

Universal LifeStyles

Universal Enhancement: Raising the Bar

by
Thomas E. Pomeranz, Ed.D.

Universal Enhancement

The Whole Future Catalog

BY JOHN E. WOODWARD

You aren't that blind in real life... you just see things that others can't see. You're not that deaf in real life... you just hear things that others can't hear. You're not that lame in real life... you just walk differently than others. You're not that dumb in real life... you just think differently than others. You're not that ugly in real life... you just look differently than others. You're not that old in real life... you just feel differently than others. You're not that poor in real life... you just have differently than others. You're not that sick in real life... you just feel differently than others. You're not that disabled in real life... you just live differently than others.

Jargon Genie™
It happens all the time... you get lost in a complex jargon and jargonese... you're not that dumb in real life... you just think differently than others. You're not that ugly in real life... you just look differently than others. You're not that old in real life... you just feel differently than others. You're not that poor in real life... you just have differently than others. You're not that sick in real life... you just feel differently than others. You're not that disabled in real life... you just live differently than others.

Portable Handicapped Parking Space™
No transfer should be without one! Unlike to... Create a built-in parking space with blue access logs and room for people with... Works on concrete, asphalt, dirt and grass in any weather for temporary use only... not intended to replace permanent, designated parking spaces.

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Stall Widener™
They portable hydraulic jack... They portable hydraulic jack... to widen those cramped bathroom stalls... Special feature... press them back again... Kingpin 6 for all locksets (not included).

Portable Curb Cut™
This handy device... in... portable... and... enough... for use on the highest curbs... Come with a lifetime warranty and an attractive design.

Door-Be-Gone™
Turnstiles and heavy fire doors holding you back? Push and... Amazing new electronic device... material... and... enough... for use on the highest curbs... Come with a lifetime warranty and an attractive design.

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Definitions

Disability: Pathology of the individual:

- ☑ Cataracts
- ☑ Arthritis
- ☑ Cerebral Palsy
- ☑ Asthma

Handicap: Impairment in performance; unable to:

- ☑ see objects at a distance
- ☑ negotiate stairs
- ☑ close doors
- ☑ grasp objects with hand

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Barriers cause handicaps, not disabilities.

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Emancipation

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

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Back Wards Of The Community

A community characterized by:

Loneliness, Fear, despondency, discrimination, anxiety, hostility, boredom, sorrow, indifference, pity, segregation, poverty, degradation, despair, hopelessness, rejection, failure, prejudice, intimidation, isolation.

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Life In The Community

Would you like to trade places?

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Janteloven

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?


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Call It What You Will

People may be segregated for many different reasons:

Type of Segregation	Factor
<input type="checkbox"/> Native American Reservation	Ethnic
<input type="checkbox"/> Low Income HUD Housing	Poverty
<input type="checkbox"/> Japanese Internment Camp	Nationality
<input type="checkbox"/> Inner City Ghetto	Race
<input type="checkbox"/> Leper Colony	Disease
<input type="checkbox"/> Nursing Home	Age and Infirmary
<input type="checkbox"/> Latino Barrio	Cultural background
<input type="checkbox"/> Developmental Center	Intellectual disability

Check the box where you wish to live.



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There Is...



...no separate but equal!



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Segregated Bathrooms

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

IQs 100 or greater	IQs Less than 70
	
Fresh scents & décor Stalls for privacy Paper towels	Barren No stalls No paper towels

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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.

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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.



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Disenfranchised...

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



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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 ¾ of the Acadian Population of Nova Scotia)

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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

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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

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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




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Shame On Us

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

- Institutionalization - in the name of "treatment"?




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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 have value.




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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.

Harriet McBryde Johnson



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It's a Matter of Perspective

Crime	→	Disability
Evidence	→	Data, tests
Suspect	→	Provisional diagnosis
Interrogation	→	Interview
Investigation	→	Evaluation, assessment
Trial	→	Placement meeting

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

Jury	→	Placement committee
Convicted	→	Diagnosed
Conviction overturned	→	Misdiagnosed
Multiple Convictions	→	Multiply handicapped
Awaiting Sentencing	→	Waiting list
Sentenced	→	Placed

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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

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

Escape	→	AWOL, Leave without permission
Prison Yard	→	Day activity room
Solitary	→	Time out room
Parole Board	→	Discharge committee
Parole Officer	→	Case manager

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

Penal System	→	Service system
Work Release	→	Day activity program
Inmate	→	Resident
Big House	→	State Institution
Cell	→	Bedroom
Guard Tower	→	Nurses Station

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

Exonerated → *No Diagnosis*

Cell Block → *Hall, Suite, Unit, Wing*

Chain Gang → *Mobile Work Crew*

Hard Time → *Industrial therapy*

Release → *Discharge*
Will the day ever come when the "victims" of the service system are emancipated and given a reprieve?

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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



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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?




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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"?



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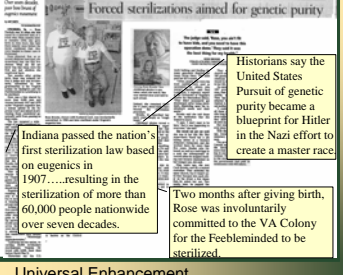
Shame On Us (cont'd)

Forced sterilizations aimed for genetic purity

Indiana passed the nation's first sterilization law based on eugenics in 1907.....resulting in the sterilization of more than 60,000 people nationwide over seven decades.

Historians say the United States Pursuit of genetic purity became a blueprint for Hitler in the Nazi effort to create a master race


Two months after giving birth, Rose was involuntarily committed to the VA Colony for the Feeble-minded to be sterilized



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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"?




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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"!



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Don't Miss The Point

Treating people badly makes their condition worse!




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

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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."



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Freedom

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

Burton Blatt

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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*

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Segregation

That was then...

...this is now!

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Segregation Is Segregation

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

The pat of her hand keeps us in ours.

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They Say Nobody Wants Us

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Support Staff

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

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Segregation

Segregation is harder to spot... when they call it "Special"

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We Can't Get Out

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

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We Can't Get In

Inaccessible is a fussy, complicated way of saying Segregated.

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Segregation

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

RING FOR SERVICE

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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.

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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?

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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?

Burn at the stake
Abandon Chain to a wall
Serve as the town fool

The Structure of Scientific Revolution; Thomas Kuhn 1962

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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?

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Anomaly (cont'd)

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

Utilize aversive shock
Medicate into submission
Place in time-out rooms
Control through a level system
Sterilize women
Apply cost-response systems
Use forceful over-correction

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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!

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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 internment 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!**

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History of Reparation Payments

1952 Germany	\$822 Million	Holocaust Survivors
1971 USA	\$1 Billion + 44 Million Acres	Alaska Natives
1985 USA	\$105 Million	Sioux of So. Dakota
1985 USA	\$12.3 Million	Seminoles of FL.
1990 USA	\$1.2 Billion	Japanese Amer.
20?? USA	Inclusion	People with Intellectual Disabilities

Data from Black Reparation Now! Doreen Baxter Lewis

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Choose One

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

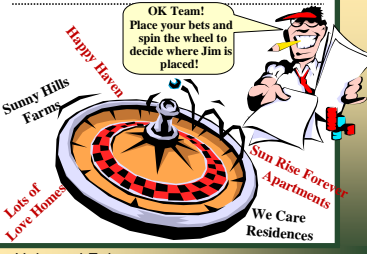


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Placement "Wheel of Misfortune"

OK Team! Place your bets and spin the wheel to decide where Jim is placed!

Happy Haven
 Sunny Hills Farms
 Lots of Love Homes
 Sun Rise Forever Apartments
 We Care Residences

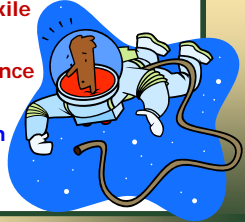


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Placement-Defined

- Cast out of the tribe
- Sent into exile
- Displaced
- Sudden disappearance


Placement – An intervention for the intolerably different.



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Placement Defined (cont'd)

During Queen Victoria's reign, the term placement came into use by the pioneers of Social Work. It likely derives from place cards, once used at formal dinners – one must know one's place.



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Community

It's Easy To Get Out
 It's Hard To Get In




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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.



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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)



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Placement List


Being a priority on a "placement list" is not seeing the light at the end of the tunnel, it is standing on the edge of the precipice.



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Group Home...

...a residence where the inhabitants maintain all their life's belongings in 1/2 a bedroom.



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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.

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It's My Home

When people are "placed" or "admitted" the Welcome Wagon will not come.



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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?



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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?




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"Do" Inclusion?

Is someone doing inclusion to you?

If people were not segregated, we would not be "doing inclusion."

Support an inclusionary life!



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Going To The Community

Group Home The Community



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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!




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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.



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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.

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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



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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




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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



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Inclusionary Trek

To boldly go where everyone else has gone before.




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Even If I'm Wrong

OK! Let's say I'm wrong!

Treating people with dignity and respect is not an effective intervention.

So what's the downside?




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An Envable 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



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An Envable 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



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


– Todd Rieley, Ph.D.



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Altering behavior is never a prerequisite to getting promoted into a reasonable life.

– Rob Horner, Ph.D.



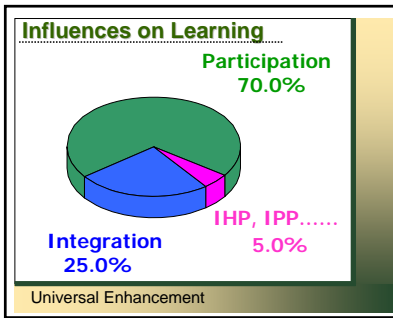
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Diagnostic Living

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

Thomas E. Pomeranz Ed.D.

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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 "mode" of service delivery?	Custodial/ Medical	Developmental/ Behavioral	Individual Support

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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	Change the environment 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 providers talk about their services?	Community outreach	Community-based	The Community

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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

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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

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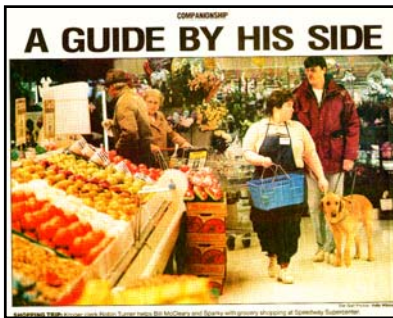
Intervention Strategies...

...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.

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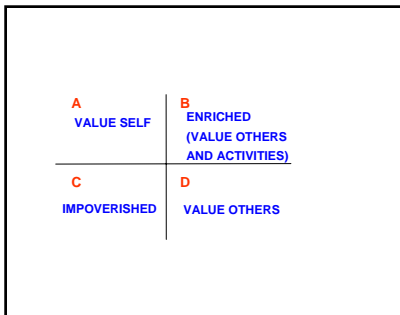
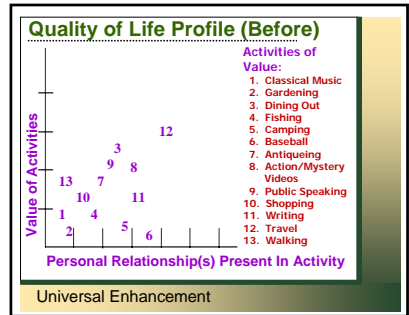
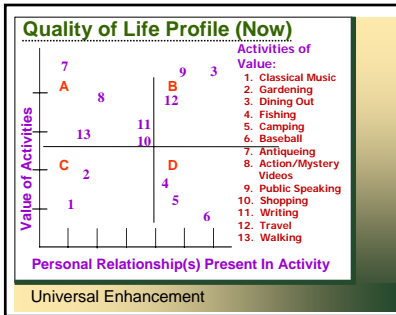
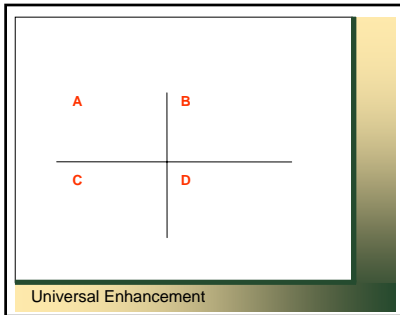
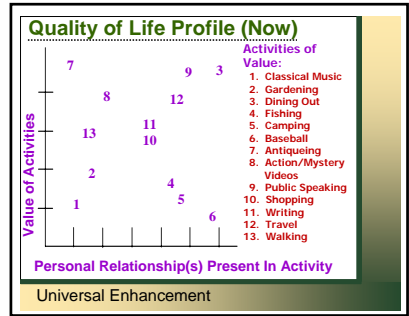
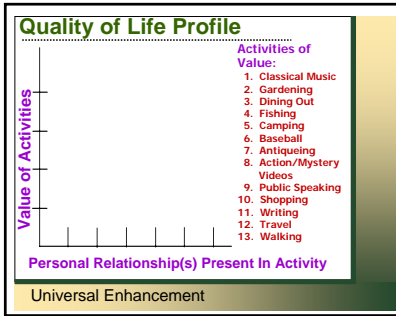
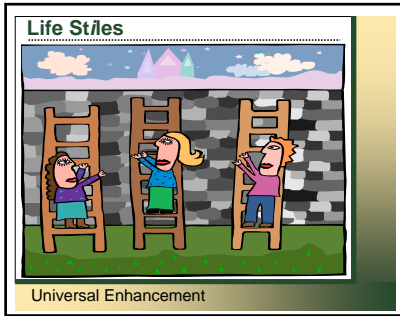


Generic Supports

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.

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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


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Drive Through Integration

Does drive through integration promote valued experiences and facilitate relationships?

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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)



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Community Participation

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

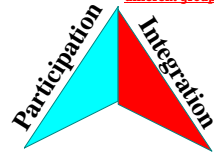


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Community Relationship

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

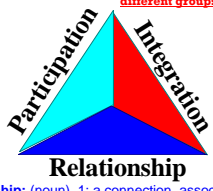


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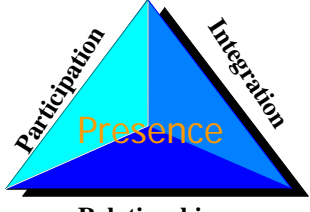
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Presence

Participation

Integration


Relationship



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Three "I's" And a "P"


Interdependence – Mutually reliant on each other
Individuality – The aggregate of qualities and characteristics that distinguish one person from others
Inclusion – Being a member of a group
Productivity – Yielding favorable or useful results



Universal Enhancement

Natural Consequation

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



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
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Universal Enhancement

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 Peeler, Jr., "The Community Living Paper"

Universal Enhancement

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.

Universal Enhancement

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

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.

Universal Enhancement

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

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.




Universal Enhancement

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

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.

Universal Enhancement

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

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.

Universal Enhancement

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

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.

Universal Enhancement

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

Delivering the eulogy at the funeral of a young man who died before his dreams came true.



Always having the coffee pot on because people stop in often to visit.


Going to the local tavern on St. Patrick's Day to enjoy the music and the celebration.

Sharing dinner together and making a party out of washing the dishes.

Universal Enhancement

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

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.

Universal Enhancement

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.

Universal Enhancement


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

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 because he missed seeing you out this morning.

Universal Enhancement

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

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.

Universal Enhancement

Images of Life In The Community (cont'd.)

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.

Jack Pealer, Jr. "The Community Living Paper"

Universal Enhancement

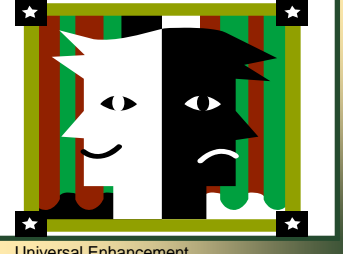
When Life Has Changed

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"

Universal Enhancement

We Discovered His Personality



Universal Enhancement

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?



Universal Enhancement

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." Walt Wolfensberger




How do we assist people to obtain socially valued roles?

Universal Enhancement

Values of Universal Enhancement


Life is Uncertain: Eat Dessert First




Best Vitamin for Having Friends: B-1

Universal Enhancement


Being Connected



Grocery



Joe's Burgers




Universal Enhancement

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





Universal Enhancement

Consumer

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

Consumer	Limited Means
Chrysler Mini Van	Public Transportation
Food Lion	Food Pantry
Hair Salon	Family/Friends Cut hair
Housekeepers/cooks	Do It Yourself
Washer and Dryer	Laundromat
Penny's, Sears	Second hand shops
Home Telephone	Pay phone at corner

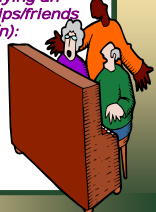



Universal Enhancement

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):

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



Universal Enhancement

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...



Universal Enhancement

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?



Universal Enhancement

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



Universal Enhancement


Being In Is Not Enough

IN the Community vs. OF the Community

Present;
Located;
There

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



Universal Enhancement

Whose Community?

When support staff "bring" a support recipient into their personal life by...

- taking them to their church;
- having them visit with their family;
- inviting them to their holiday functions;
- having them be with their friends;

...what happens to these relationships when the staff move on?




Universal Enhancement

Dear Friend...

Dear Friend:

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



Wow! There aren't enough homes! In our metropolitan areas, 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 are designed to last a lifetime. Currently, 90 residents live in 20 Rainbow Village Homes located throughout the state. Help us help more people this year by sending your tax deductible gift in the enclosed envelope. Thank you.

Sincerely,
President

Universal Enhancement

Inclusion Makes A Difference

Taken from "Journey to Inclusion"

Universal Enhancement

Community Presence

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

Community Presence (cont'd)

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 Swartzenger 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 humane society.

Universal Enhancement

Community Presence (cont'd)

I 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.

Now that I have hit the big "60+," my focus in life has shifted. AARP offers me the opportunity to receive literature containing information helpful in assessing my options for retirement.

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.

Universal Enhancement

"I Am Somebody!"

Universal Enhancement

Burden

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

Universal Enhancement

Making Introductions

Making introductions is an essential skill for support staff.

Paul, I would like you to meet Ed.

Universal Enhancement

Community Referencing

Bob, are you ready to get in the pool?

To be accepted - it helps to know the territory.

Universal Enhancement

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?
- get stylish hairstyles?

"Sue, your hair looks great and I really like your new cologne."

Universal Enhancement

Pockets and Purses

Items Carried:
String
Apple core
Styrofoam cup



Items Carried:
Wallet
Key
Case
Comb
Pen


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

Universal Enhancement

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!

Universal Enhancement


Social Capital

Many people with disabilities are socially bankrupt!
Help them obtain social capital by:

- Connecting with people of status
- Generating wealth
- Gaining competence
- Working in respected positions

Respect
Status

Invest in their future!




Universal Enhancement

Avoidance of Humiliation

The primary responsibility of support staff is to avoid at all cost, the public humiliation of the people they support.

How do the people you support look in the eyes of others?

Is that guy weird looking or what?!




Universal Enhancement

Bonding

Where would you like to go to dinner tonight?

In order to have a friend - You must be one!



Universal Enhancement

This Is A Quality Relationship?

"They are my clients"
"I am assigned to them"
"These are my cases"

"These clients are mine tonight!"
"I'm taking care of those clients"
"I'm in charge of these three"

"I have them"

"I'm over this group"

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




Universal Enhancement

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	Sly	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.




Universal Enhancement

Seeing The Individual (cont'd)

How do you see the people you support?

Violent	Manipulative
Addictive	Angry
Destructive	Obstinate
Obsessive	Aggressive
Defiant	Hostile
Vulgar	Promiscuous
Deceptive	Disgusting



Universal Enhancement

Building Relationships

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

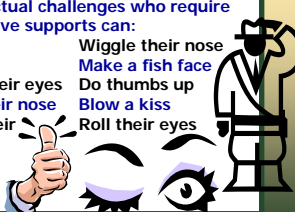


Universal Enhancement

Objectives In An ISP

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

Salute	Wiggle their nose
Wink	Make a fish face
Cross their eyes	Do thumbs up
Hold their nose	Blow a kiss
Snap their fingers	Roll their eyes




Universal Enhancement

Objectives In An ISP (contd)

Make a pig nose	Click their tongue
Whistle	Give the power sign
Make a snoring sound	Give the victory sign
Crack their knuckles	Thumb their noses
Give a high five	Give a "wencher"

What does that mean?



Universal Enhancement

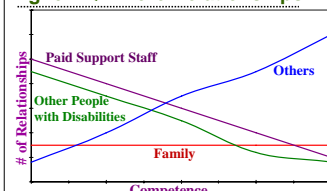
Sentiments



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

Universal Enhancement

Higher IQ—More Relationships



The more competent and capable the person, the greater number of relationships that are likely to be formed.

Universal Enhancement

Being Missed



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

Universal Enhancement

Who Do You Love and Who Loves You?



Universal Enhancement

Community

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




---John O'Brien

Universal Enhancement

Friendship

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

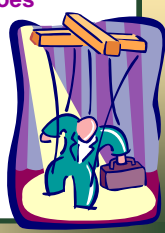


Aristotle

Universal Enhancement

Independence

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



Judy Heumann, Assistant Secretary of Special Education and Rehabilitation Services

Universal Enhancement

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 kindly cherished memories
- Supporting others in the grieving process

Universal Enhancement

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.

Universal Enhancement

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



Focuses on identifying and providing the supports and assistance an individual may need in order to participate


Universal Enhancement

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.



Universal Enhancement

Inclusionary Model (cont'd.)

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

Universal Enhancement

Humor



LEFT: Dennis Pletcher uses his kitchen fingers to help cutting off bread
Dennis Pletcher is playful during a lunch break at Lafayette Work Center.

Universal Enhancement

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

Universal Enhancement

Inclusionary Model (cont'd.)

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

Universal Enhancement



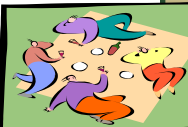
LEFT: Scott Sellers is working out on a Nautilus machine at the West County YMCA in Chesterfield.

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



Universal Enhancement

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 Begins" a handbook on Inclusive Education, Edward South School, Syracuse, NY, March 1991.

Universal Enhancement

Living Independently



Universal Enhancement

Inclusion is asking for people...not just about them.




Universal Enhancement

Don't advocate for people. Advocate with them.



Universal Enhancement

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

Universal Enhancement