had paid in settlements with 900 others.

The gov

more than

ing to pay

Two months after giving birth, Rose was involuntarily committed to the VA Colony for the Feebleminded to be sterilized.

Shame On Us (cont'd)

-Frontal lobotomies - in the name of "medical management"?

-Indeterminate idleness and boredom - in the name of "free time"?

-Prohibition of self-determination in the name of "protect from harm"?

-Mechanical restraint - in the name of "behavior management"?

Shame On Us (cont'd)

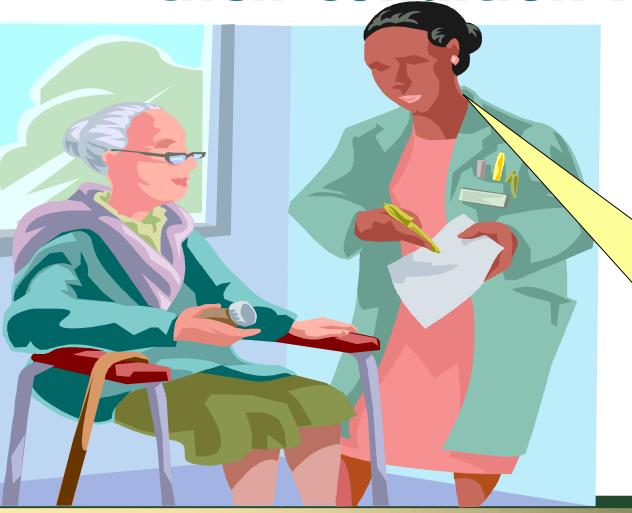
 Excessive use of psychotropics in the name of "therapeutic medication regimes"?

Denial of civil rights –
in the name of
"guardianship"?

The time has come that we can no longer justify the indignities imposed on people with intellectual disabilities in the name of "professionalism"!

Don't Miss The Point

Treating people badly makes their condition worse!



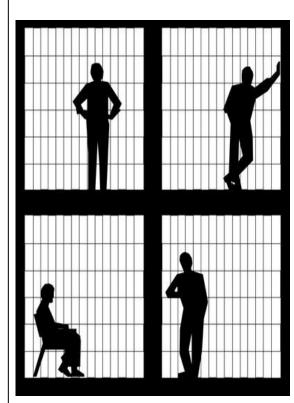
Mrs. Bush, what would you like for breakfast tomorrow?

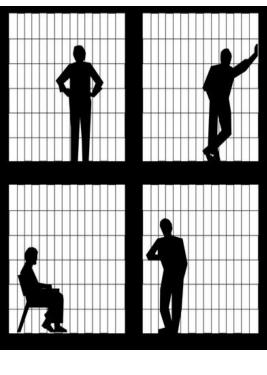
Institutional Revisionists

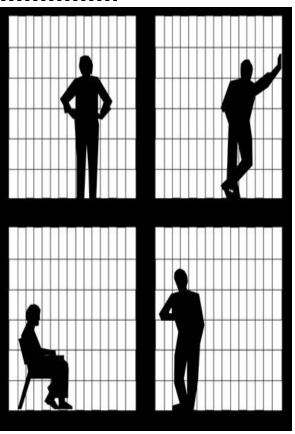
- There are revisionists regarding the treatment of:
- Native Americans by the early settlers
- Jews by the Nazi's
- Slaves by their owners
- Asians in internment camps by the US Government
- People with intellectual disabilities by the "system."



Freedom







...imprisonment and segregation can be made more comfortable, but they can never be made into freedom or participation.

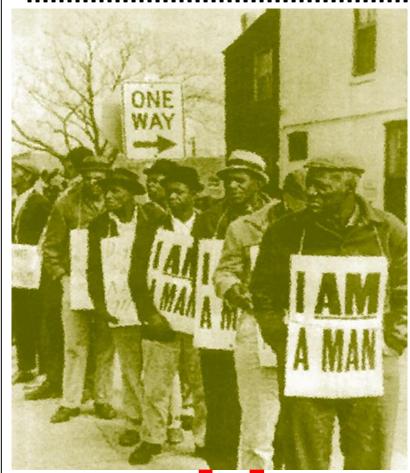
Burton Blatt

The Dark Side

We do not suffer so much the lack of structural architects and interior designers as we do the absence of ideational architects and moral interventionists.

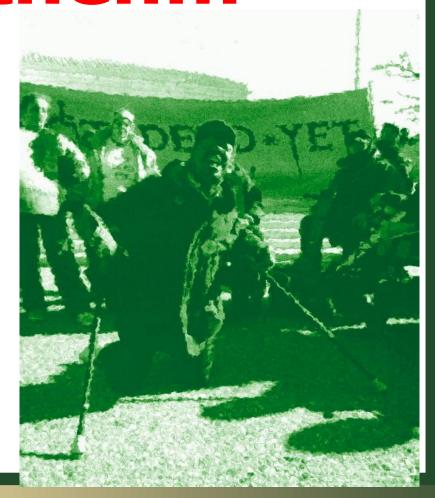
Burton Blatt
The Dark Side of the Mirror

Segregation

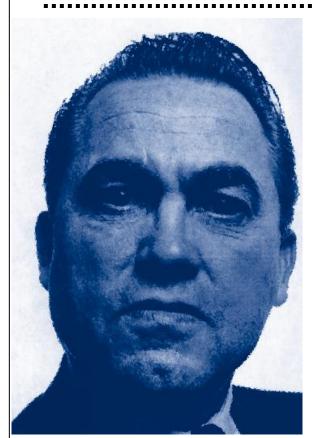


...this is now!

That was then...



Segregation Is Segregation



Governor George Wallace's troopers kept Alabama's Negroes in their place.







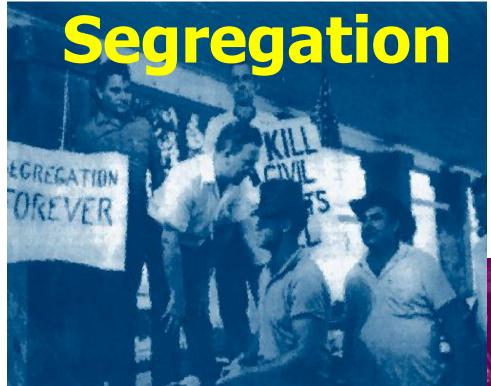


Support Staff



More than 8 million Americans make a living by running our lives.

Segregation

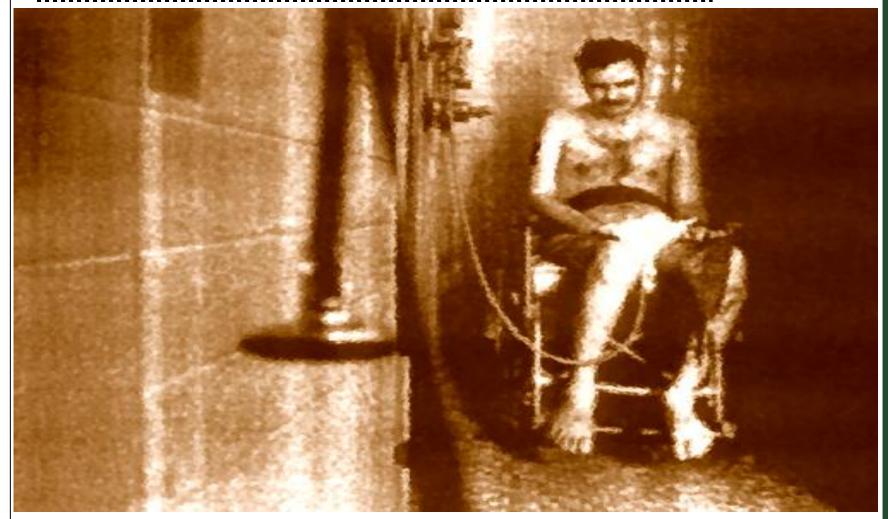


is harder to spot...

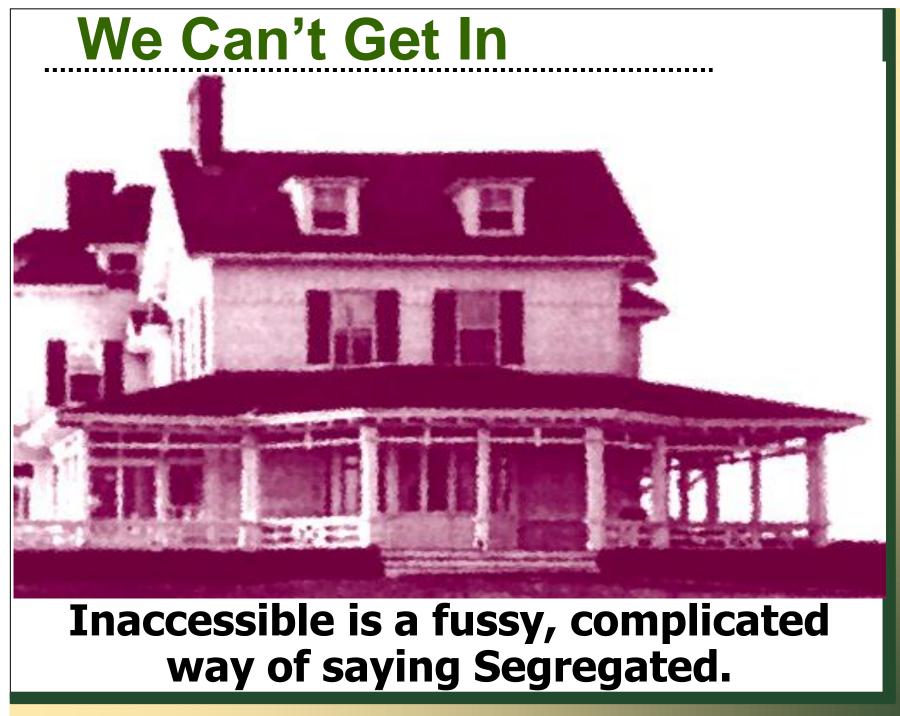
when they call it



We Can't Get Out



2.5 million Americans are locked up for the crime of having a disability.



Segregation



Our predecessors in civil rights had to go to the streets to change the rules... and make compromises we can't stomach.

RNG FOR & SERVICE

Upon his retirement, from the Spastic **Society of Britain** the Director was asked if he could envision the day when someone with cerebral palsy would head that charity....



"That would be like putting dogs and cats in charge of the Humane Society," he quipped.

Facilitate Quality

Shift the paradigm or... it will shift you!



Anomaly

Our reality blinds us to the injustices.

The shifting paradigm of best practice reveals the injustices.

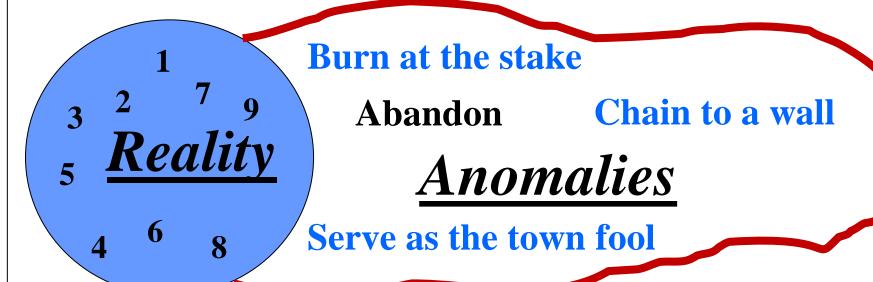
Is it acceptable to:

- 1. Sterilize women with intellectual disabilities?
- 2. Use forceful over-correction?
- 3. Place people in time-out rooms repeatedly?
- 4. Use physical/mechanical restraint as an aversive consequence?
- 5. Utilize cost-response programs?
- 6. Medicate into submission?



Anomaly (cont'd)

- 7. Apply a level system to earn your freedoms?
- 8. Use aversive shock as an intervention?
- 9. Require individuals to work in cruel conditions in the name of industrial therapy?

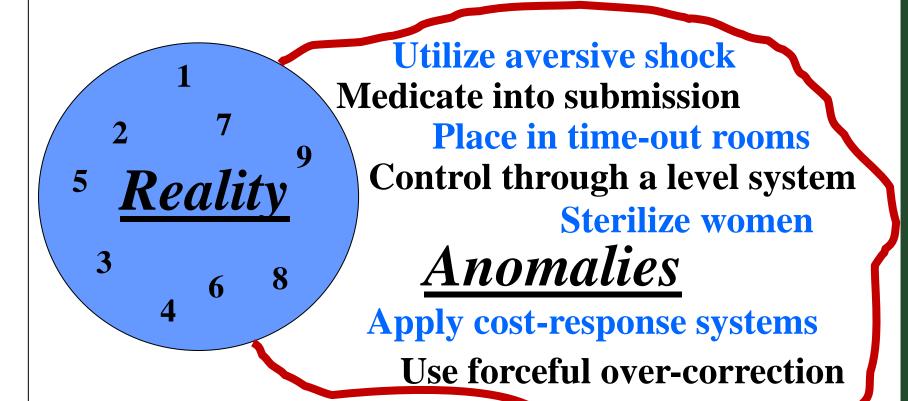


The Structure of Scientific Revolution; Thomas Kuhn 1962

Anomaly (cont'd) Is it acceptable to deny individuals an opportunity to: 1. Achieve adult status? 2. Work? 3. Engage in informed consensual sexual expressions? 4. Participate in their daily routines? 5. Select their housemate/s? 6. Decide where they wish to live? **Universal Enhancement**

Anomaly (cont'd)

- 7. Look their best?
- 8. Live in an accessible environment?
- 9. Select their support staff?



Quit Complaining

- Gaining independence,
- Use of generic supports,
- Maximizing assistive technology,
- Closure of facility based services and
- Stream-lining regulations ...

...may result in the loss of jobs!

People with disabilities do not owe us a living!



Reparation...

...the act of making amends

Historically, many minorities and marginalized groups were the target of discrimination and injustice. They now seek

REPARATION!

- Native Americans banished to reservations
- Asian Americans banished to interment camps
- European Jews banished to concentration camps
- Black Slaves banished to plantations
- People with intellectual disabilities banished to...

Reparation for people with intellectual disabilities requires the ultimate sacrifice of the perpetrators Inclusion!

History of Reparation Payments

\$822 Million	Holocaust Survivors
\$1 Billion + 44 Million Acres	Alaska Natives
\$105 Million	Sioux of So. Dakota
\$12.3 Million	Seminoles of FL.
\$1.2 Billion	Japanese Amer.
Inclusion	People with Intellectual Disabilities
	\$1 Billion + 44 Million Acres \$105 Million \$12.3 Million \$1.2 Billion

Choose One

The difference is two little letters... In a home VS. At home



VS.

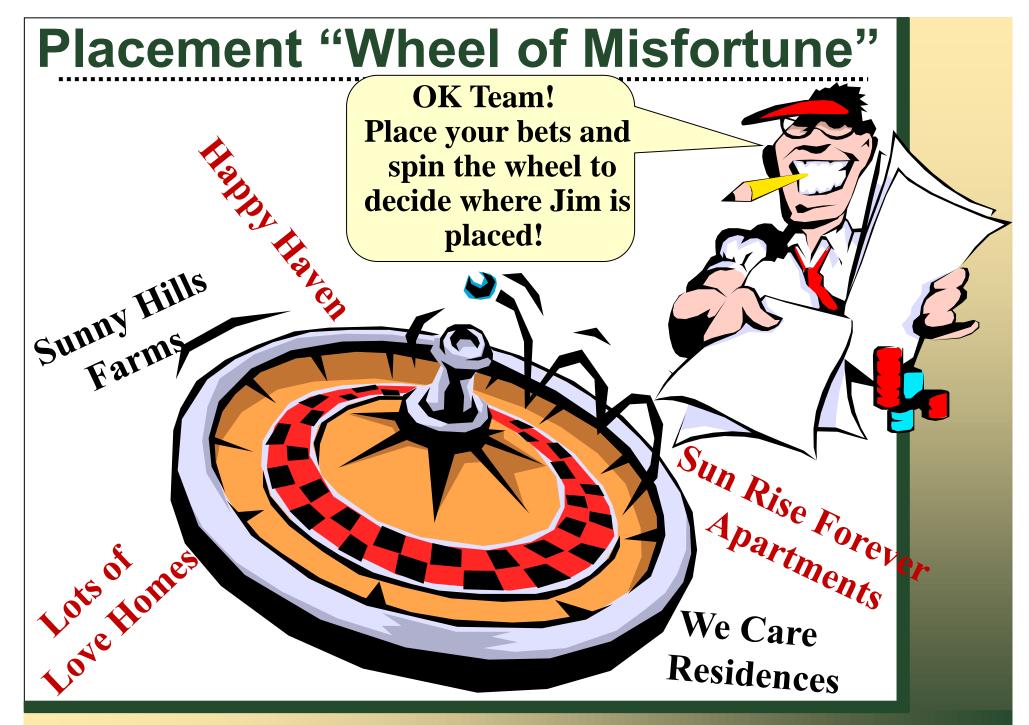


It's Their Home

Do you: nswer their do

answer their doorbell, use their bathroom, answer their phone, open their mail, enter their bedrooms, sit on their beds... in the homes of the people you support, without their permission?

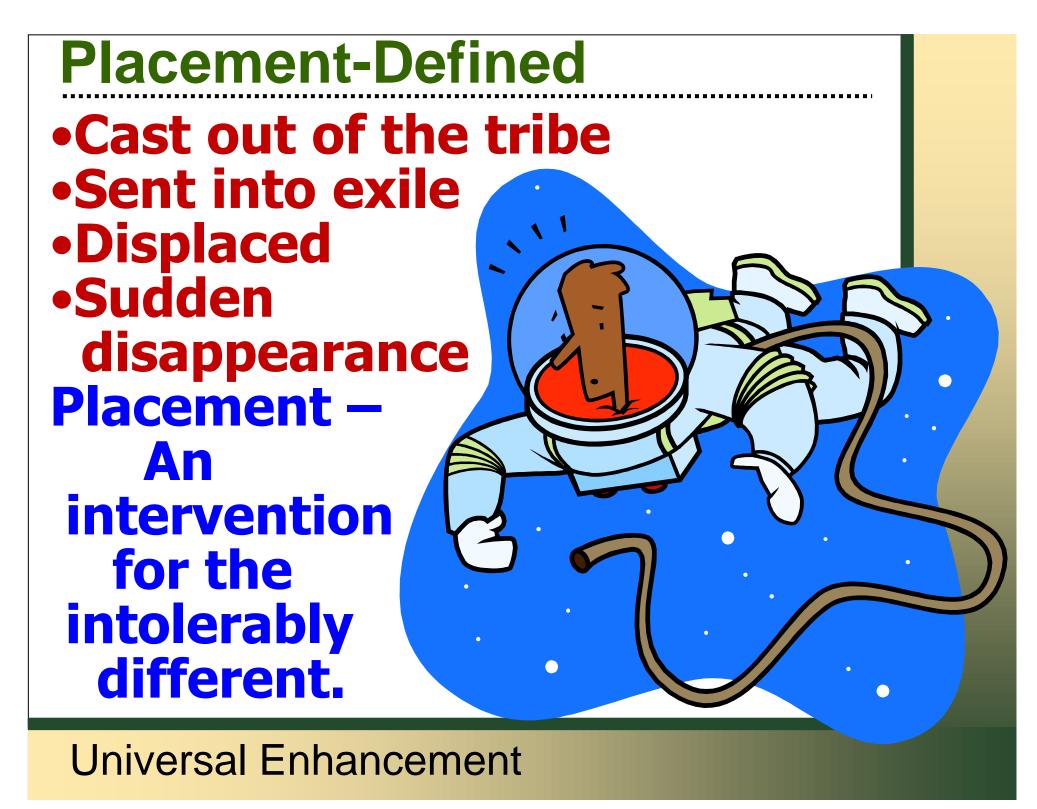


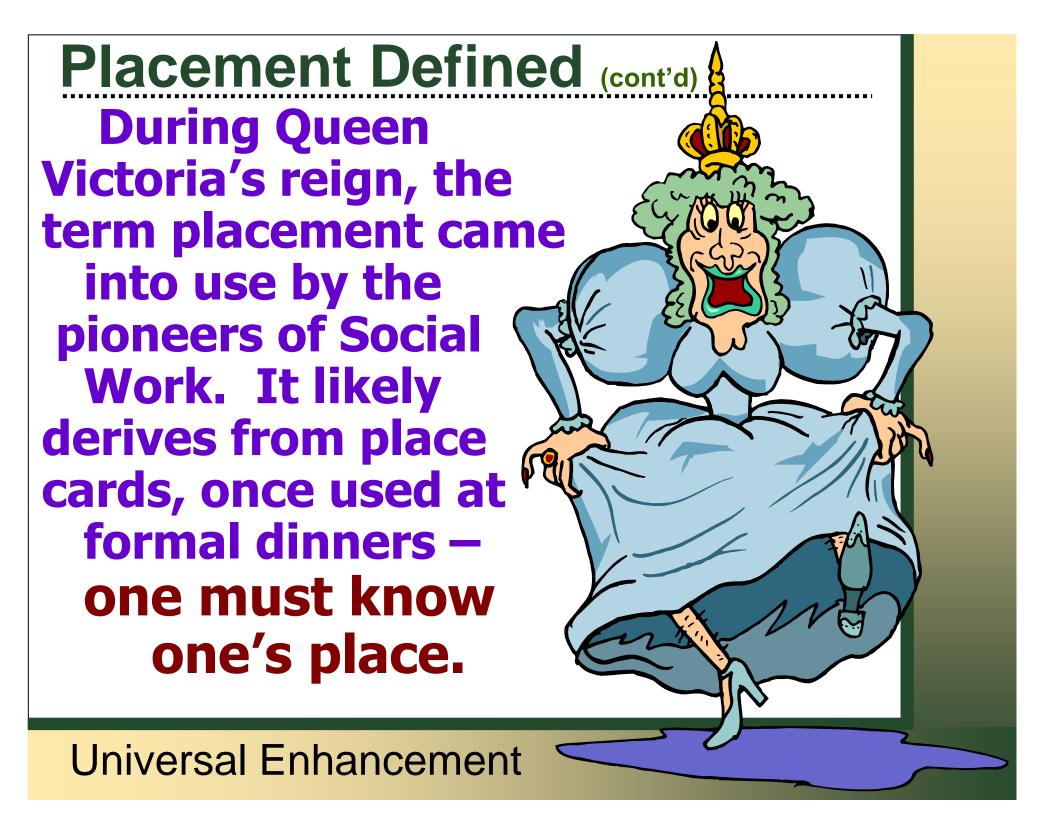


Disguised

"Current services, systems are delivered with virtually total unconsciousness of major realities involved and all of this is disguised/ interpreted as good, effective and progressive."

Wolf Wolfensberger







Welcome to Society!

The following was given to individuals who were about to be released from a state mental retardation institution in 1967.

"We congratulate you on being given this chance to take your place in society. During this period you will be on probation and you must not only obey all of the laws of your community, but also these:

1. You must not leave your present place without first notifying us.

2. You must not drive or own a car.

3. You must not drink alcoholic beverages or enter a bar.

4. You must not get married.

Welcome to Society! (cont'd)

- 5. You must not get engaged, go steady or date.
- 6. You must not make any written contracts in regard to purchase of articles on time payments without first talking to your social worker. See worker before using "lay-away" plans.
- 7. You must be home by 12:00 am; earlier if requested by employer or other person in charge.
- 8. You must not leave the state.

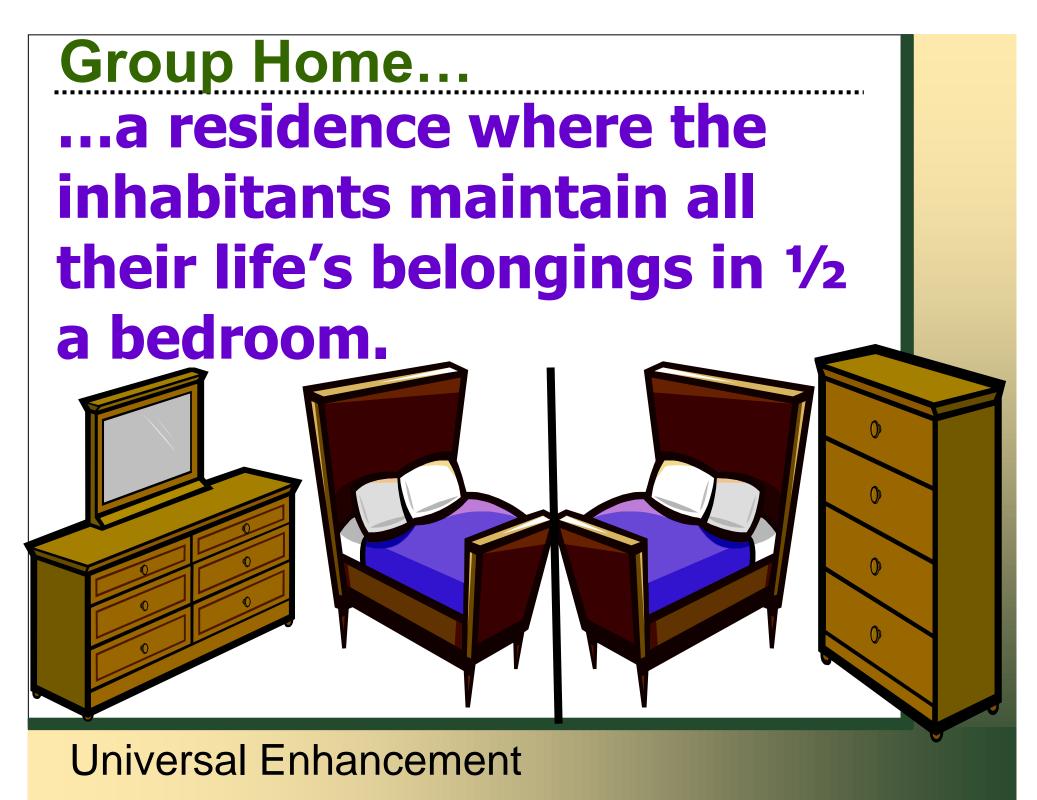
Carry this reminder with you at all times and read it frequently. Violation of any one of the above rules

may result in your return to the school."

Superintendent, Lincoln State School

From James W. Ellis, Villa Nova Law Review (vol. 37)





Welcome!

When the people you support move in... are they welcome? Are you a newcomer to Liberal or know of someone?

Give me a call.



Naomi Rine • 624-4559

I'm your Western Welcome Lady in Liberal. I have information on Liberal and gift certificates from the leading merchants for the newcomers.



Home

Did the neighbors come bearing gifts of food & flowers when the residents moved into their new home?

Does the Girl Scout come to the door to deliver two boxes of Thin Mints?

On Halloween night, are trick or treaters given

treats by the residents of their home?

Did the residents go to the post office to fill out a change of address card when moving in?



Home (cont'd)

Do the teenagers down the street ask to shovel their walk after a big snowfall? Are the residents asked to join the Neighborhood Association?

Does the Alderman from the ward come to their home to campaign?

Do the residents have a presence in their neighborhood?



"Do" Inclusion?

Is someone doing inclusion to you? If people were not segregated, we would not be "doing inclusion." Support an inclusionary life!





Immigrants

People living "institutional lives" practice customs and rituals foreign to their new land. As immigrants to their new home (the community), they are expected to:

- close the bathroom door
- respect personal space
- use appropriate eating utensils
- demonstrate courtesy
- engage in age-appropriate leisure activities

Teach these customs!

Acculturate

Assimilate - to integrate somebody into a larger group so that differences are minimized or eliminated.

Acculturate - to absorb the culture of another group of people or individual.

People with developmental

disabilities should be acculturated - mere

assimilation is not

sufficient.

What Is Supported Living?

The provision of support is independent/non-contingent of the individual's residence - the lease or mortgage is in the resident's name.

The person determines where they reside.

The person determines with whom, if anyone, they reside.

The person selects the support agency and the support staff.

The System: The Community

In a social service system

people are known by what's wrong:

by their condition or label

In community

people are known as individuals

In a system

people are incomplete and need

to be changed or "fixed"

In community

people are as they are, with

opportunities to follow their

own dreams

In a system

relationships are unequal;

service workers do things "for" clients

and don't look for any contribution in return



The System: The Community (cont'd.)

In community

relationships are reciprocal, give and take; and the diverse gifts of many people are recognized In a system

people are broken into parts and separated into groups

In community

people have the chance to be accepted as whole persons, and viewed as part of the whole society

In a system

problems are solved by consulting authorities, policies, procedures

In community

people can make honest efforts and acknowledge honest mistakes and fears

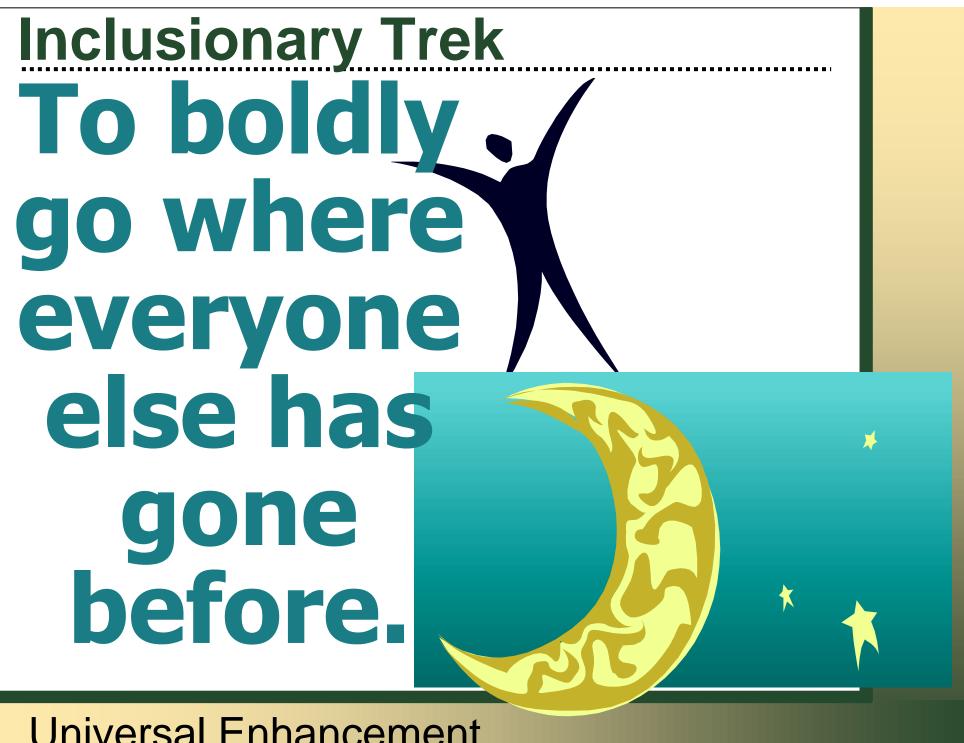
The System: The Community (cont'd.)

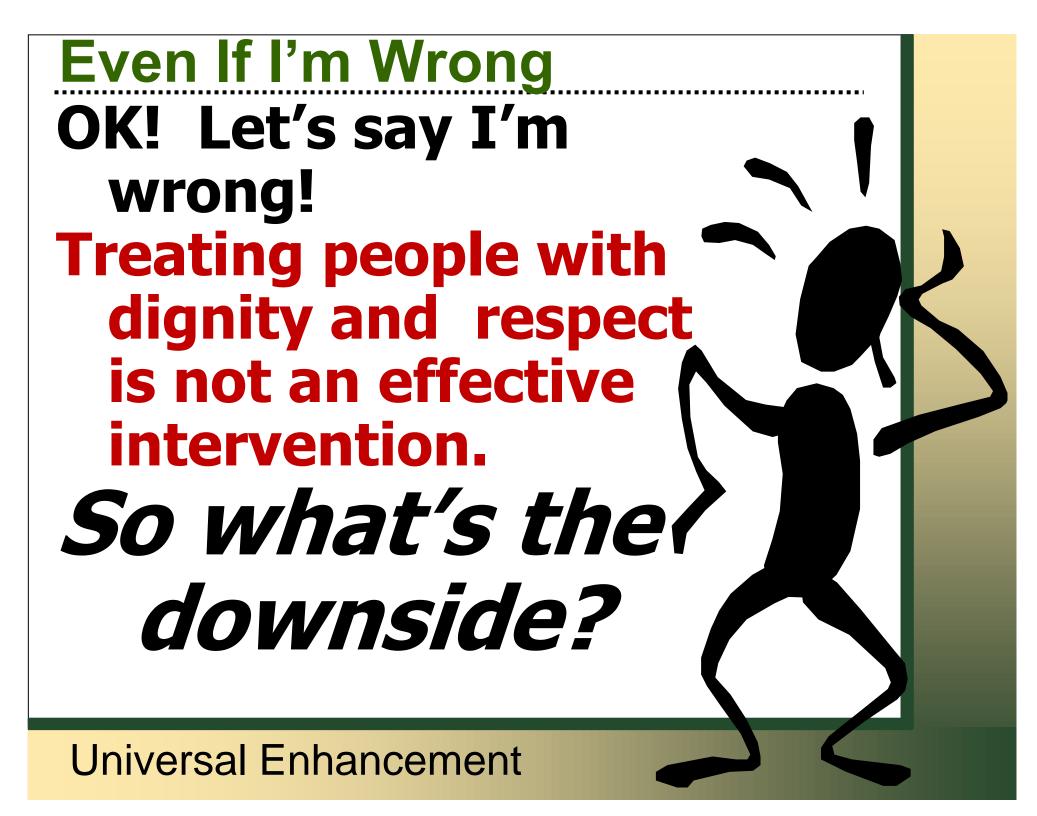
In a system

all problems have a rational solution In community

there is room for confusion, and mystery, and recognition that some things are beyond human control







An Enviable Life

Is....

being missed when away

being loved and having others to love

 believing that you are making a difference

- being respected
- having a passion
- being excited that this is a new day

An Enviable Life (cont'd)

- making a last will and testament
- having your family and friends around you when you pass away
- being remembered for your contributions
- having people donate to a charity in your memory
- living to an old age and not looking back with regret



More Life

It is equally important that we fill years with more life as it is to fill life with more years!



Getting a life for people and coaching them into it – is the intervention.

-- Todd Risley, Ph.D.

Altering behavior is never a prerequisite to getting



promoted into a reasonable life.

-Rob Horner,Ph.D.

Diagnostic Living

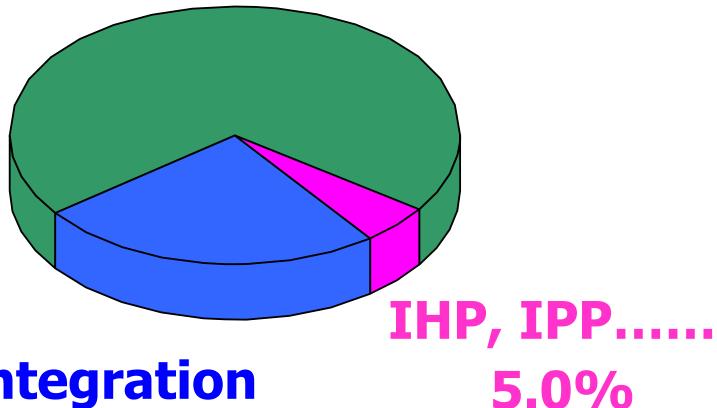
How people live should be determined by how they wish to live; not by their diagnosis.

Thomas E. Pomeranz Ed.D.



Influences on QOL

Participation 70.0%



Integration 25.0%

Three Phases in the Development of Services for People With Disabilities

Focal Question	Institutional Reform Period	Deinstitutionalization Period	Community Membership Period
Who is the person of concern?	The Patient	The Client	The Citizen
What are the "typical" service settings?	An institution	A group home, sheltered workshop, special school	The persons' home, local business, neighborhood
How are services organized?	A facility	A continuum of options	The unique array needed by each
What is the "model" of service delivery?	Custodial/ Medical	Developmental/ Behavioral	Individual Support

Three Phases (cont'd)

Focal Question	Institutional Reform Period	Deinstitutionalization Period	Community Membership Period
What receives the highest priority?	Cleanliness, health & safety	Skill development/ behavior management	Self- determination relationships
What are the major focuses of intervention?	Control or cure of the condition	Change behavior e	Change the nvironment and attitudes
What is the focus of quality assurance?	Professional practice & standards of care	Documented programming/ goal attainment	Quality of life as experienced by the person
How do provider talk about their services?	rs Community outreach	Community- based	The Community

Three Phases (cont'd)

Focal Question	Institutional Reform Period	Deinstitutionalization Period	Community Membership Period
What are services called?	Care	Programs	Supports
What is the planning model used?	Individual Plan of Care	Individual Habilitation Plan	Personal Futures Plan
Who controls the planning process?	A professional (often an MD)	The interdisciplinary team	The individual
What is the context of decision-making?	Standards of professional practice	Team consensus	Personal circles of support

Where's Your Focus...

...in supporting people?

Process

People

Protocols Surveys Relationships Religion Signatures Objectives Hobbies Sexuality Programs Timelines Happiness Friends Instructions Schedules Family Retirement





Intervention Strategies... ...for people with disabilities-Prevent Cure **Place** The hierarchy of intervention takes on a new meaning-If you can't eliminate 'em, fix 'em, or remove 'em.

Responses to Diversity

Marginalization
(out of site,
out of mind)

Extermination
Aggression
Segregation
Avoidance

Reform

(you can be with us, only if you are like us)

Rehabilitation Assimilation



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Responses to Diversity (cont'd)

Tolerance (if we must...)

Burden
Resignation
Patronization
Benevolence

Valuing (diversity as normal) Respect
Understanding
Acceptance
Equal worth
Mutual benefit
Belonging





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COMPANIONSHIP

A GUIDE BY HIS SIDE



Star Staff Photos / Kelly Wilkinson

SHOPPING TRIP: Kroger clerk Robin Turner helps Bill McCleary and Sparky with grocery shopping at Speedway Supercenter.

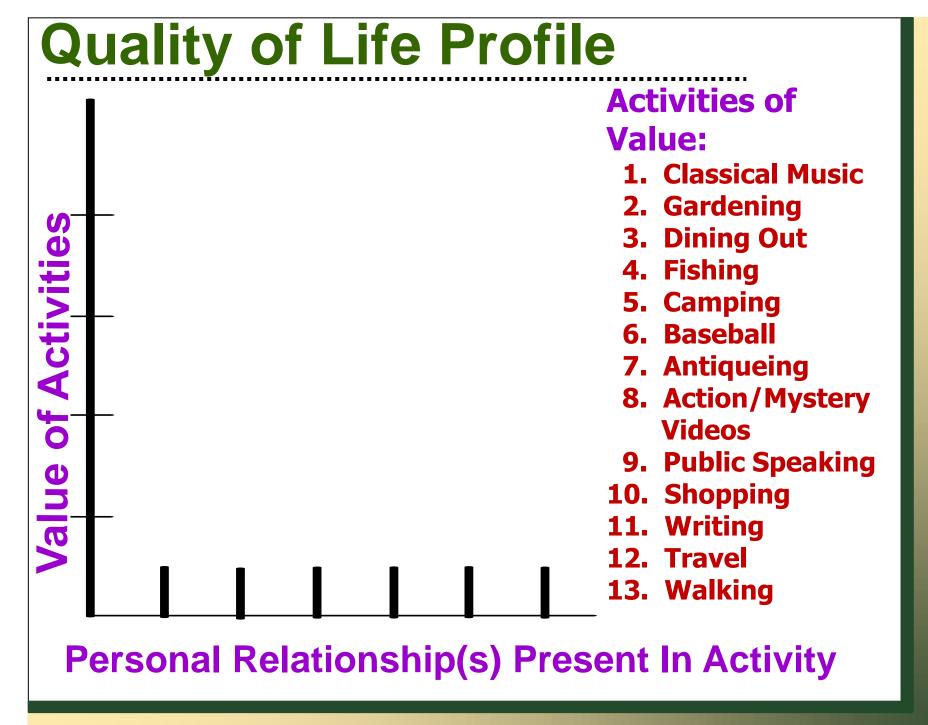
Generic Supports

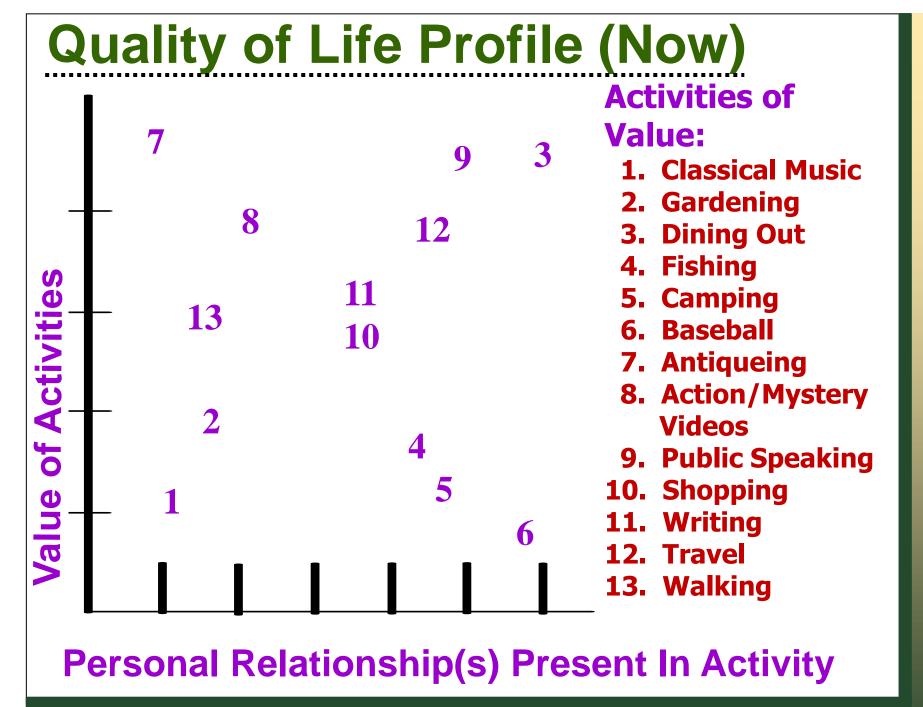
Generic: Relating to or descriptive of an entire group or class; general.

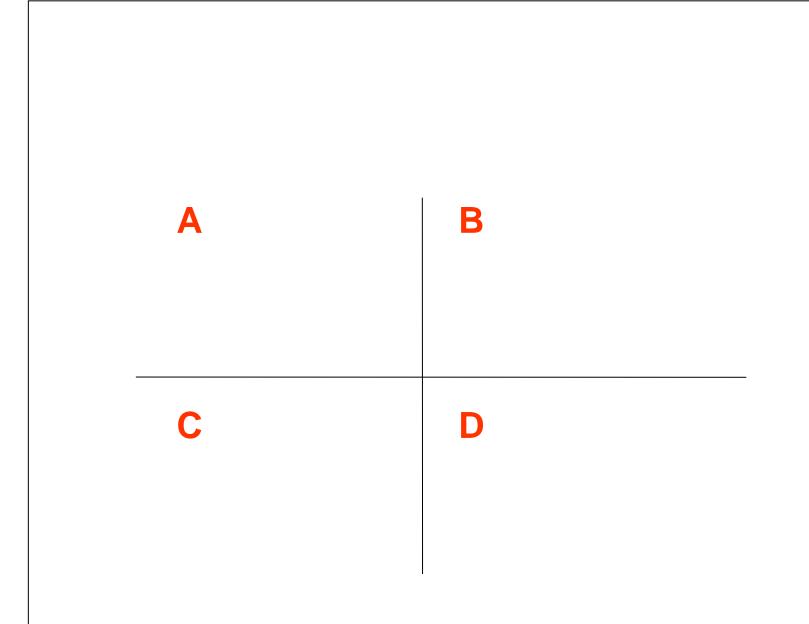
The role of support staff is not to provide support, but to help people obtain it.

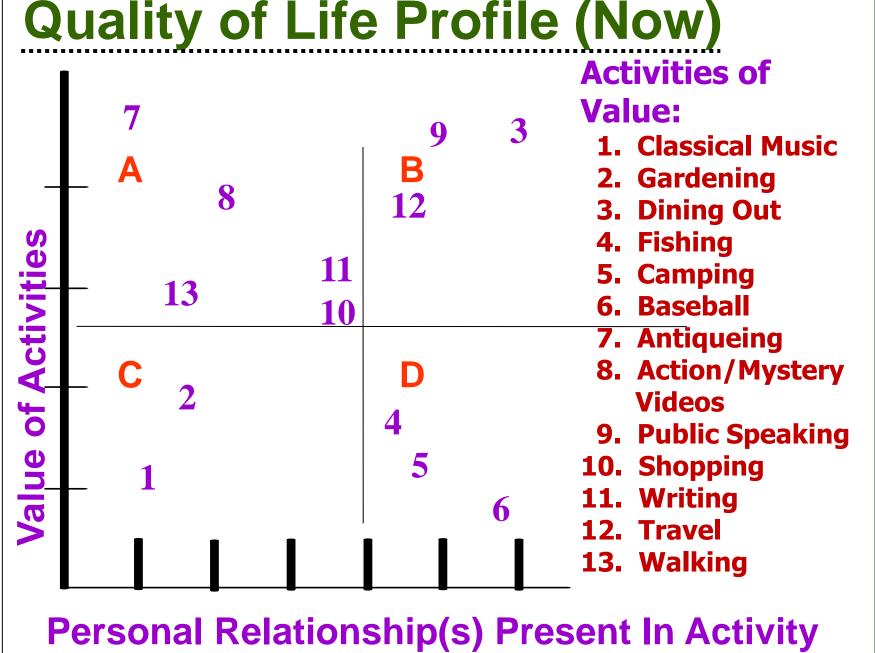
Life Stiles

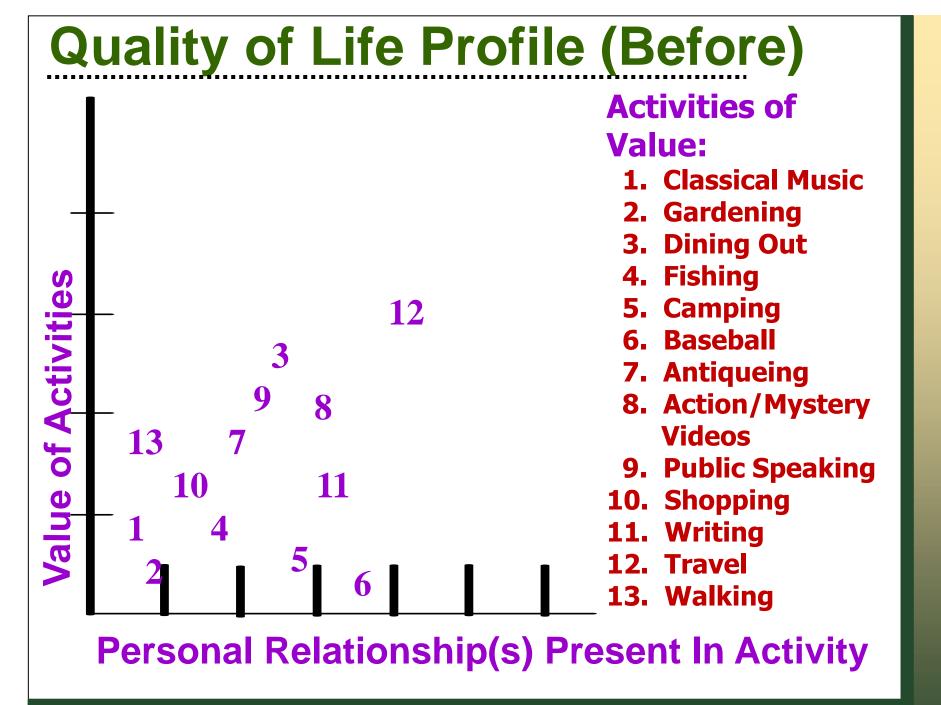












VALUE SELF

ENRICHED
(VALUE OTHERS
AND ACTIVITIES)

C

IMPOVERISHED

VALUE OTHERS

Community Integration

Integration (noun) 1: The act or process or an instance of integrating: As an incorporation as equals into society or an

organization of individuals or different groups (as races)

Webster's Ninth New Collegiate Dictionary, Merriam-Webster, Inc., Publishers

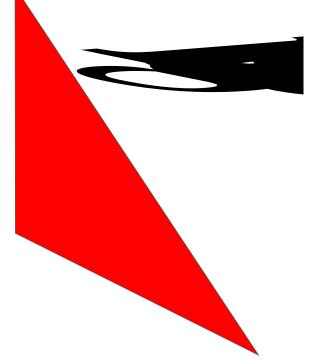


Drive Through Integration



Does drive through integration promote valued experiences and facilitate relationships?

Integration: (noun) 1. The act of process or an instance of integrating; as incorporation as equals into society or an organization of individuals of different groups (as races)



Community Participation

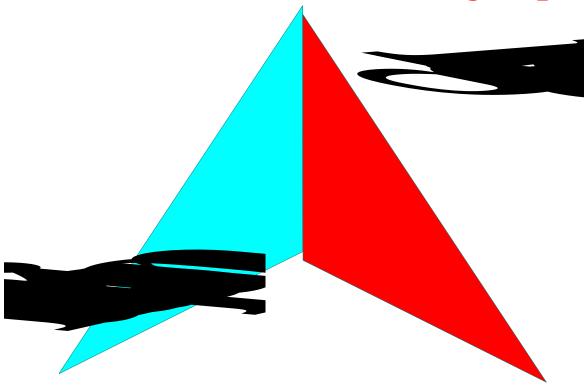
Participation (noun) 1: The act of participating 2: The state of being related to a larger whole



Webster's Ninth New Collegiate Dictionary, Merriam-Webster, Inc., Publishers

Participation: (noun) 1: the act of participating 2: the state of being related to a larger whole

Integration: (noun) 1. The act of process or an instance of integrating; as incorporation as equals into society or an organization of individuals of different groups (as races)



Community Relationship

Relationship (noun)
1: a connection,
association or
involvement
2: an emotional or
other connection

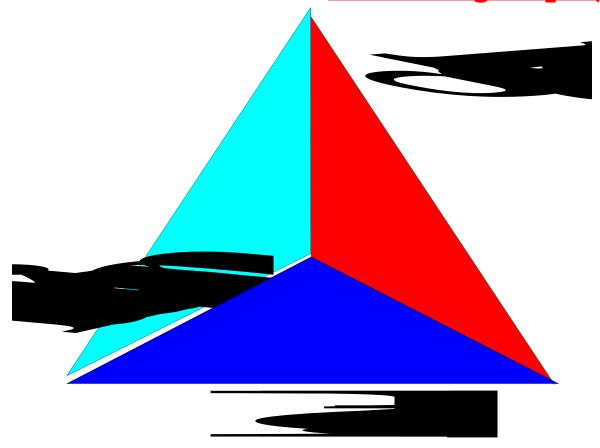
between people

Webster's Ninth New Collegiate Dictionary, Merriam-Webster, Inc., Publishers

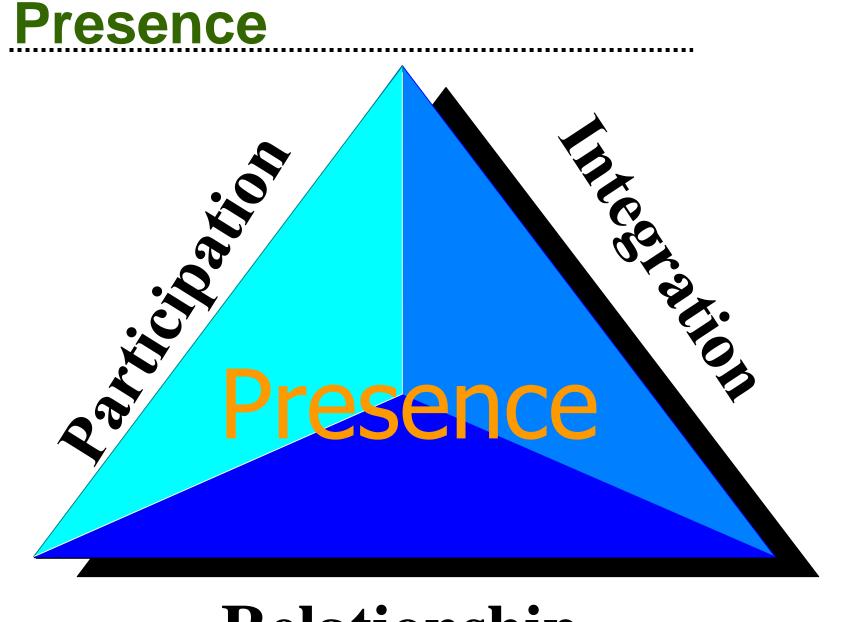


Participation: (noun) 1: the act of participating 2: the state of being related to a larger whole

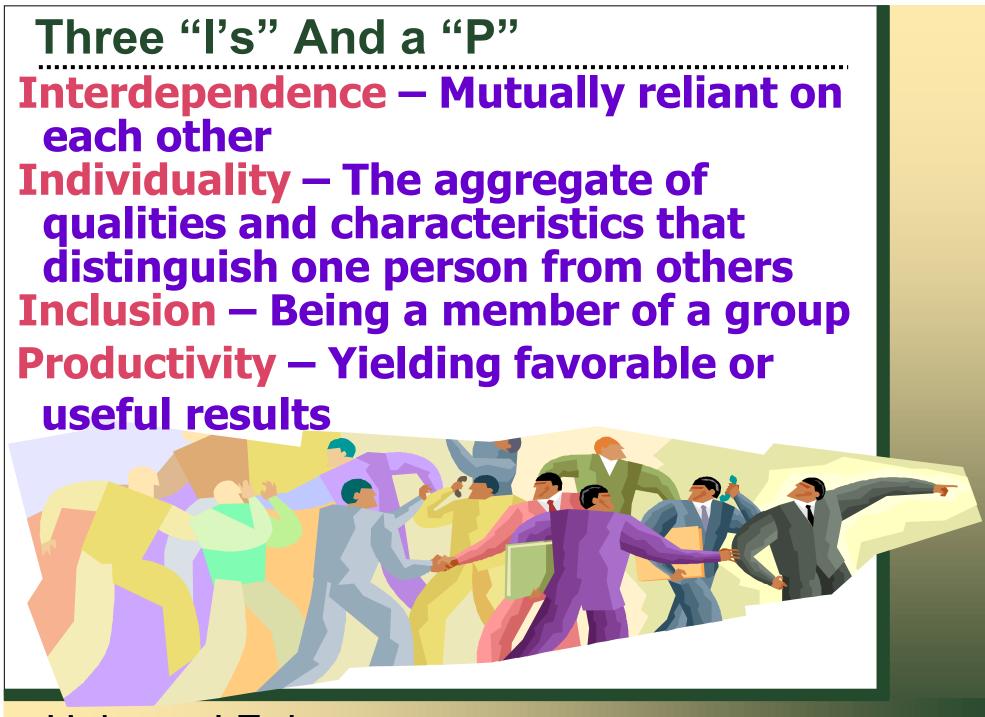
Integration: (noun) 1. The act of process or an instance of integrating; as incorporation as equals into society or an organization of individuals of different groups (as races)



Relationship: (noun) 1: a connection, association, or involvement 2: an emotional or other connection between people



Relationship



Natural Consequation

Alcoholic A

Enjoys his employment

Positive relationship with spouse

Hobbies like fishing and golf

Involved, caring parent

Frequent interaction with friends





Alcoholic B

Dislikes job/unemployed

Divorced

No interests

Estranged from kids

No friends

Natural Consequation (cont'd)

Which individual has the greatest probability of achieving sobriety? Which individual has the most to lose if he fails to achieve sobriety?

A Good Community

A good community insures itself by trust, by good faith and good will, by mutual help. It depends on itself for many of its essential needs and is shaped from the inside. When a community loses its memory, its members no longer know one another. How can people know each other if they never know one another's stories? If people don't know the story, how do they know whether to trust? People who don't trust one another do not help one another. Jack Pealer, Jr., "The **Community Living Paper"**

Images of Life In The Community

Being 3-1/2 years old and having your pre-school teacher think you're absolutely irreplaceable; and being the one child in the class who has a severe disability.

Getting to ride the same bus to school with your brother now that there is a lift on the bus.



Listening to a friend tell her favorite story over and over again, and hearing something each time; knowing that for her to risk asking you to listen again is a sign of her capacity to trust in you.

Watching your son walk across the high school stage on graduation night, just as all the other graduates have done, knowing that his "autism" hasn't gone away, but celebrating the fine young man he is becoming.

Getting your first apartment at 21 with a kid you went to high school with - you were the kid in the "multiply handicapped" class; he was the volunteer from the honors program.

Using your electric wheelchair to be an usher at church on Sundays.

Being forgiven for failing a friend because you forgot a promise you had made and intended to keep.

Having a laugh with friends in an up-scale restaurant when you're served red skin potatoes that have been sculpted to look like giant mushrooms.

Taking your turn at the microphone during the annual community concert in the park; having the children gather around you afterwards to show them how you play the spoons.

Treating a friend to lunch because you want to share some of your winnings from the raffle you won at the local high school football game last week.

Helping put a roof on your neighbor's house even though you've never done anything like that before.

Keeping in touch with a friend who is away.

Knowing your newspaper carrier by name, and having him know yours.

Having your friends from the church and your family organize a schedule so you can recover from surgery at home, not in the nursing home.

Sharing your home with a friend for six years now after living in institutional places for more than 20 years.

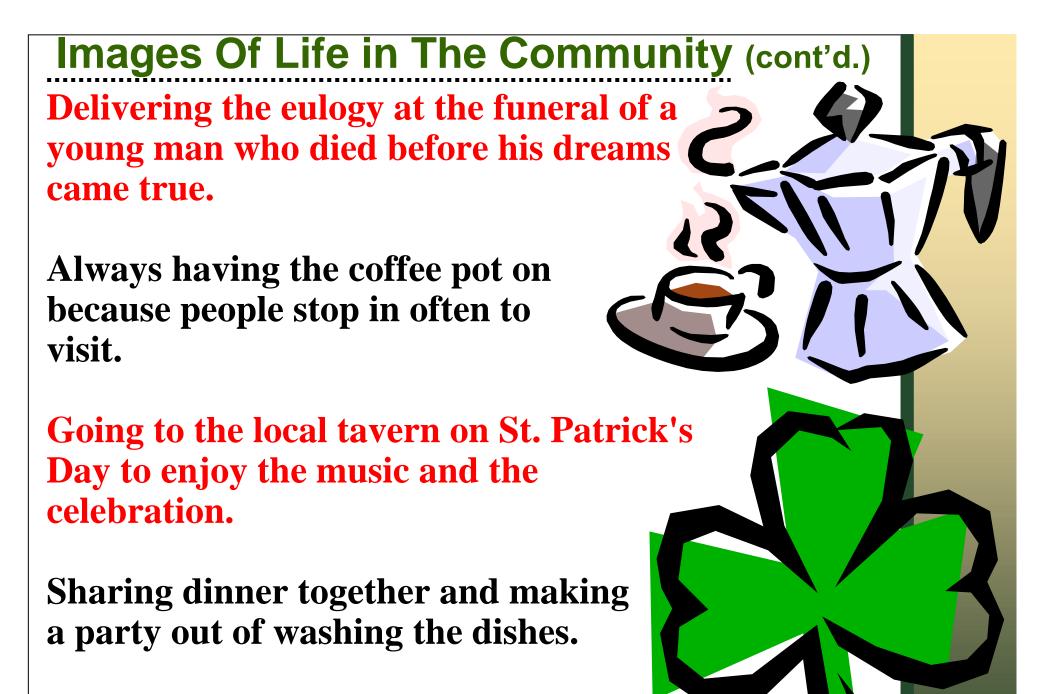
Sitting around looking at photos with a few friends, and telling, listening to and remembering the stories.

Having a couple of friends volunteer to help take the old wallpaper off and put up new.

Living in your own home even though the seizures haven't stopped; getting the help you want and need from people you select and who come when you decide they should.

Feeling confident enough about yourself and your parents to let them know, at age 22 (and having a developmental disability), that home would be a little better if it were your home; having them take you seriously and begin to plan with you to make that possible.

Having your co-workers throw a surprise birthday party for you after you all "clock out" for the night.



Sitting on a front porch on a street full of front porches, chatting softly with your neighbor on a summer night.

Writing letters to the editor and articles for the local newspaper.

Looking up a phone number and calling a friend with the good news that you've moved into your own place, after never "succeeding" in the telephone program you worked on for years in the group; finally having something worth using the phone for.



Images Of Life in The Community (cont'd.)

Being a teenager who has four high school band "letters" and President's physical fitness medal, is elected to the homecoming court, and has Down Syndrome.

Visiting the same campground on the same weekend every summer so that you can visit with the family you befriended on your first trip there five years ago.

Being patiently tutored in gardening by your 76- year-old neighbor, hoping the lessons will continue for years because some things, happily, take a long time to learn.

Being invited to share a favorite story with the children in the first grade class and being asked back on a regular basis.

Taking supper to the neighbors who have just lost their grandfather.

Looking for work; managing a challenging insulin injection procedure for yourself pretty much on your own; taking care of the house when your family is away and having an intellectual disability.

Having your neighbor stop over becaust he missed seeing you out this morning.

Remembering the person you credit with first teaching you to play basketball; being friends with that person long enough that you're taller than him now; knowing that when you first met and he gave you those first lessons he lived in a institution.

Having Sunday brunch at a friend's house nearly every Sunday for a couple of years so you can visit, have someone else do the cooking, play with the kids, and do your laundry without spending any money.

Hosting the annual Christmas party for the housing Association you belong to; being a part of creating and keeping traditions.

Getting to hold and rock to sleep your neighbor's grandchildren when they come to visit, even though some people still treat you as a dangerous person.



When Life Has Changed

When life has changed in desirable ways for people with disabilities, their allies, and others involved with them, strategies of collaboration and trust most often prevail. People invest in knowing one another well--in knowing the stories of others and in sharing their own. Jack Pealer, Jr., "The Community Living Paper"



Valued Relationships

How many relationships do the people you support have other than

with:

family members?

paid professionals/ staff?

individuals with

disabilities?
How does an individual's

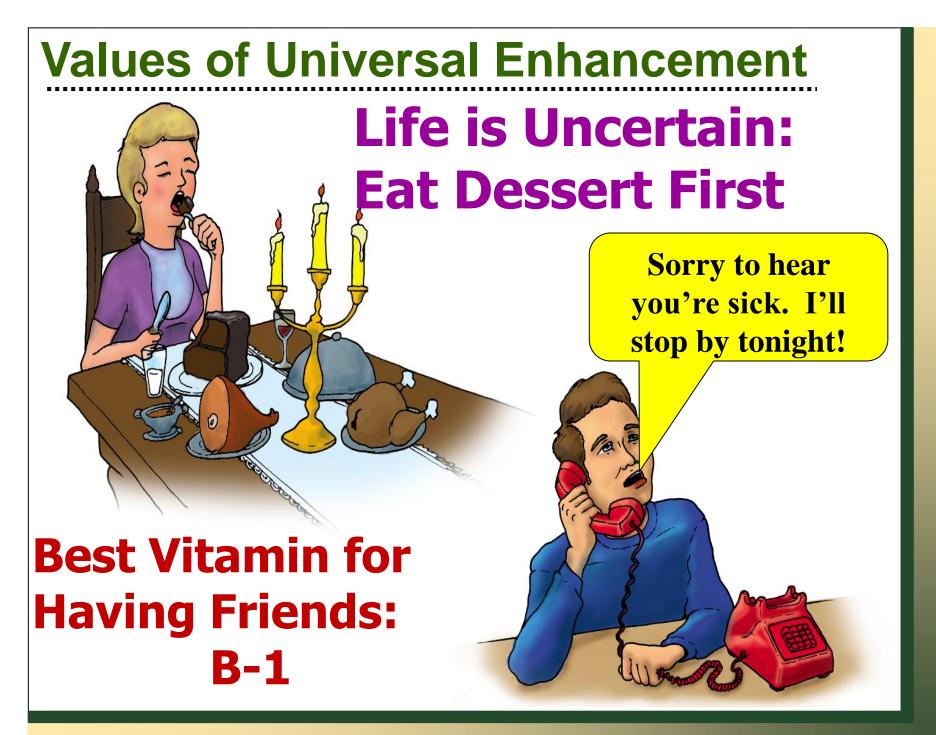
competence influence the nature of their relationships?

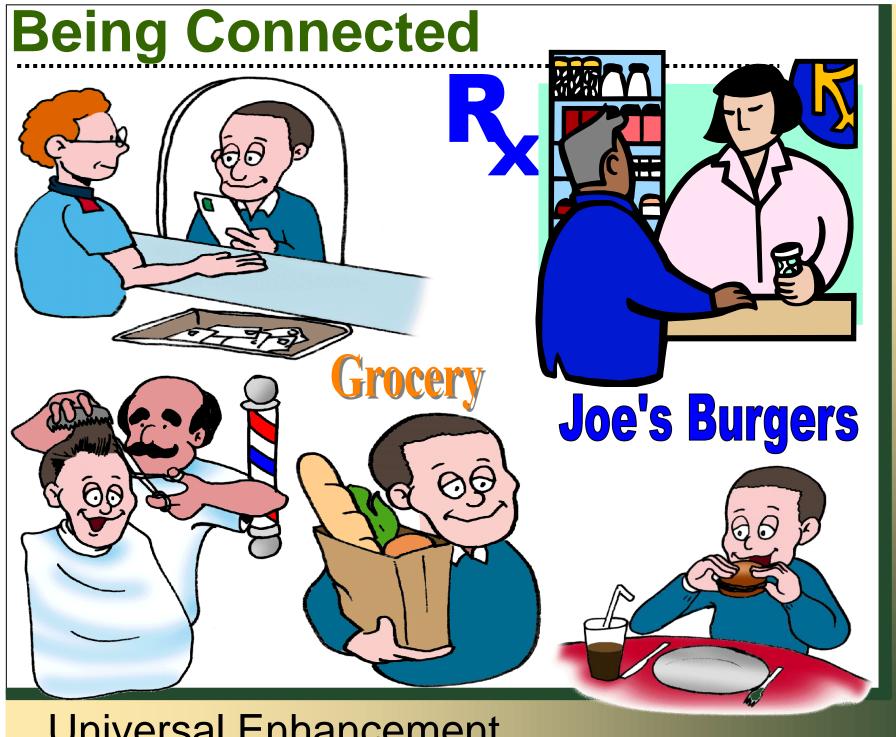
Valued Roles

"People in valued social roles are apt to be accorded the good things in life, while people in socially devalued roles are apt to be mistreated."



How do we assist people to obtain socially valued roles?





Third Place

A place to "go home to"

Repeated interaction with regulars

An atmosphere that promotes

social contact

Cafe
Barber Shop
Bar
Laundromat
Exercise club
Sidewalk bench
House of worship
Library



Consumer

How can people who are "consumers" have a life free of the system?

Consumer

Chrysler Mini Van
Food Lion
Hair Salon
Housekeepers/cooks
Washer and Dryer
Penny's, Sears
Home Telephone



Limited Means

Public Transportation
Food Pantry
Family/Friends Cut hair
Do It Yourself
Laundromat
Second hand shops
Pay phone at corner



Pathway to Friendship

Every relationship/friendship one forms in their life, other than with family, is developed as a result of playing an active role. The relationships/friends that one has nurtured as a(n):

Parishioner who collected the tithe at church...
Camper who won first place in diving at the Girl/Boy Scout Camp...

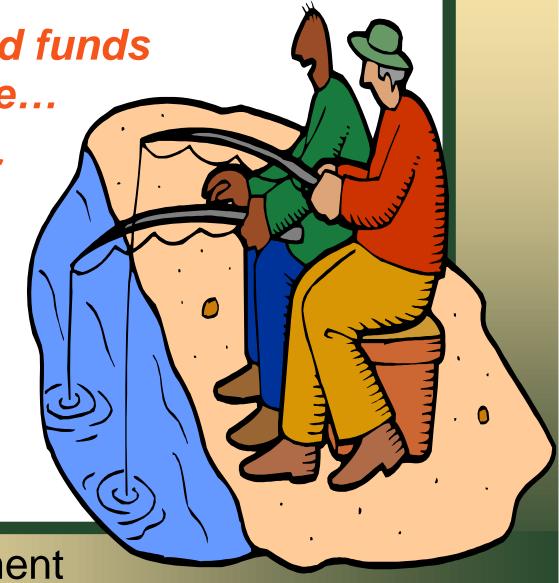
Pathway to Friendship (cont'd)

Employee who brought tomatoes to work from their garden...

Volunteer who raised funds for a worthy cause...

Member who ran for office in a social club...

Athlete who played shortstop on a softball team...



Volunteering

Volunteering is an essential life

activity and:

•is a demonstration of appreciation and thanks

enhances sense of self

facilitates relationships

increases skill acquisition

promotes adult status

•enhances QOL through meaningful engagement

How do you encourage volunteering?



Pathways To Friendship (cont'd)

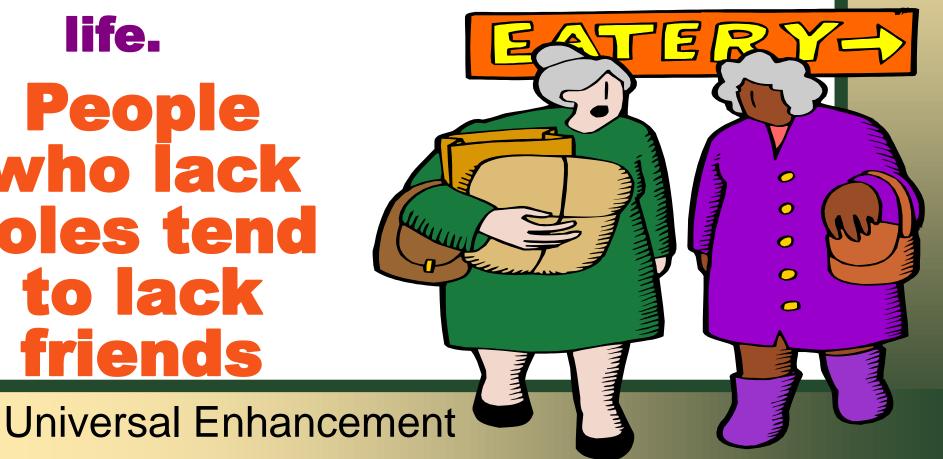
Student who played in a high school band...

Parent who volunteered time at their child's school as a room monitor...

...enhances the quality of one's

life.

People who lack roles tend to lack friends



Being In Is Not Enough

IN the Community vs. OF the Community

Present;

Located;



Connected to;

Having a presence;

Assimilated with others;

An integral part; Included

As in . . .

OF the Jewish faith

Member OF the Pomeranz family

Member OF the Garden Club

To The People
People with disabilities

need pride and power!

Civic engagement is a strategy to that end - Voting

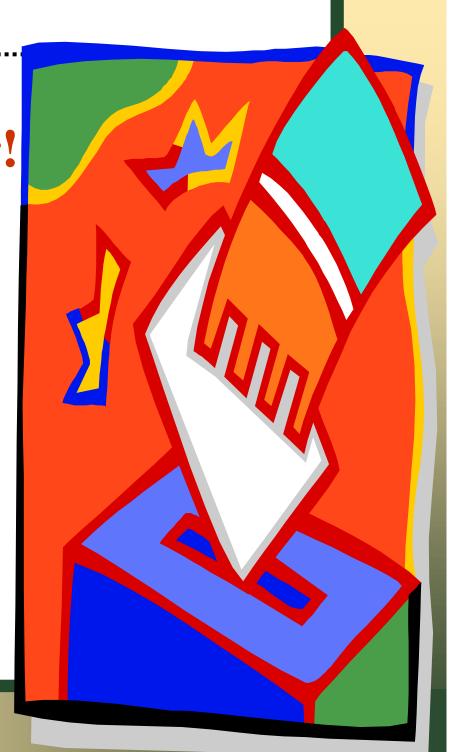
Campaigning

Fund raising

Donating to a cause

Petitioning for issues

Participating at hearings





Dear Friend...

Dear Friend:

All creatures Great and Small need homes of their own. Draw a line to match each creature with a home.



Wait! There aren't enough homes! In our metropolitan area, there are 658 children and adults with developmental disabilities waiting for safe and comfortable homes. This year, Rainbow Village hopes to open four new homes for people in need. But we can't do it without your support. Please join us as we make quality living a reality for people who have no place to call "home". By doing so, you will directly provide permanent homes that that are designed to last a lifetime. Currently, 90 residents live in 20 Rainbow Village Homes located throughout . Help us help more people this year by sending your tax deductible gift in the enclosed envelope. Thank you.

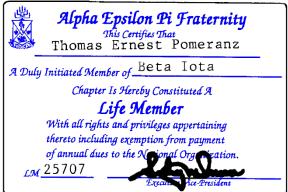
Sincerely,

President

Inclusion Makes A Difference DIVERSITY RESPONSIBILITY **TRUST** CARING **JOY GROWTH SHARING COOPERATION** RESPECT **UNDERSTANDING INCLUSION ACCEPTANCE COMMUNITY** Taken from "Journey to Inclusion"

Community Presence







2305526 DR THOMAS POMERANZ

International Number Auth. Code 891288 534 657 000 9 95

Sometimes my activities are spontaneous. I am never sure when I will need the extra cash for an unexpected night out with friends.

Some of my friendships have endured from college. I am a life member of my college fraternity. It's great to get news on how my "brothers" are doing.

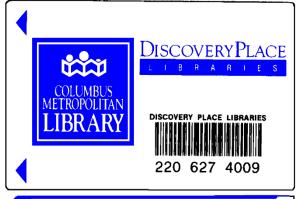
Given how much I travel, this card gets a workout. Since I am often away from home, I like to stay in touch with my friends.

Universal Enhancement

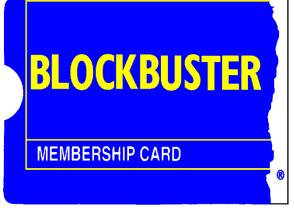
6352

Community Presence (cont'd)

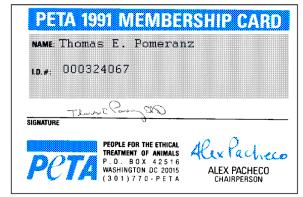
humane society.



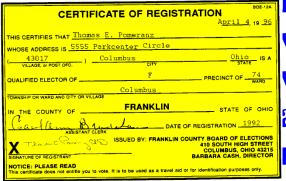
Reading is important to me. I can hardly wait for the next Stephen King thriller. My colleagues at work are big Stephen King fans too.



I like movies - especially "blow 'em up, blood and guts flicks."
On weekends I usually watch Steven Segall and Arnold Swartzenager action movies with a couple of my buddies.
Though I don't volunteer as much as I would like, I do enjoy working with animals at the



Community Presence (cont'd)

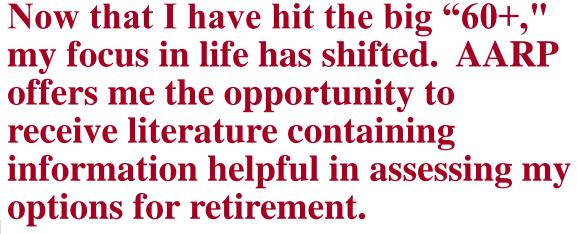


T make myself heard -- I try to vote in every election. Influencing who is elected to govern my country and community is an important responsibility I have as a citizen.



Thomas E. Pomeranz 4484 Laclede Ave. Saint Louis, MO 63108-2204





My membership in AAA really comes in handy. I can't tell you how many times they have routed my vacations or gotten me going in an emergency.



"I Am Somebody!"

Burden

There is no greater load than the man who carries no load at all.



Making Introductions

Making introductions is an essential skill for support staff.

Paul, I would like you to meet Ed.





The Dress Standard

When leaving their homes in the morning, people you support should present themselves no differently than the staff who support them!



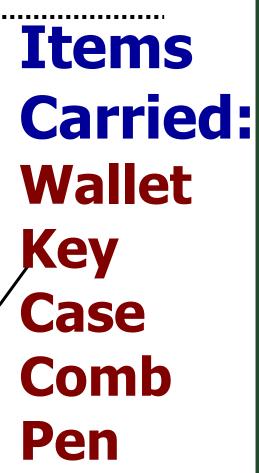
Are the people you support encouraged

to: • wear jewelry?

- carry wallets/purses?
- apply perfume?
- use cosmetics?
- eget stylish hairstyles?

Pockets and Purses

Items
Carried:
String
Apple core
Styrofoam
cup



The items we allow individuals to carry are directly correlated to our perception of their ability.

Clothing Protector

Code word for bib.

Provide individuals who are not neat when eating with:

Kitchen aprons

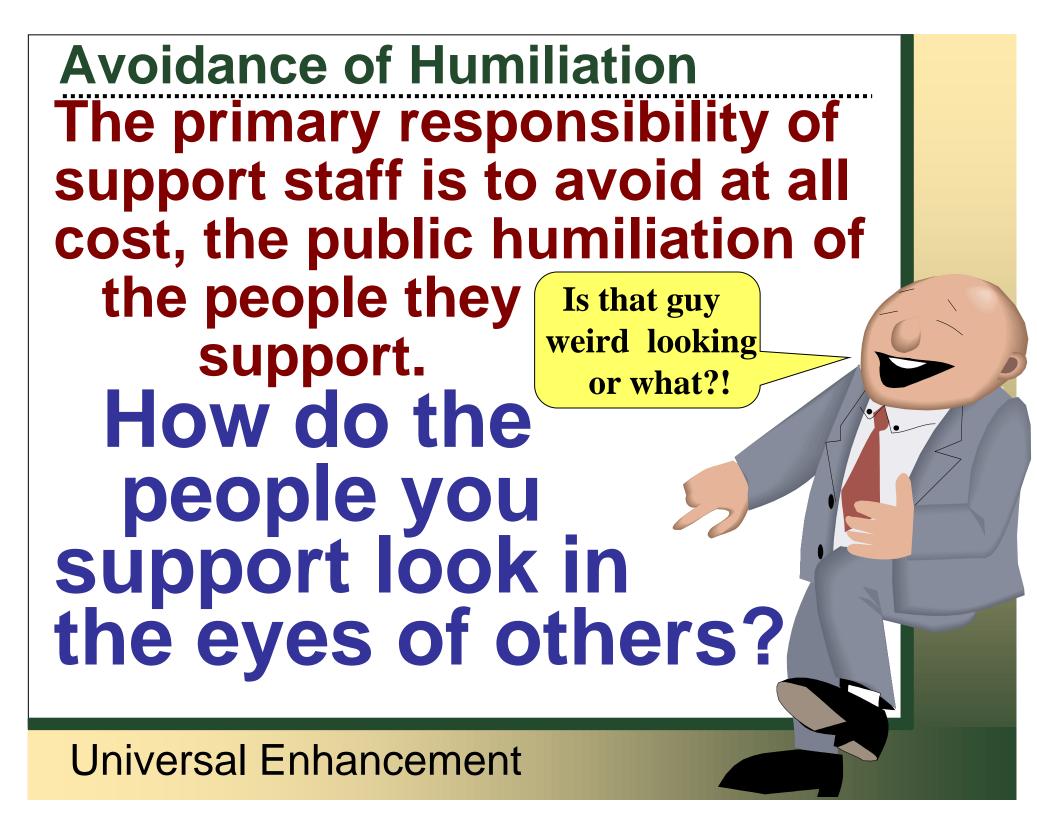
Barbecue aprons

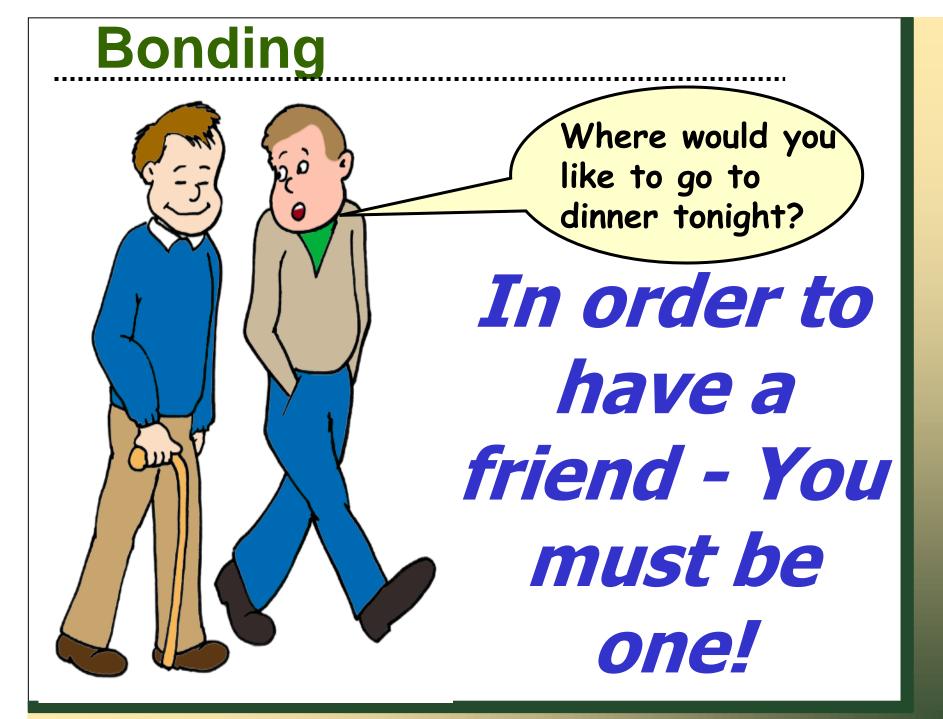
Chef's aprons

Disposable restaurant aprons

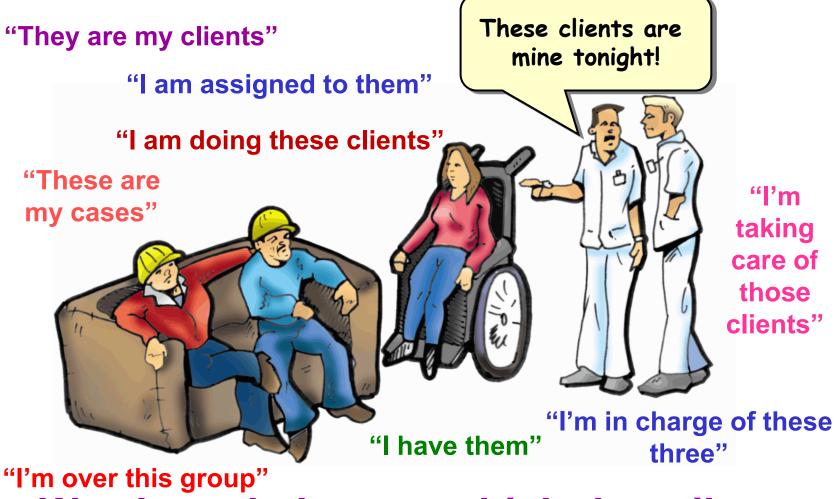
Covering people with towels and other linens during meal-time is only acceptable for babies!











Words and phrases which describe a management or controlling function serve as obstacles to bonding.

Seeing the Individual

Can you identify these traits in the persons for whom you provide support?

Loving Honest Independent Caring

Faithful Kind Optimistic Sincere Industrious Sensitive Cautious Assertive

Forgiving Shy Patient

Empathetic Determined Spontaneous

Creative Motivated Generous

We must be able to see through the individual's disabilities and challenges and appreciate the beauty

of their personality.

Seeing The Individual (cont'd)

How do you see the people you

support?

Violent

Addictive

Destructive

Obsessive

Defiant

Vulgar

Deceptive

Manipulative

Angry

Obstinate

Aggressive

Hostile

Promiscuous

Disgusting



Building Relationships

When was the last time you had "fun" with one of the people you



Objectives In An ISP

When individuals with significant intellectual challenges who require pervasive supports can:

Salute

Wink

Cross their eyes Do thumbs up

Hold their nose

Snap their

fingers

Wiggle their nose

Make a fish face

Blow a kiss

Roll their eyes



Objectives In An ISP (contd)

Make a pig nose Whistle

Make a snoring sound
Crack their knuckles
Give a high five

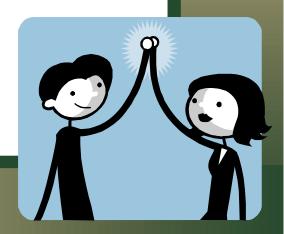
What does that mean?

Click their tongue
Give the power
sign

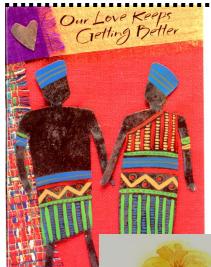
Give the victory sign
Thumb their noses

Give a "wencher"



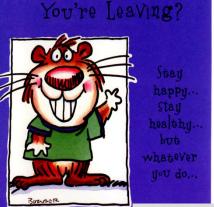


Sentiments



I used to wonder if what people said was true -that love keeps getting better as time goes by ... And non I know the answer. at least for us, because the longer we're together, the more I find to love about you.





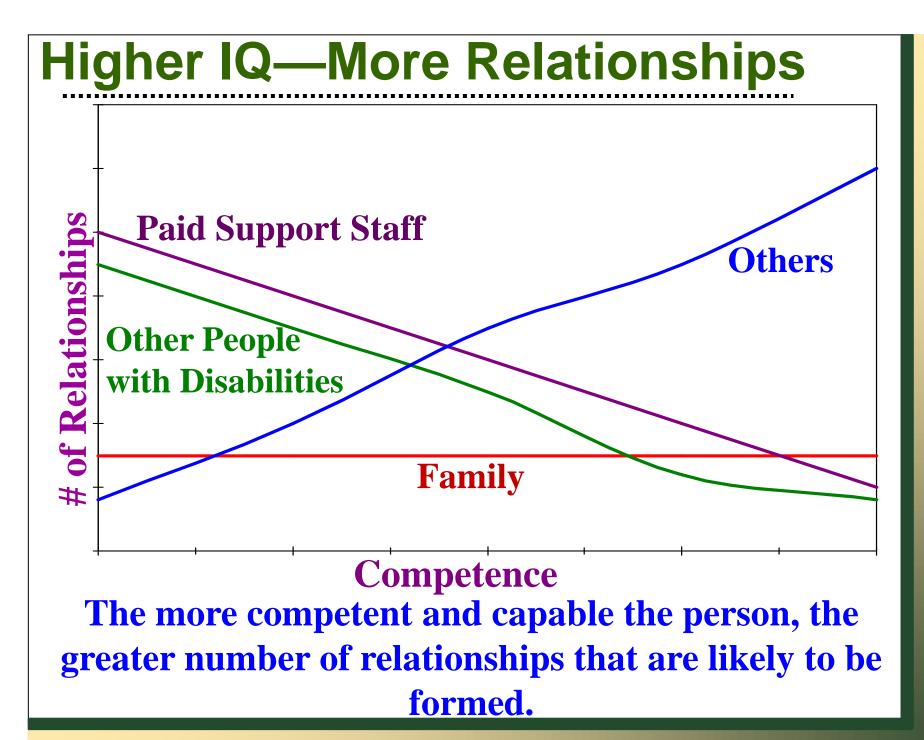
..Stay in touch.

Best Wishes!



THANK YOU Some people have a special way Of knowing what to do To make things nice for others-And that's just the way with you!

Do the people you support send/receive these sentiments, indicating how they feel about others and how others feel about them?



Being Missed



Having relationships - and being part of your community means being missed by others when absent.



Community

"The community is not there to find-it has to be built."



--John O'Brien

Friendship

"Friendship is a thing most necessary to life, since without friends no one would choose to live, though possessed of all other advantages."

Aristotle

Independence

"Independence does not mean doing things yourself...
It means being in control of how things are done."

Judy Heuman, Assistant Secretary of Special Education and Rehabilitation Services



Dignity in Death

What roles do housemates, friends and non-paid supports play in:

Serving as pall bearers

Delivering a eulogy

Writing an obituary

Deciding on burial arrangements i.e.: clothing, artifacts, coffin

Participating in ritualistic mourning i.e.: attending wake, gathering of friends

Developing a memorial service

Expressing condolences to the deceased family i.e.: sympathy cards

Requesting items valued by the deceased to kindle cherished memories

Supporting others in the grieving process

What Is Inclusion?

a climate of acceptance is created -no one is rejected or locked out.

acknowledges that everyone has different skills, talents and gifts to offer -- no one has to be good at everything.



all individuals work together as a team in a partnership - we don't work in isolation.

Inclusionary Model

Provides individuals with an opportunity to be integrated into normative settings

Emphasizes the importance of an individual's fullest participation in all activities, regardless of the individual's general competence and ability

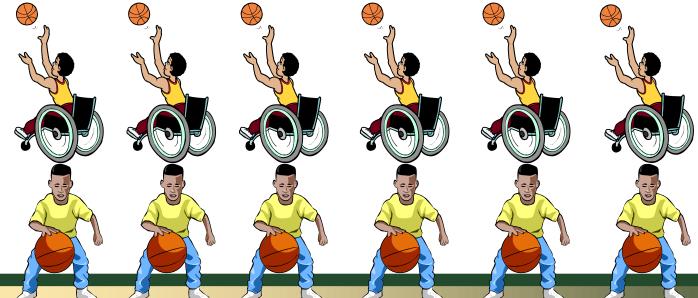


Parallel Integration

....is an oxymoron.

Parallel: Being of equal distance apart. straight lines that do not intersect.

Integration: The bringing of people of different groups (e.g. racial, ethnic) into equal association.



Inclusionary Model (cont'd.)

Is characterized by gentleness, openness and humor -- it is not rigid, regimented or authoritarian

Humor



LEFT: Dennis
Richter uses his
scissor-fingers
to feign cutting
off friend
Dennis Price's
ponytail during
a lunch break at
Lafayette Work
Center.

Inclusionary Model (cont'd.)

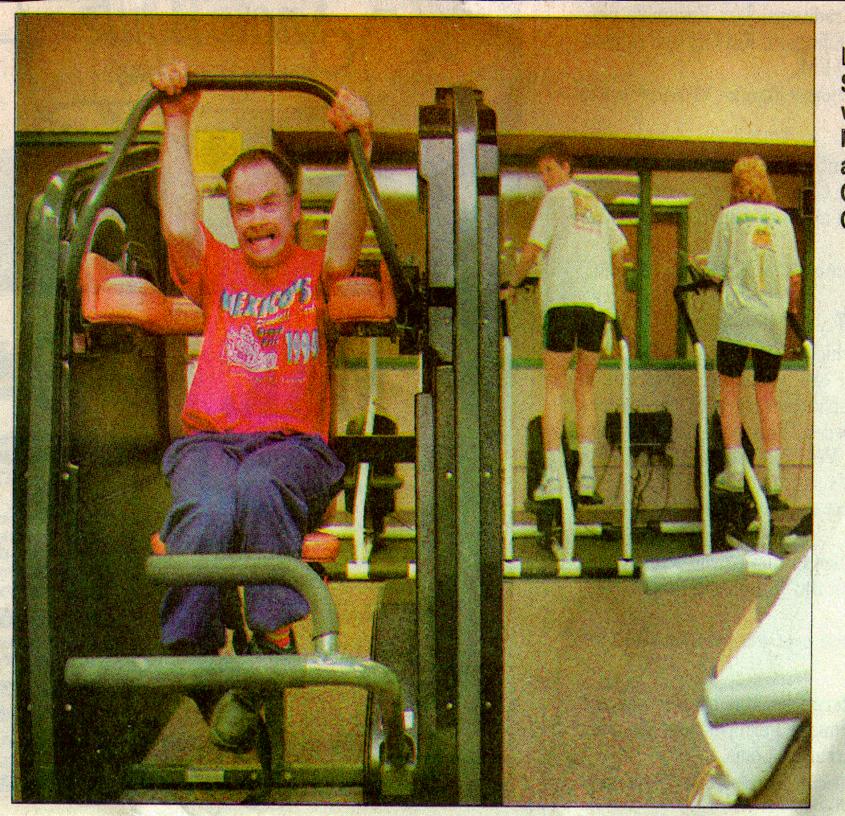
Is characterized by gentleness, openness and humor -- it is not rigid, regimented or authoritarian

Talking openly about differences in a productive, positive way — not ignoring differences or talking about them in stereotypical ways

Is a daily, ongoing process -- not just mainstreaming for employment, recreation, religious and health care functions

Inclusionary Model (cont'd.)

Recognizes that "habilitation" is a result of meaningful participation and not a goal in and of itself



LEFT: Scott
Sellenriek
working out on a
Nautilus machine
at the West
County YMCA in
Chesterfield.

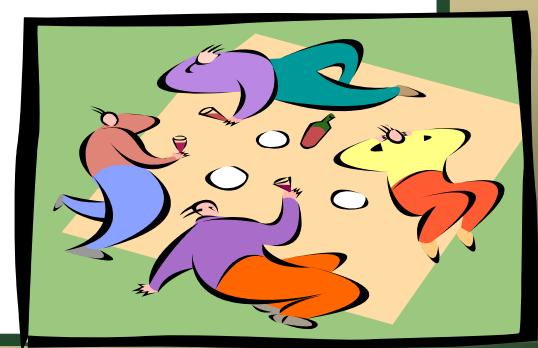
Inclusionary Model (cont'd.)

Recognizes that "habilitation" is a result of meaningful participation and not a goal in and of itself

Celebrates the relationship that the individual forms with others as a result

of participation

Advocates for the individuals right to learn how to make choices and decisions



Inclusionary Model (cont'd)

Is something that changes all the time.

It is a series of small adjustments, not just a replicated model.

Is characterized by an attitude of possible – to discover what is possible – not placing blame, getting stuck or giving up. Inclusion is "solution oriented."

Creates opportunities for people to learn together.

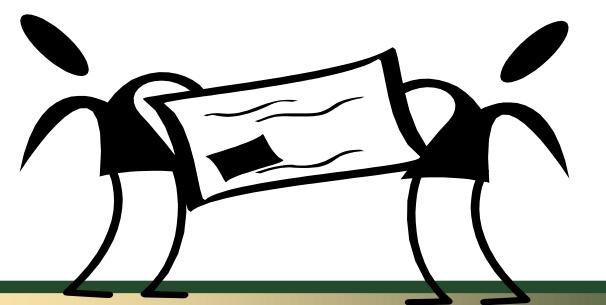
Reprinted & adapted from "Including Kids: How It Happens" a handbook on Inclusive Education; Edward Smith School, Syracuse, City School District, Syracuse, NY, March 1991.

Living Independently





Don't advocate for people. Advocate with them.



The greatest obstacle to discovering the shape of the earth, the continents and the ocean was not ignorance, but the illusion of knowledge.

Daniel J. Boorstein