Enhancing Quality of Life:

Strategies for Meeting and Exceeding the Home and Community Based Waiver Final Rule



Kern Regional Center
With Thomas E Pomeranz, Ed.D.



California Corrective Action Plan CAP

 The State of California is NOT in compliance with the Finale HCBW Rule as of this date

- Only 11 states will be able to meet the Finale Rule as of March 17, 2023
- The Statewide Transition Plan STP's terminated March 17, 2023
 - California submitted a Corrective Action
 Plan (CAP) through June 30, 2024,
 to fully demonstrate compliance

It is recognized by some states that it will be necessary to transfer Waiver Recipients from those Providers who fail to meet the Finale Rule by the CAP's termination

California

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California Corrective Action Plan CAP

Ensuring individuals have

The State is requesting an extension through June 2024 to implement the following regulatory criteria:



 Ensuring individuals have the option for a private room and/or choice of roommate

California

Ensuring individuals have a choice of non-disability specific settings

The Dog

The dog has finally caught up with the car!





What Is Right What is right is not always popular; what is popular is not always right.



The Bus

The paradigm is shifting, you can either be on the bus or under it.



OR



Best Practices Bestelle Assure those Best already **Practices** occur are in your **Pervasive** organization and constant!

Best Practice (cont'd)



Doing the RIGHT thing

with ALL the people

ALL the time!

Talk vs Actions Actions

Voice

I can not hear what you are saying; your actions are drowning out your voice.

Wolf Wolfensberger

Culture Shift

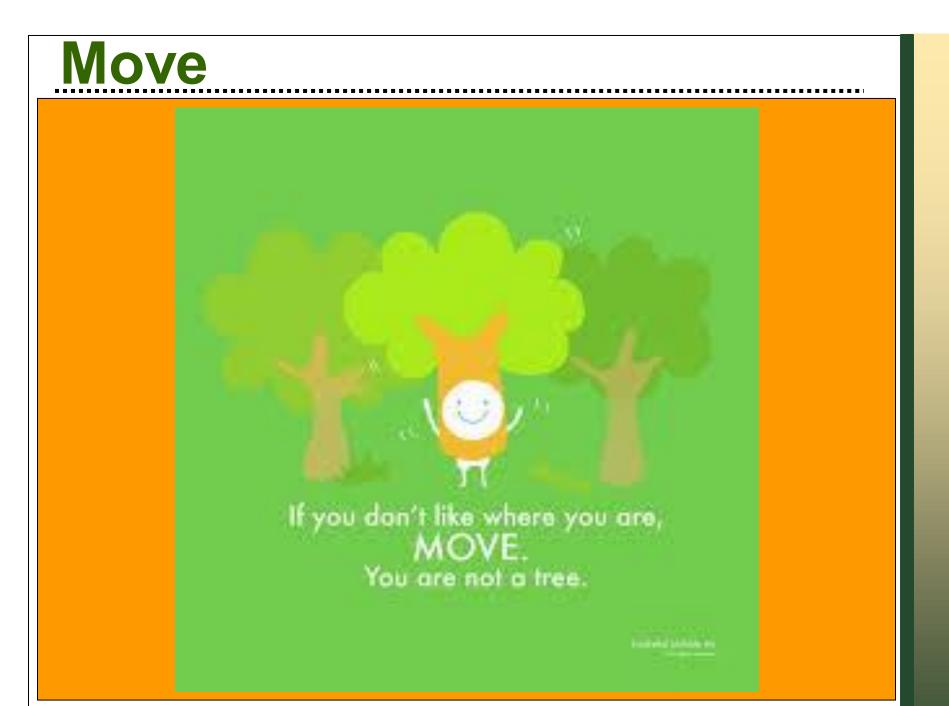
You cannot change a culture simply by buying new tools, sending people to training or asking them to change.

If you want to change your work culture, you have to change the work systems that created that culture in

the first place and have been shaping it every day from

that point forward!





Shift Happens

Whether you want it or not. Whether you expect it or not. Whether you participate in it or not.....



Shift Happens (cont'd)

Shift does indeed hannen

It is critical to identify the beliefs, demonstrate the behaviors and apply the skills that will support

As a result, we need to work HARD to use what we know about the change process to help to deal effectively with major shifts in people's professional and personal lives.

George Suess, CEO, ARC of Delaware County & Consultant

Monkey or Monk

Monkey Mind

- Overwhelmed by multiple branc
- Coasts in the passenger se
- Complains, compares, criti
- Overthinks & procrast nate
- Short term gratification
- Demanding & entitled
- Changes in whim
- Amplifies negatives & fear
- Self –centered & obsessed
- Multitasking
- Controlled by angry, worry &
- Does whatever feels good
- Looks for pleasure
- Looks for temporary fixes

Monk Mind

- Focused on the root of the issue
- Lives intentionally & consciously
- Compassionate, caring, collaborative
- Analyses & articulates
- Disciplined
- Long term gains
- Enthusiastic, determined, patient
- Commits to a mission, vision or goals
- Works for breaking down negatives
- Self-care for service
- Single tasking
- Controls & engages energy wisely
- Seeks self-control & mastery

Universal Enhancement

Looks for meaning

Looks for genuine solutions

Are You Somebody?

I used to ask "why dogs somebody do something about that?" Then I realized that I was somebody!

It Must Be Considered

"It must be considered that there is **nothing more** difficult to carry out, nor more doubtful of success, nor more dangerous to handle, than to initiate a new order of things. For the reformer has enemies in all those who profit by the old order, and only lukewarm defenders in all those who would profit by the new order, this lukewarmedness arising partly from fear of their adversaries, who have the laws in their favor; and partly from the incredulity of mankind, who do not truly believe in anything new until they have had actual experience of it. Thus it arises that on every opportunity for attacking the reformer, his opponents do so with the zeal of partisans, the others only defend him halfheartedly, so that between them he runs great danger."

Chapter VI, The Prince, Niccolo Machiavelli



"Great spirits have always encountered violent opposition from mediocre minds."

Albert Einstein



A New Direction

IF YOU ALWAYS DO What you have always DONE,



Being Changed People do not resist change. They resist being changed. **Universal Enhancement**

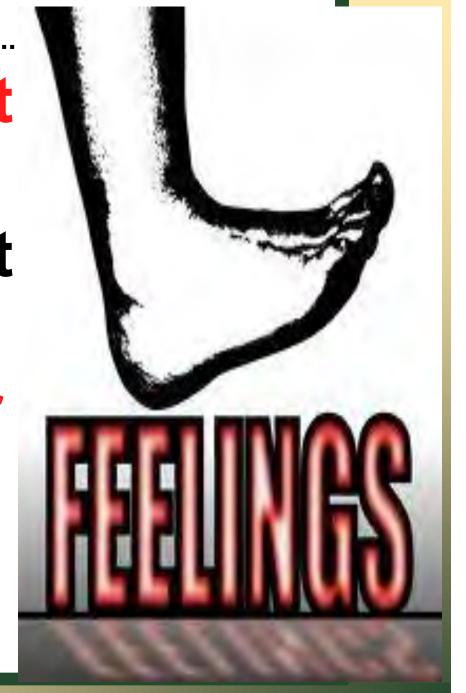
Say, Do, Feel

People will forget what you said.

People will forget what you did.

People will never forget how you made them feel!

Maya Angelou



What's First

R before I or T

Relationships before

Issues
Or
Tasks



The Effective Reformer

Be radical With your vision,





conservative with your action.

Burton Blatt

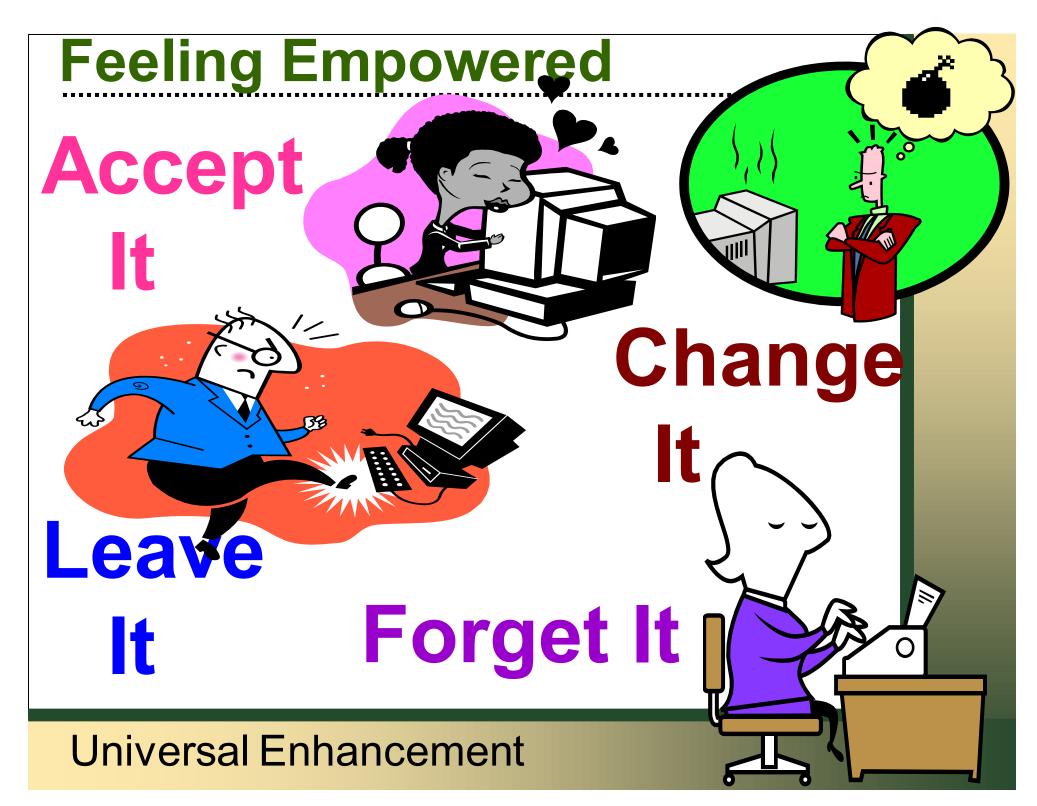
Challenge The Process

Knowing how to rock the boat without sinking it, is the challenge!





Vision Where there is no vision people perish." Proverbs 29: 18 **King James**



Change Something



Buckminster Fuller

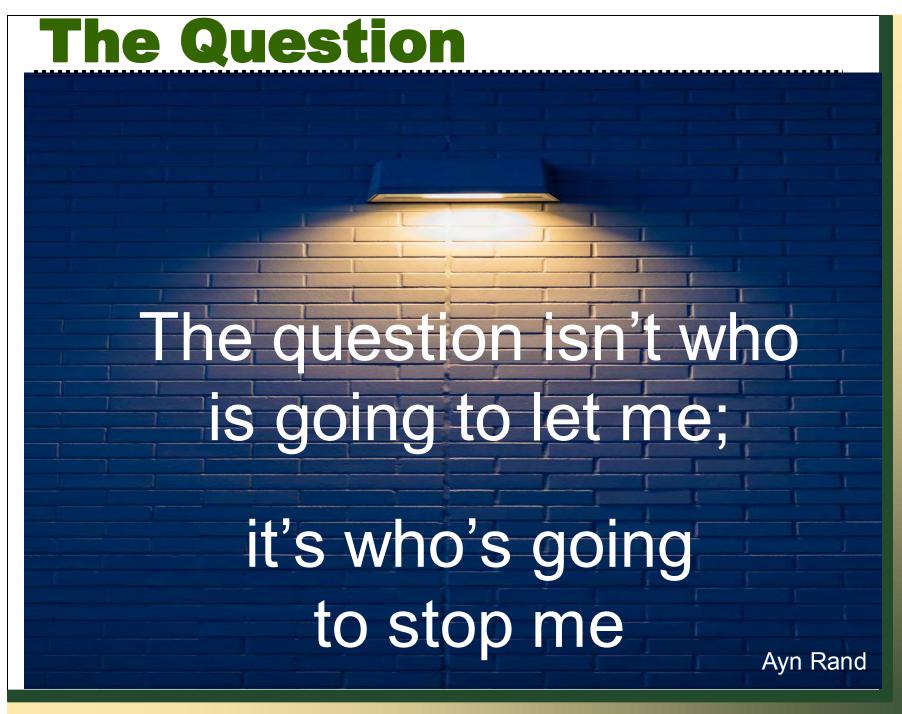
"You never change things by fighting the existing reality. To change something, build a new model that makes the existing model obsolete."

Coercion Is Not Conversion

When shifting an organization's culture or expecting staff to embrace new Cooperation requires respect. practices... Coercion Coercion is demands terror

Universal Enhancement

not Conversion.



Make It Happen

If it is not illegal, immoral or unethical...



Is it better to err and ask for forgiveness, than not to have acted at all?

Olmstead Act

In OLMSTEAD V. L. C. (98-536) 527 U.S. 581 (1999) ("The Olmstead Decision"), the Supreme Court construct (1994) ("The Olmstead Decision"), the Supreme Court construct (1995) ("The Olmste

The Department of Justice regulations implementing the II of the AD equire public entities to admit their sections, programs and activities in the most use setting appropriate to the needs of qualified individuals with disabilities.

Olmstead Act (cont'd)

The decision effects not only all persons in institutions and segregated settings, but also people with disabilities who are at risk of institutionalization, including people with disabilities on waiting lists to receive community based services and supports.



Olmstead Act (cont'd)

Translation:

People with disabilities must receive services and supports in the least restrictive community setting.





Medicaid Transitions



On July 30, 1965, President Lyndon B. Johnson signed into law legislation that established the Medicare and Medicaid programs.

Medicaid is a joint federal-state program that provides health coverage or nursing home coverage to certain categories of low-asset people. It is a means-tested program.

Intermediate Care Facilities for Individuals with

Developmental Disabilities (ICF/MR) is a disability benefit
that is offered through United States Medicaid funding.
Section 1905(d) of the Social Security Act enacted benefits
and made funding available for "institutions" (which
consisted of four or more beds) for individuals with "MR" or
other developmental disabilities.

Faith



Medicaid Transitions (cont'd...)

Medicaid Waiver programs help provide services to people who would otherwise be in an institution, nursing home or hospital to receive long-term care in the community. Prior to 1991, the Federal Medicaid program paid for services only if a person lived in an institution – referred to as a setting rule. Under a Medicaid Waiver, the state can waive certain Medicaid program requirements.



The New CMS HCBS Rules

The New CMS HCBS set expectations for setting in which HCBS residential and day services can be provided. The rule requires that "community-like" setting be defined by the nature and quality of the experiences of the individual receiving the services.

In all settings, the rule requires that:

-The setting is selected by the individuals from options that include non-disability specific settings and options for privacy in residential settings. (e.g. a private room or unit).

Individuals must have choice of providers, services and setting and that choice must be documented by a person-centered plan.

-Each person has the right to privacy, is treated with dignity and respect and is free from restraint.

The New HCBS Rules (cont'd)

-People have optimal opportunity for independence in making life choices without regimented daily activities; can access their physical environment and may interact with family and friends, just as people who are not receiving home and community based services do.

In residential settings owned or controlled by a service provider, additional requirements must be met:

-Each individual must have the same responsibilities and protections from eviction that tenants have under state or local landlord/tenant laws. If such laws do not apply, a lease or other legally binding agreement is in place to provide those protections.



The New CMS HCBS Rules (cont'd)

- -Each individual must have privacy in their sleeping or living unit, with a lock and key controlled by the individual and appropriate staff.
- -Individuals must be allowed to furnish and decorate their own sleeping and living areas, to have access to food at any time, and to have visitors of their choosing at any time.
- -Individuals sharing a living unit must have choice of roommate.

These requirements may only be modified if the individual has a need that justifies deviation that is documented in the individual's person-centered plan.

HCBS cannot be provided in settings that include: hospitals, skilled nursing facilities, institutions for mental disease and ICFs.



New CMS HCBS Rules (cont'd)

The rule also defines settings that are "likely not" community-like. CMS requires states to provide justification that these settings are not institutional in nature. Justification must include input from the public. CMS requires approval of settings that fall into one or

more of the following categories:

-"Any setting that is located in a building that is a publicly or privately operated facility that provides inpatient institutional treatment;

-A building on the grounds of, or immediately adjacent to, a public institution; or -Any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS."



CMS Transition Plan Requirements

The new CMS rules require states to submit a transition plan within one year of the March 17, 2014 effective date. The transition plan must describe the process by which the state will ensure that service settings used in each of its HCBS waivers meet community-like expectations. States may be granted a maximum of five years to transition settings that are not compliant.

States in the process of amending or renewing a waiver must submit a transition plan with the waiver amendments or renewal. Within 120 days of submitting an amendment or renewal, the state must submit for CMS approval a comprehensive transition plan for all waivers.

The plan must be available for public comment for at least 30 days and be available from a minimum of two forms of public notice.

Reverse Integration

Federal Perspectives

CMS expressed concern that Kentucky "has added language suggesting that bringing individuals from the community into service settings — particularly non-residential settings — would enable them to meet the integration requirements of the HCBS settings rule."

CMS Grants Initial Approval to Kentucky and Ohio STPs; Expresses Concern About Reverse Integration

The Centers for Medicare & Medicaid approval to two more Statewide Transition Plans (STPs), Kentucky's and Ohio's, shortly after giving final approval for the first time, to Tennessee's STP, in documents attached to Kentucky's initial approval letter, CMS gave the clearest picture so far of its stance on "reverse integration." the practice of bringing individuals from the broader community to a disability setting in order to achieve the integration requirements of the HCBS Rule.

CMS expressed concern that Kentucky "has added language suggesting that bringing individuals from the community into service settings — particularly non-residential settings — would enable them to meet the integration requirements of the HCBS settings rule," The agency states directly that "states cannot comply with the rule simply by bringing individuals without disabilities from the community into a setting; compliance requires a plan to integrate beneficiaries into the broader community." CMS says "reverse integration, or a model of intentionally inviting individuals not receiving HCBS into a facility-based setting to

participate in activities with HCBS beneficiaries is not considered by CMS in itself to be a sufficient strategy for complying with the community integration requirements outlined in the HCBS settings rule." Under the rule, "with respect to non-residential settings providing day activities, the setting should ensure that individuals have the opportunity to interact with the broader community of non-HCBS recipients, and provide opportunities to participate in activities that are not solely designed for people with disabilities or HCBS beneficiaries that are aging but rather for the broader community. Settings "cannot comply with the community integration requirements of the rule simply by only hiring, recruiting, or inviting individuals who are not HCBS recipients into the setting to participate in activities that a non-HCBS individual would normally take part of in a typical community setting."

FMI Kentucky's initial approval letter is available at https://www.medicaid.chip-program-information/.pdf.%

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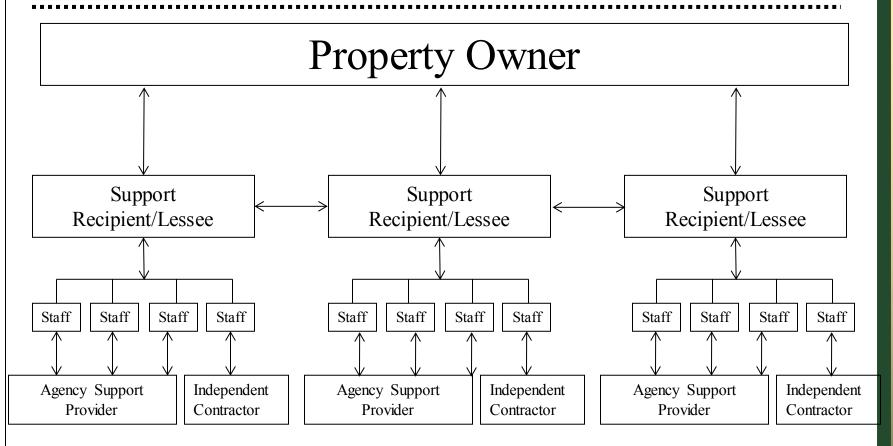
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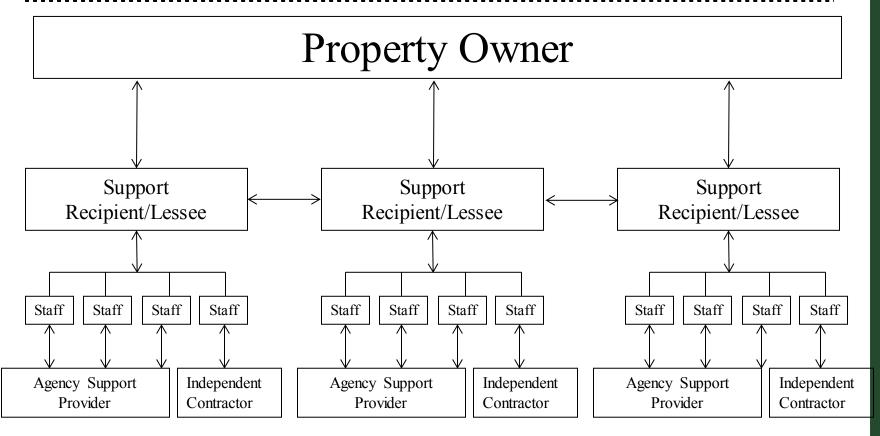
Universal Enhancement

NASDDDS National Association of State Directors of Develo

Let's Unwind It



The property owner may be the: resident/s, resident's family/s, agency, support provider, unknown and unrelated entities, housing foundation, HUD, etc.



The support recipient/lessee must be afforded the same rights and responsibilities as any lessee would be accorded by virtue of law. Additionally, all covenants and ordinances as standing are applicable.



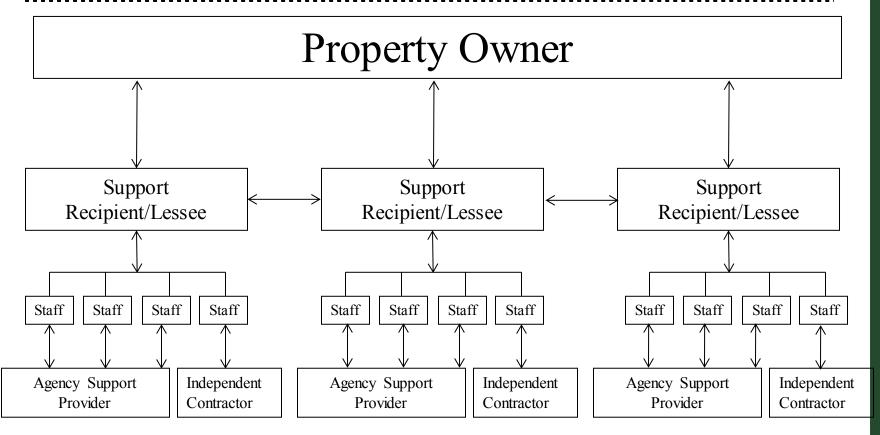
Office or Home? (cont'd)



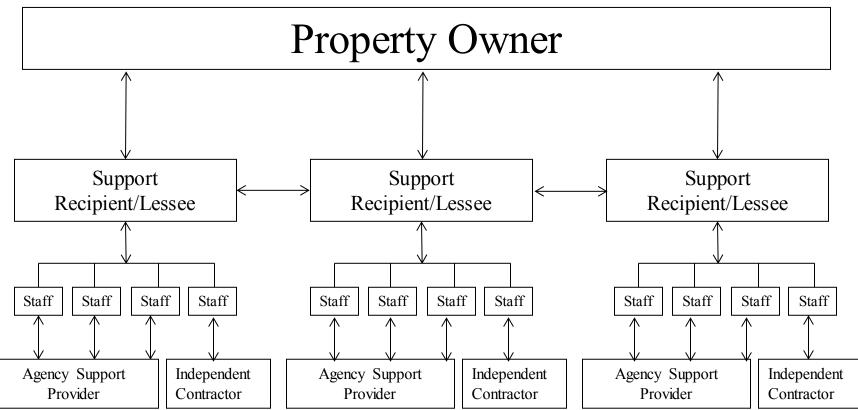
Office or Home? (cont'd)



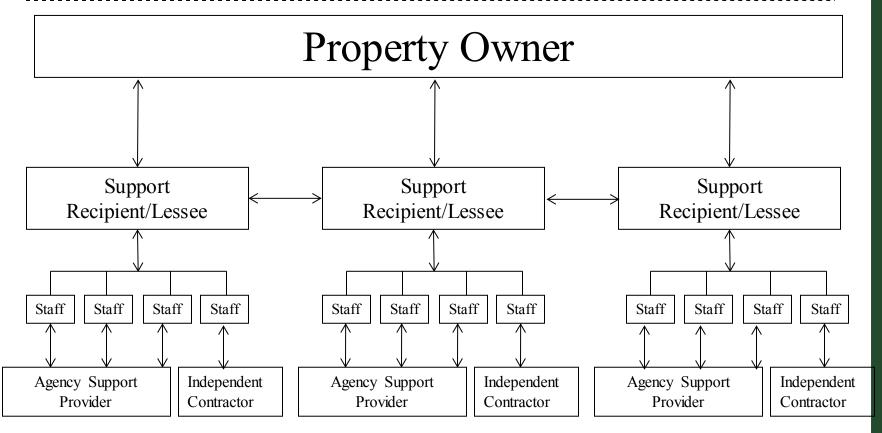
To meet the office needs of a Home Manager without intruding upon the residents?



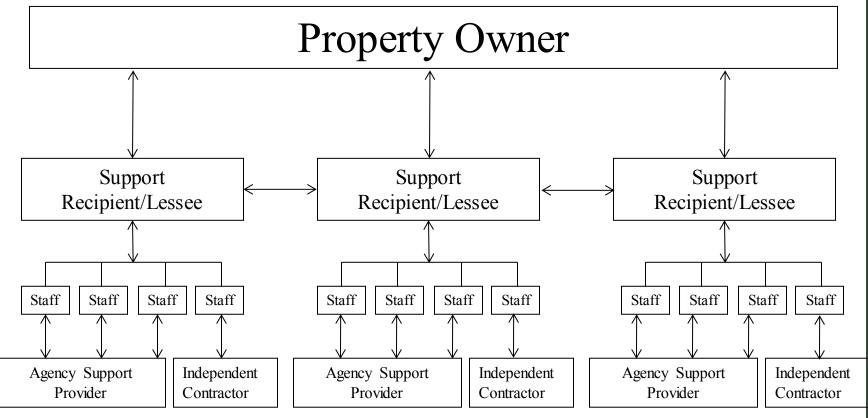
The Lessee's cohabitation should be a function of preference or fiscal necessity. Each housemate shall determine with whom they reside. Cohabitation should hold only the expectation of "sharing space not lives", unless so preferred.



The lessee/s shall have full authority to hire and "fire" the staff who provide the support. Though a lessee may utilize several support staff, said staff may be from the same agency, different agencies or independent contractors. If the support recipient cohabitates with another individual, who also requires support, each of their support staff may be hired, evaluated and terminated independently of each other.



Unless otherwise specified by HCBW Regulation, the Support Staff may be a personal friend, family member or acquaintance acting as an independent contractor. Their obligation, duties and responsibilities are determined by the contractual relationship established between the Support Recipient and the staff.



The Support Provider's relationship with the Support Recipient is "at will"; meaning the Support Recipient may sever any and all relationships specified by the contract.

Me: ❖ Chose where you live? _. Chose who you live with? Have personal space and time alone? Come and go as you please? Set your own schedule? Choose how to spend your money? Choose who cuts your hair? Choose which grocery store you go to? Choose which pharmacy you use? Choose which doctor you see? Chose where you work Choose which church/religious service (if any) you attend?

HCBW Finale Rule Values GREAY Free from Restraint Assure Privacy Choice of Provider Choice of Setting Generic Supports **Non-Regimented Routines** Respect and Dignity California **Accessible Settings** © WorldAtlas.com **Integrated Life**

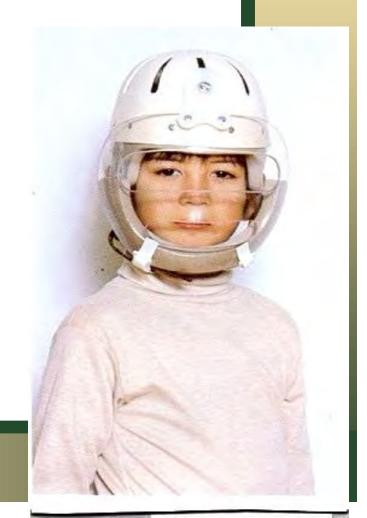
Inclusionary Opportunities

There are four types of restraints:

- * Physical * Mechanical
- * Chemical * Environmental
- Restraint is neither good nor bad, it depends upon how, why, when and where it is used
- It is always frequently difficult, if not impossible, to know the purpose of a restraint by merely looking
- In all incidences, the use of restraint requires the review assessment by trained and experienced clinicians/professionals to assure appropriate use
- Whenever restraint is authorized, it is essential that is consistent with all policy and regulatory

Freedom Of Movement Controlling vocalizations restrict movement! **Put that** down!! Leave him alone!! Come here!! Universal Enhancement

Mechanical Restraint A device to impair bodily movement:



Restraint



Is this person secure or behaviorally restrained? **Neither** explanation is acceptable.

Fooling The Surveyors

Mechanical restraints for behavioral purposes, in violation of regulatory requirements and the individual's rights.



The Great Houdini





Even Houdini himself wouldn't be able to get out of this mechanical restraint if he had significant limitations in grasping as a result of cerebral palsy.

Least Restrictive



This Plexiglass restraint was designed for a young man who engages in extreme self injurious behavior. He has blinded himself in one eye, knocked out several teeth and caused serious damage to his ears. Many alternatives were attempted to address his needs and thus eliminate the SIB.

Unfortunately, none were successful. This restraint allows him to see his hands, move them freely within the Plexiglass area and manipulate items.

Mechanical Restraint

A device to impair bodily movement:

-For positioning and body alignment



Arm Restraint



This is an excellent example of a mechanical arm restraint used for the purpose of positioning and as a medical protective device. This individual, as a result of his Cerebral Palsy, engages in severe extension and flailing arms. That movement has resulted in injury to his arms by hitting door frames and walls. This restraint keeps him safe.

Mechanical Restraint

A device to impair bodily movement:

- -For positioning and body alignment
- -As a medical protective device



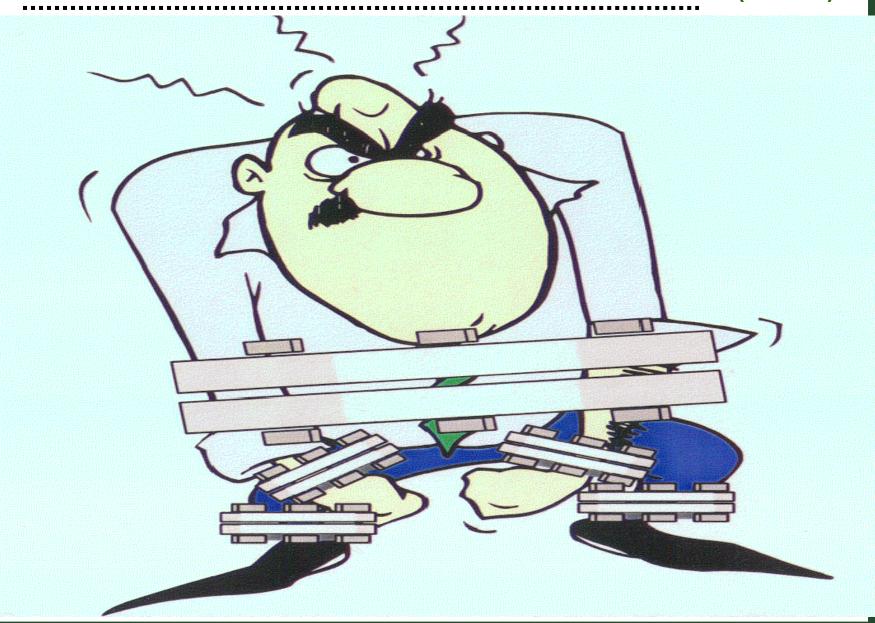
Medical Protective Restraint



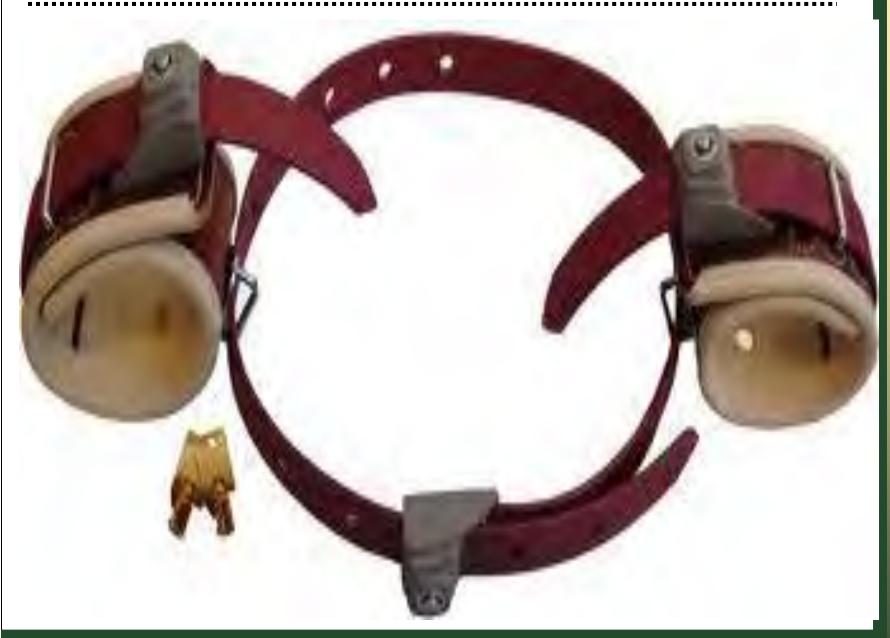
Mechanical Restraint (cont'd)

- A device to impair bodily movement:
- -For positioning and body alignment
- -As a medical protective device
- -To consequate behavior
- -For crises

Crisis Mechanical Restraint (cont'd)



Crisis Mechanical Restraint



Crisis Mechanical Restraint



Five Point Restraint



Used in psychiatric hospitals when an individual is highly

Crisis Restraint

Used only in extreme situations, such as an individual on hallucinogenic drugs who is a danger to themselves or others.



This Is No Joke THINK HE JUST MOVED! BDD ONE MORE!"

Chemical Restraint





Drugs Used on Aggression in Those With Low I.Q.'s Provide No Benefit, Study Says

By BENEDICT CAREY

The drugs most widely used to manage aggressive outbursts in intellectually disabled people are no more effective than placebos for most patients and may be less so, researchers report

The finding, being published Friday, sharply challenges standard medical practice in mental health clinics and nursing homes in the United States and around the world.

In recent years, many doctors have begun to use the so-called antipsychotic drugs, which were developed to treat schizophrenia. as all-purpose tranquilizers to settle threatening behavior - in children with attention-deficit problems, college students with depression, older people with Alzheimer's disease and intellectually handicapped people.

The new study tracked 86 adults with low I.Q.'s in community housing in England, Wales and Australia over more than a month of treatment. It found a 79

percent reduction in aggressive the widening use of antipsychotic behavior among those taking dummy pills, compared with a reduction of 65 percent or less in those taking antipsychotic drugs.

The researchers focused on two drugs, Risperdal by Janssen, and an older drug, Haldol, but said the findings almost certainly applied to all similar medications. Such drugs account for more than \$10 billion in annual sales, and research suggests that at least half of all prescriptions are for unapproved "off label" uses - often to treat aggression or irritation.

The authors said the results were quite likely to intensify calls or a government review of British treatment standards for such patients, and perhaps to prompt more careful study of treatment for aggressive behavior in patients with a wide variety of diag-

Other experts said the findings were also almost certain to inflame a continuing debate over

drugs. Patient advocates and some psychiatrists say the medications are overused.

Previous studies of the drugs' effect on aggressive outbursts have been mixed, with some showing little benefit and others a strong calming influence. But the drugs have serious side effects, including rapid weight gain and tremors, and doctors have had little rigorous evidence to guide practice.

"This is a very significant finding by some very prominent psychiatrists" - one that directly challenges the status quo, said Johnny L. Matson, a professor of psychology at Louisiana State University in Baton Rouge, coauthor of an editorial with the study in the journal Lancet.

While it is unclear how much the study by itself will alter prescribing habits, "the message to doctors should be, think twice about prescribing, go with lower doses and monitor side effects very carefully," Dr. Matson continued, adding:

"Or just don't do it. We know that behavioral treatments can work very well with many pa-

Other experts disagreed, say-

A finding challenges practices in clinics and nursing homes.

ing the new study was not in line with previous research or their own experience. Janssen, a Johnson & Johnson subsidiary, said that Risperdal only promotes approved uses, which in this country include the treatment of irritability associated with autism in

In the study, Dr. Peter J. Tyrer, a professor of psychiatry at Imperial College London, led a research team who assigned 86 people from ages 18 to 65 to one of three groups: one that received Risperdal; one that received another antipsychotic, the generic form of Haldol; and one that was given a placebo pill. Caregivers tracked the participants' behavior. Many people with very low I.Q.'s are quick to anger and lash out at others, bang their heads or fists into the wall in frustration. or singe the air with obscenities when annoyed.

After a month, people in all three groups had settled down, losing their temper less often and causing less damage when they did. Yet unexpectedly, those in the place o group improved the most, significantly more so than those on medication.

In an interview, Dr. Tyrer said there was no reason to believe that any other antipsychotic drug used for aggression, like Zyprexa from Eli Lilly or Seroquel from AstraZeneca, would be more effective. Being in the study, with all the extra attention it brought was itself what apparently made the difference, he said.

"These people tend to get so lit tle company normally," Dr. Tyrei said. "They're neglected, they tend to be pushed into the back ground, and this extra attention has a much bigger effect on them that it would on a person of more normal intelligence level."

The study authors, who included researchers from the Univer sity of Wales and the University of Birmingham'in Britain and the University of Queensland in Bris bane, Australia, wrote that their results "should not be interpreted as an indication that antipsy chotic drugs have no place in the treatment of some aspects of behavior disturbance."

But the routine prescription of the drugs for aggression, they concluded, "should no longer be regarded as a satisfactory form of care."

The drugs most widely used to manage aggressive outbursts in intellectually disabled people are no more effective than placebos for most patients and may be less so, researchers report.

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Universal Enhancement placebo group improved the most

Can't Prove It....

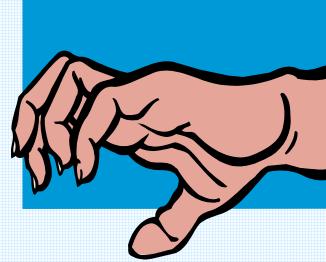
...but I believe that: 60% of all individuals with a primary diagnosis of developmental disabilities and a secondary diagnosis of mental illness have a "trumped up" diagnosis of the mental illness to meet best practice guidelines for prescribing medication. What do you think?

Physical Restraint

Impairing another's bodily movements by using your own body:

To enhance developmental competence

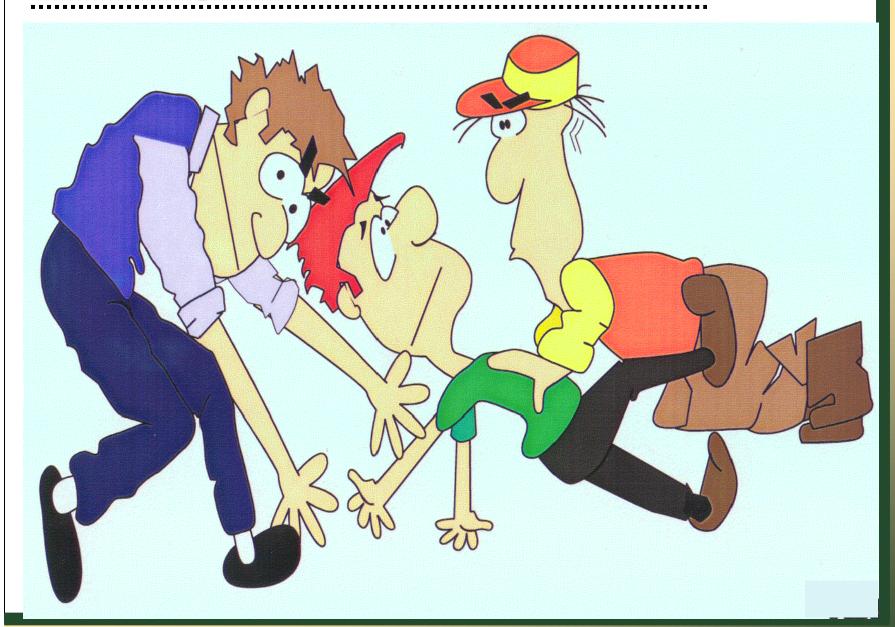
To protect from harm



Prone Physical Restraint



Therapeutic Hold



Physical Restraint

Impairing another's bodily movements by using your own body:

To enhance developmental competence

To protect from harm

To consequate behavior - contingently applied



Assure Privacy

The state of being free of public attention

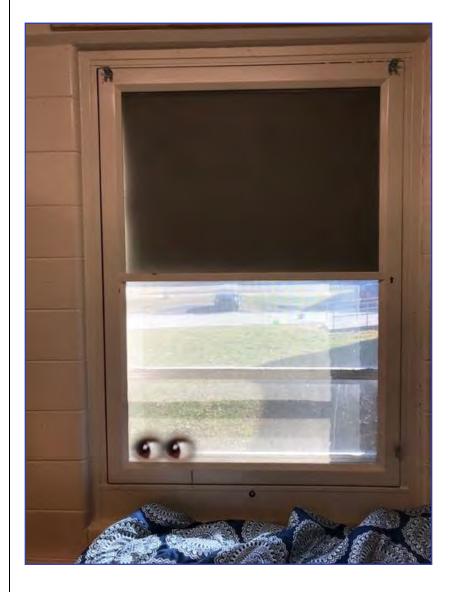


Privacy helps us establish boundaries to limit who has access to our bodies, places and things. It is a fundamental right, essential to autonomy and the protection of human dignity, serving as the foundation upon which many other human rights are built.

The ability of an individual to SECLUDE THEMSELVES or INFORMATION ABOUT THEMSELVES

Privacy is essential to who we are as human beings!

Look Here

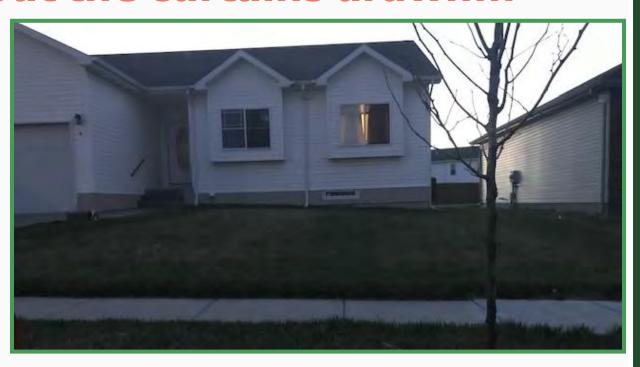


Even though this window has a partial screen, it does nothing to promote privacy. There is a direct line of sight from the street to the bedroom.

For All To See

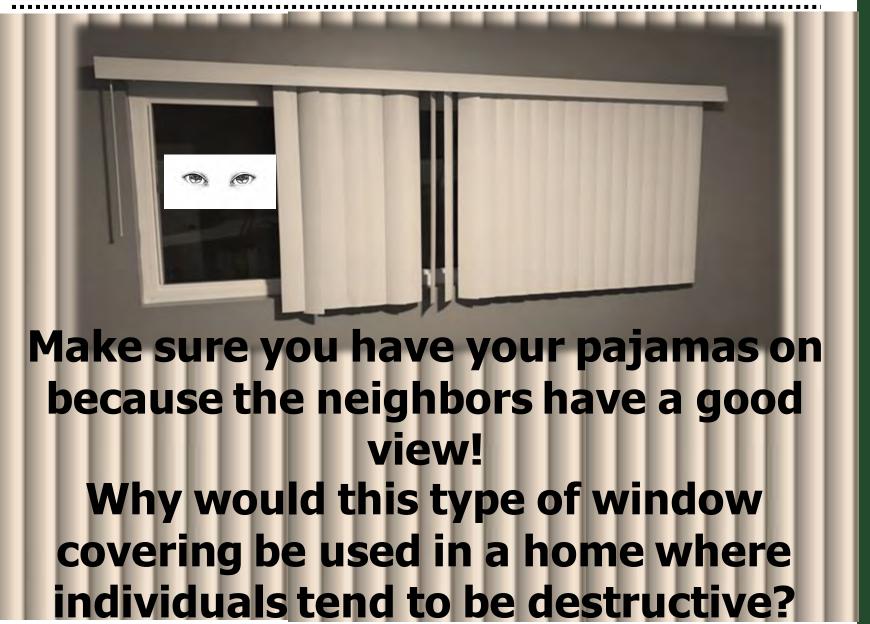
Three women live in this two bedroom home that faces the street. One resident was getting dressed in the early morning, in front of her window without the curtains drawn...





Bedroom Door? As astonishing as it may seem, the bedrooms in this residence have no doors thus no privacy. This is a residence licensed by the state.

Peekaboo



Privacy

Nothing like everyone knowing your "business"

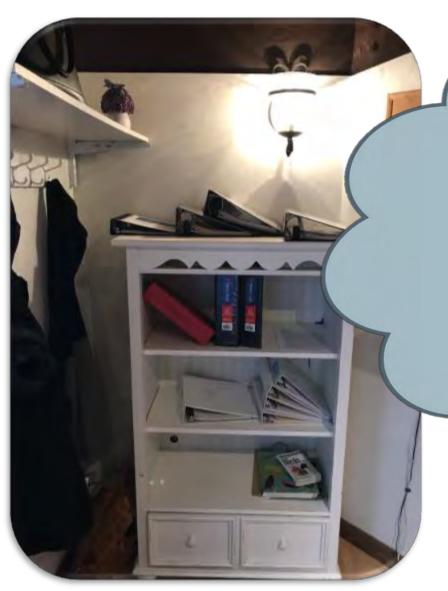


HIPAA

This garage is used as an office for the residential manager of this home that supports three individuals. The garage door is frequently open with all the resident records unsecured.



Public Disclosure



These shift logs, notating the most intimate and personal information regarding the residents of this home, are readily accessible to all; a violation of HIPAA!

Public Disclosure (cont'd)



The program records of the four residents in this home are available to all. Their initials are on the books as a way of "suggesting" confidentiality.

Easy Access



The program records for the six residents in this home are situated in the dining room.

This location provides easy access for the staff to record data and shift notes.

Obviously, all involved seem to be unaware of HIPPA requirements which mandate securing such personal information.

Choice of Provider

A provider of HCBW services can be a person, or an organization

Organization

- Not for Profit
- For Profit
- Sectarian
- Non-Sectarian
- Governmental
- Quasi governmental

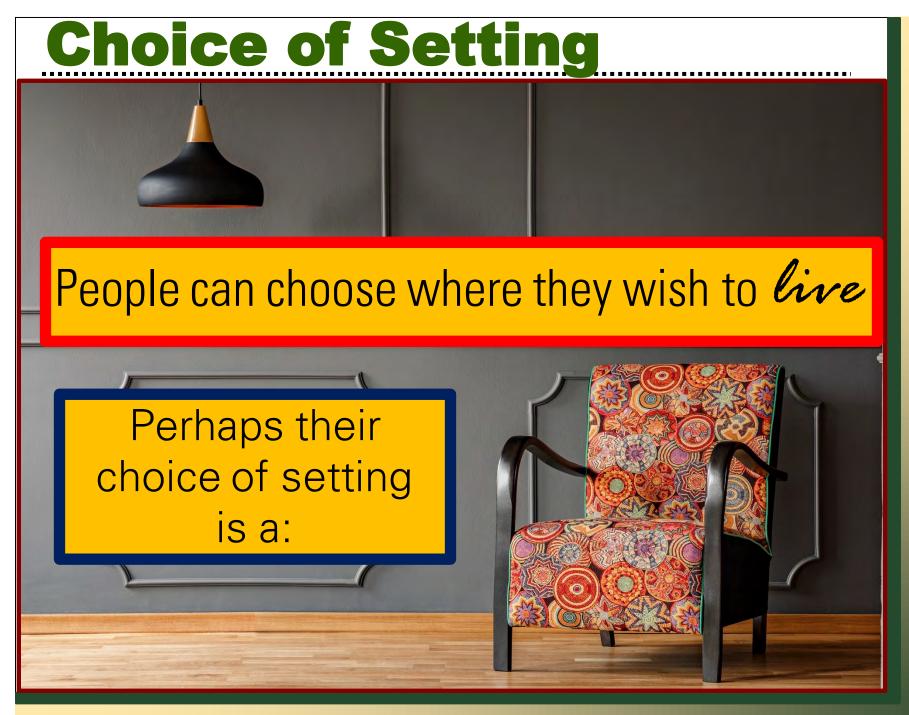




Person

- Professionally trained
- Friend
- Relative
 - -Spouse
 - -Parent
 - -Brother/Sister

The HCBW standard is that the Waiver Recipient can choose both the Organization they wish to provide them the staff, as well as the staff hired or contracted by the organization.



Choice of Setting (cont'd)

- Cabin in the woods
- Cottage on the lake
- Mobile home in a mobile home park
- Apartment
- Condominium
- Extended family home
- Shared living arrangement
- Parents or other family member











It's What's Inside That Counts

These are merely a façade:

Mobile home in a park

Farm in a rural area

Ranch house in the suburbs

Brownstone in the city

A-frame in the w

Cabin in the

mountains

Cottage on the lake

We all want to live in the same place: a place where we are treated with **DIGNITY** and **RESPECT**.

People for Places

The current service system is commonly characterized by "finding people for places."

We have a vacancy in our day program. Do you have a referral?

We have an empty bed. Do you have someone to place here?

In a person centered organization, supports are created and identified to meet the needs and desires of each individual.

It's the difference between:

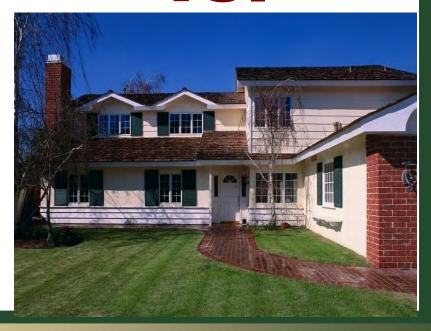
Places for People vs. People for Places

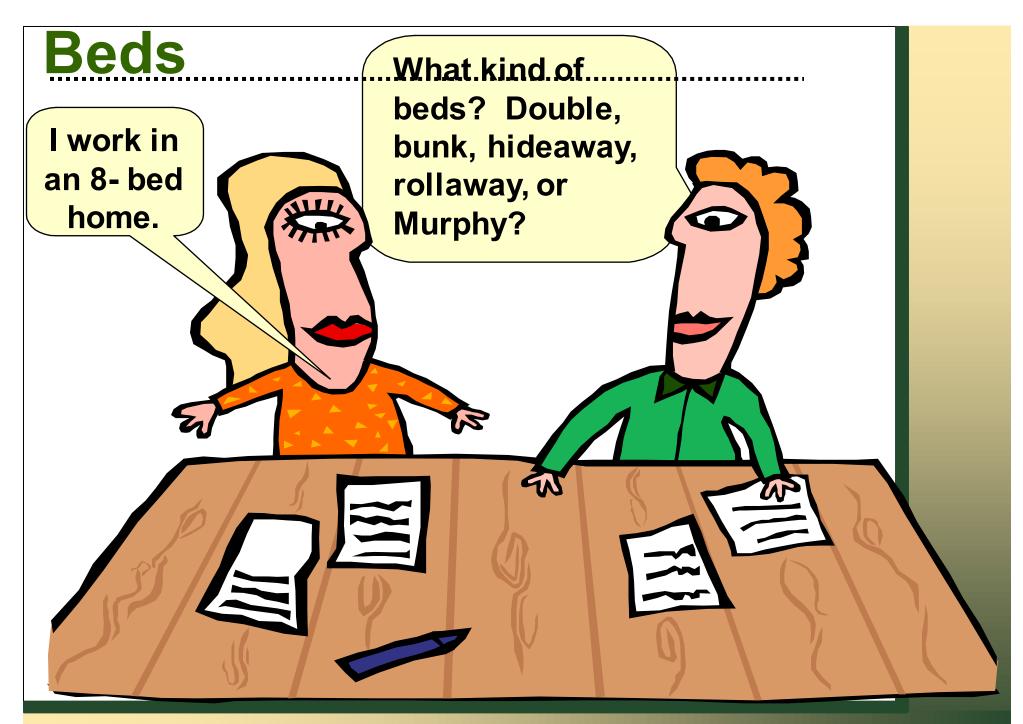
Choose One

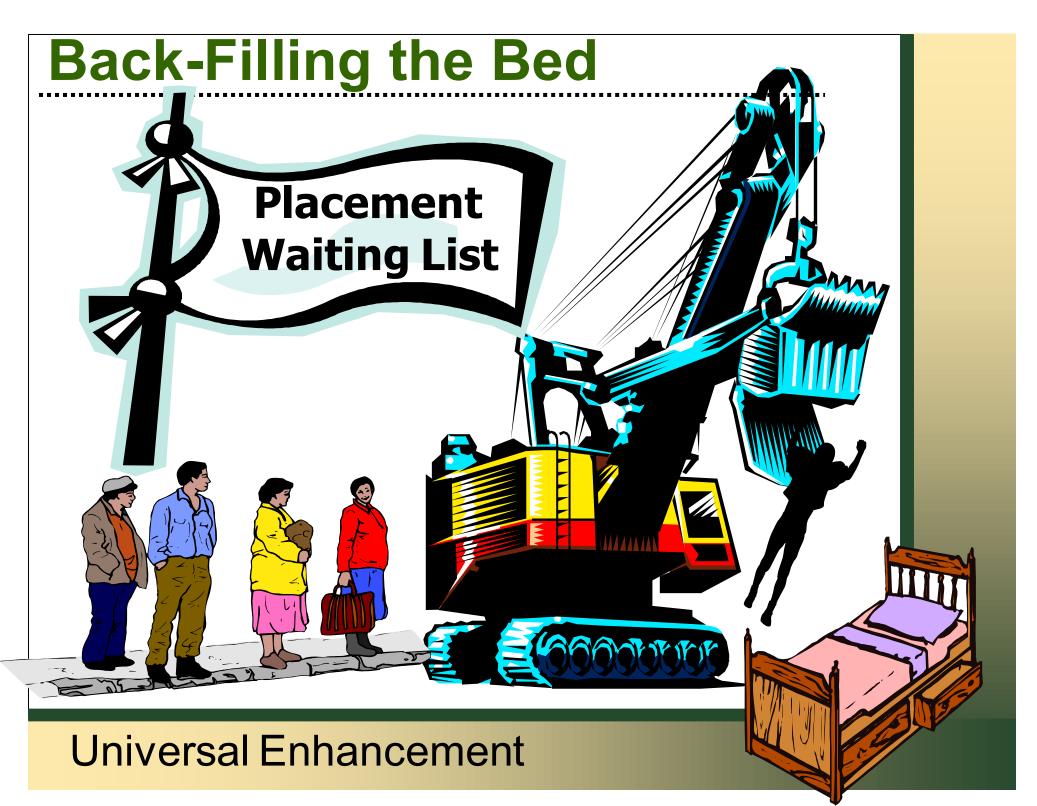
The difference is two little letters... In a home VS. At home



VS.







It's Their Home

Without the residents' permission, do you:

Answer their doorbell?
Use their bathroom?
Answer their phone?
Open their mail?
Sit on their beds?
Enter their bedrooms?

Not In My Living Room

People who are <u>in</u> a home rather than <u>at</u> home cannot keep their personal items in the living room for fear that they will be:

Stolen

Broken

Misplaced

Hoarded by others

That is not where I wish to live!



My Living Room



It's delightful to see that this individual can safely work on and maintain her jigsaw puzzle in the living room knowing that the other residents of her home will not disturb it.



Home



Group Home Stereotype

Group homes lead to stereotyping as is commonly the case with:

- Fraternities
- College Dormitories
- Convents
- Prisons
- Homeless Shelters
- Ghettos
- Nursing Homes
- Communes
- Half Way Houses
- Reform Schools



We all know who lives in each of these places – don't we?

Not A Home

Is there a defense or retort that can be made in response to these provocative statements?

•Group homes are a form of homelessness, they are pretend simulated homes.

Group homes are islands in a neighborhood

where the residents are marooned.

•Group homes lead to compromises,

either necessitated for the collective

good or to meet regulatory

demands, that most of us would

perceive as an insult!

Whenever you're ready, what's the defense?

What Is Home?

Each of us has a unique understanding of what makes a residence a **HOME**.

A place...

·where I feel loved.



- ·where I can express my individuality.
- ·that provides me a feeling of security.
- ·where my belongings and possessions are safe.
- ·that I take pride in.
- •that is always there to go back to retreat.
- ·that I call my own.
- ·that I share with family and friends.
- ·where I determine my rhythms and activities.



The place I wish to be when I take my last breath!

four Home? Check the items owned by residents in their "group home" living room: **Plants Awards** Religious artifacts Family photos Computer Radio Magazines Holiday decorations Mother's ashes Aquarium Why are these items maintained in their bedroom?

Freedom to Decorate...

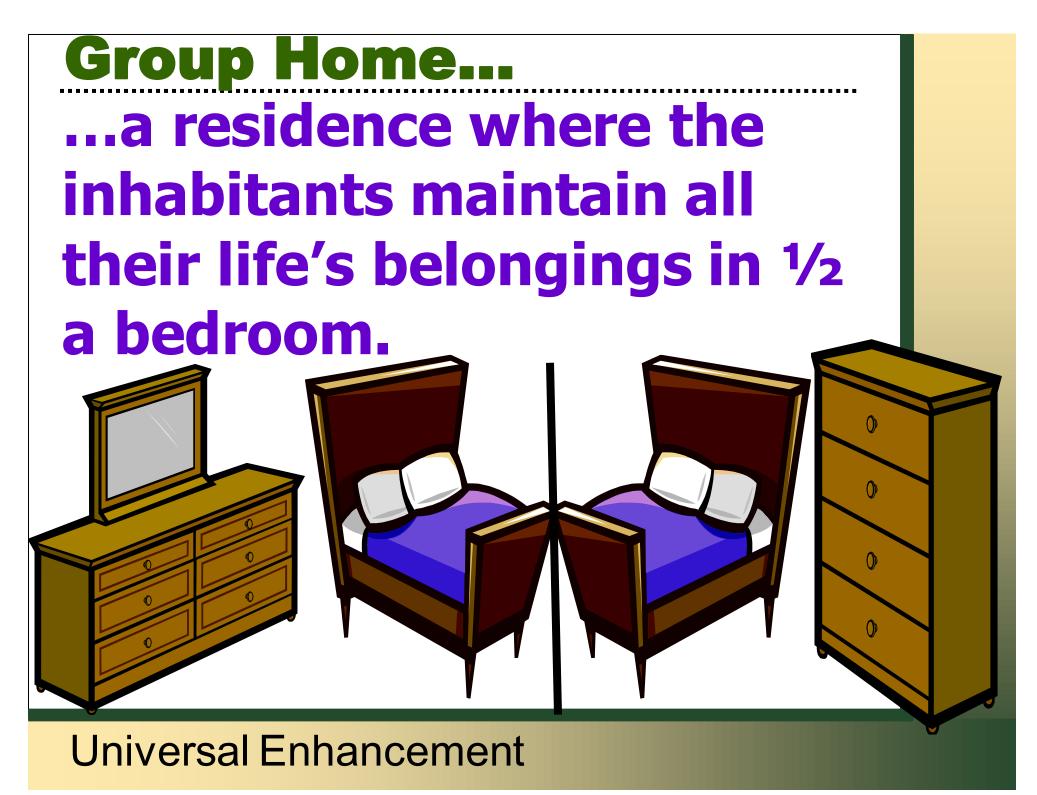


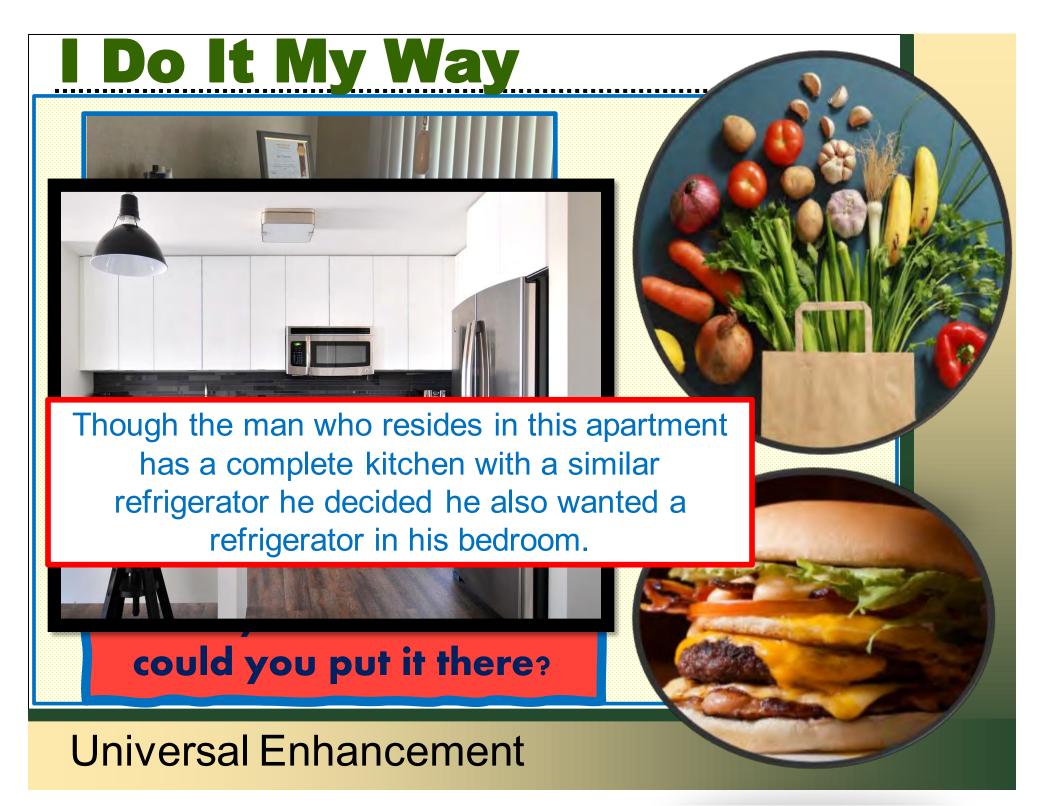
Freedom to Decorate...

If your housemates are indifferent to these personal displays, what gives your landlord the right to say, "you are not to do that".

Unless specified in the lease or

in the Individualized Support Plan!



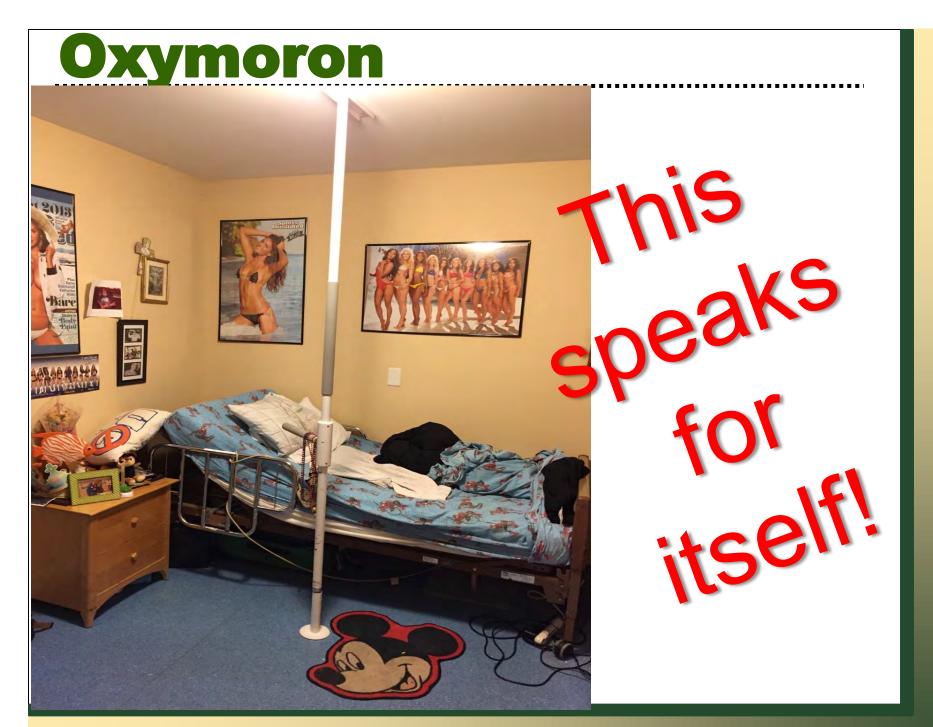


We're So Proud

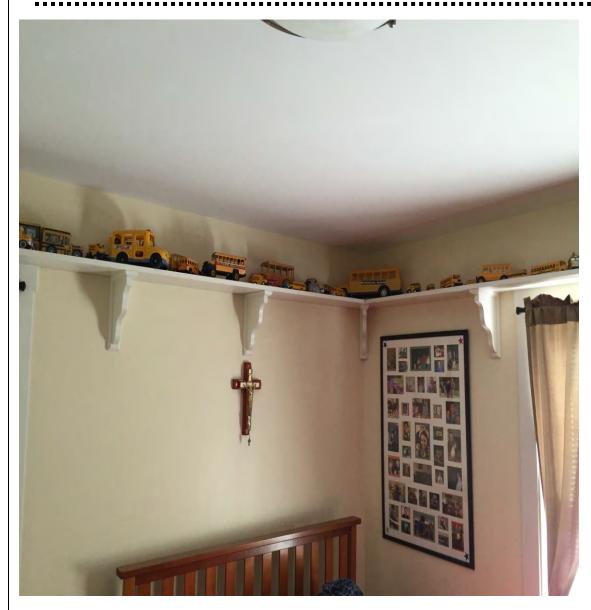
Unlike in many group homes where residents keep their personal possessions in their bedrooms, these individuals proudly display their special Olympic trophies on the mantle of their great room's fireplace.







Appropriate Display



A 40 year-old man with **Autism** is obsessed with yellow school buses. His obsession is sensitively met with this display.

Generic Supports



Means supports and services that are widely accepted and available for use by the general public





Generic Supports (Cont'd) Natural supports are personal associations and relationships typically developed in the community that enhance the quality and security of life for people, including, but not limited to, family relationships: friendships reflecting the diversity of the neighborhood and the community

Generic Supports (Cont'd)

- Food Bank
- Meals on Wheels
- Barber/Beauty College
- Customer Service Assistant
- Google Assistant
- Siri
- Pill Pack



Generic Supports (Cont'd)

- Supplemental Nutrition Assistance Program (SNAP)
- Program of All-Inclusive Care for the Elderly (PACE)
- Low Income Home Energy Assistance
- New Eyes for the Needy (Lions Club)
- Banking: digital banking apps, special accounts and accessibility services
- Secondhand clothing stores (thrift shops)







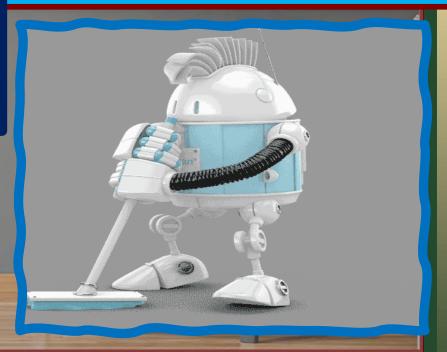
Non-Regimented Routines

Means we sometimes

Institutional Lives are Regimented !

That opportunity is much like *romance...* unpredictable but exciting

hen routines are enforced upon us practiced too regularly, we are at a risk of becoming **robots**, crificing spontaneous joys for an agined need to stick to the plan



Asking Permission

When people reside in highly "controlling" environments, permission must be sought to engage in life's everyday activities.

May I:

go outside?

have a snack?

lay down on my bed? watch TV?

take a shower?

call my Mom?

Such controlling relationships define the institutional culture.



Who Decides?

One's quality of life is significantly influenced by the decisions one is empowered and supported in making. In the lives of people with intellectual disabilities, who

decides...

with whom they spend their time? what they do during their day? where they spend their free time?



Greatest of Sacrifices The loss liberty is the price of care



Up And At 'Em

But I like to sleep later on the weekend!



Waiting

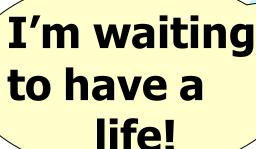
Waiting is a vulgar word – it suggests the wasting of valued time – time that is under the control of others.

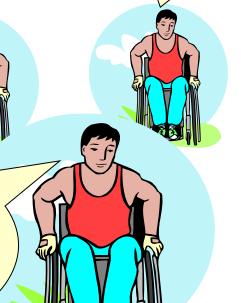
I'm <u>waiting</u> for my bath.

I'm <u>waiting</u> to have dinner I'm <u>waiting</u> to go to bed.

I'm <u>waiting</u> for my meds,









Undertow

Waiting is the undertow of life!



Precious Time

"Until we realize that adults with intellectual disabilities do, in fact, have real adult needs, interests

and concerns, we will continue to treat them as if they are children and waste their precious time."

Sarah E. Eastes Agenda for Real Life



Treasured Activities

Do the people you support indulge themselves in treasured activities?

eating a pint of Cherry Garcia at 1:00 AM

soaking in a tub filled with bubbles for an hour

falling asleep in a hammock on a summer night

going skinny dipping with your best friend

having a day to yourself and doing nothing

sleeping with all the windows open on a beautiful night



Snack Time

When there is no cookie jar to teach individuals an internal locus of control; they have snack time!

The absence of a cookie jar communicates that staff need to maintain control!





Respect and Dignity These two maxims when followed should help us treat others with dignity and respect Respect E_t Dignity BE KIND necessitates empathy BATTLE

Respect and Dignity (cont'd)



Seeing with the EYES of another,

Listening with the EARS of another,

And feeling with the HEART of another."

-Alfred Adler

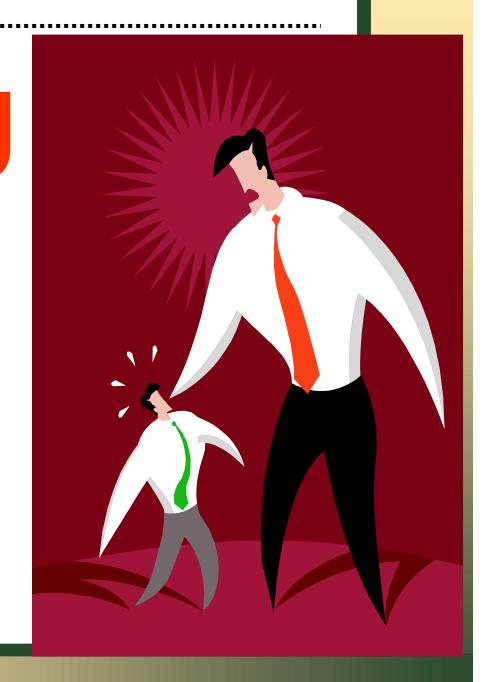


The devil is found in our behavior.

It Makes Sense

"Hurting people" hurt people.

John Maxwell



Be Sensitive

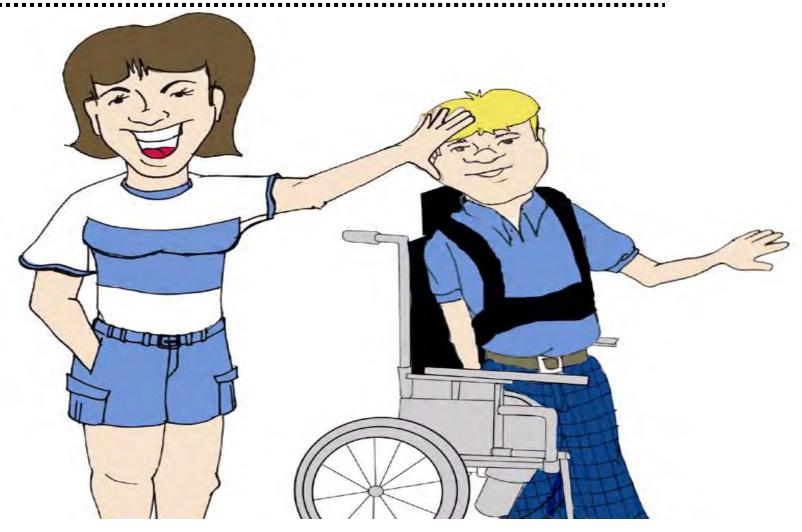
belittle is to be little.



Us And Them "Father, how could we have done these things to them?" "The first step, my son, was to learn to say 'us' and 'them'. After that, it was easy."

Unknown

Melon "Patters"



Pat your pets, heads of babies and melons.

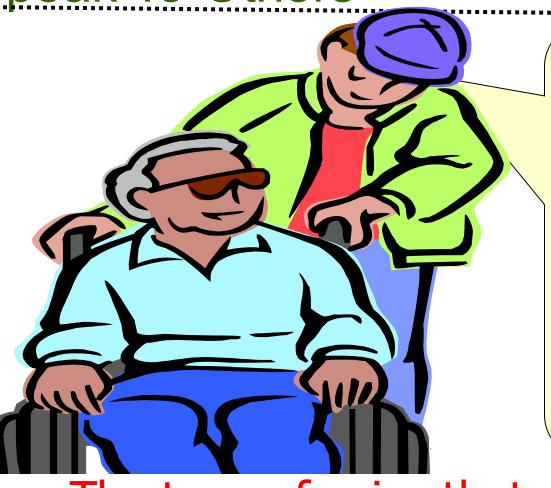


Below the Collar

When touching adults noncontingently, keep your hands below the collar and above the waist.



Speak To Others



"And how are we today, pumpkin? You sure look cute in that shirt!"

The tone of voice that we use in speaking to others is an indication of how we perceive the individual.

At All Cost...

...the people we support must look good in the eyes of others.

Do they look good having:

• excessive nasal, eyebrow or ear

hair?

• stained teeth?

• unkempt finger nails?

• extensive facial acne?

• poor fitting/seasonably inappropriate clothing?

adaptive devises needing repair/cleaning?

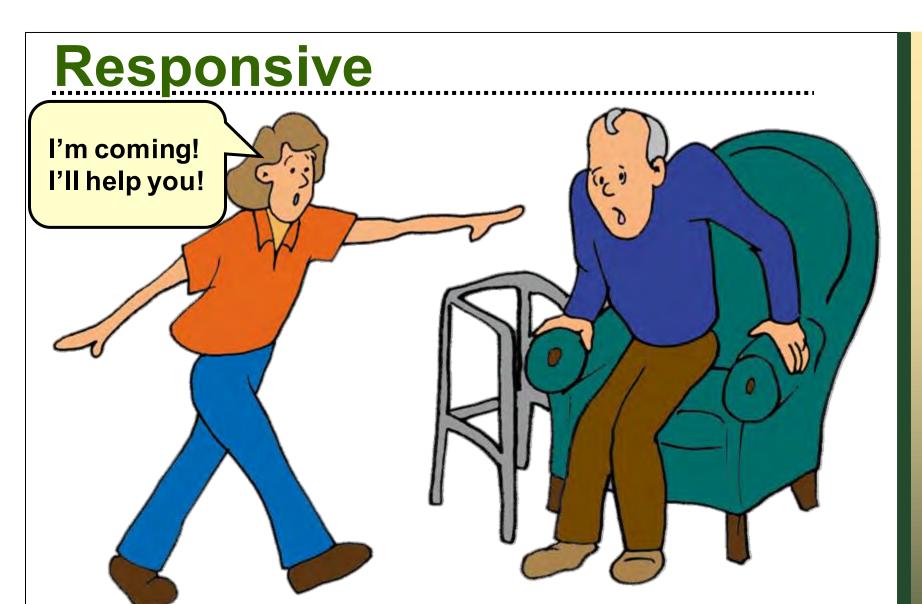
food on clothes/face?

Take Action!!



Respect

Responsive



An ability to recognize the importance of attending to the unmet needs of others

Respect

Responsive Encouraging

Encouraging

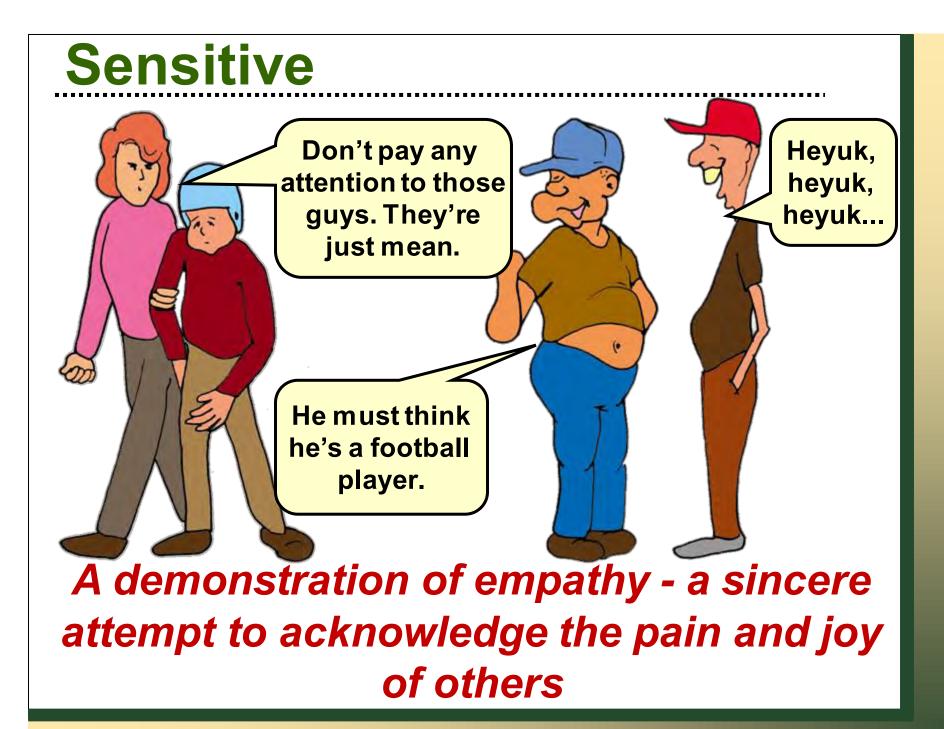


You did a great job sweeping. The carpet has never looked so clean.

Supporting others in recognizing the importance of achieving the smallest of accomplishments and sharing in the celebration

Respect

Responsive Encouraging Sensitive



Not A Solution



Zip ties are not a replacement for shoestrings This individual leaves home each morning with these shoes. What is the option if she has difficulty with shoe strings?

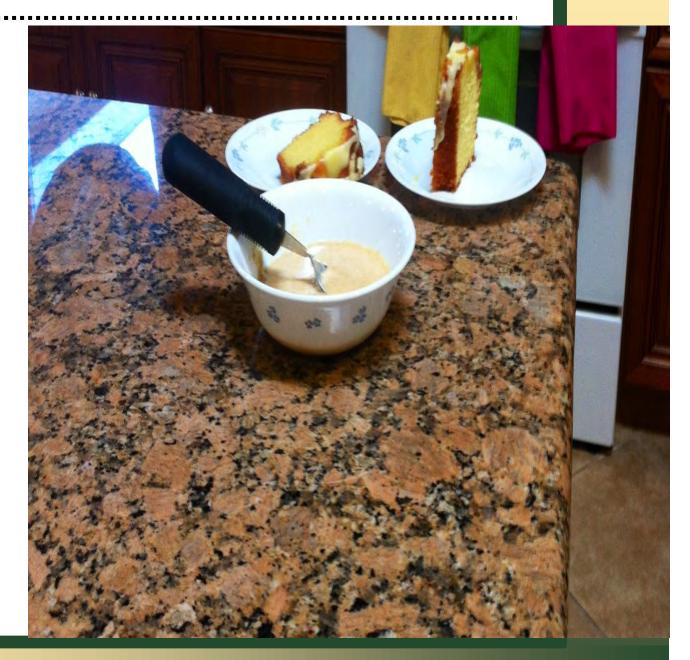
Take A Seat



This chair, adorned with a soiled incontinence pad, is prominently located in a day program room.

What Is This?

Thanks for letting me know what I'm eating!



Respect

Responsive Encouraging Sensitive Perceptive

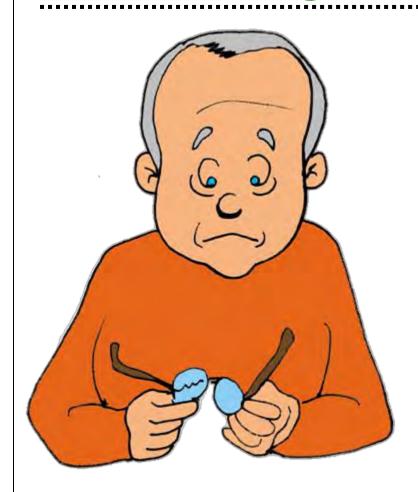


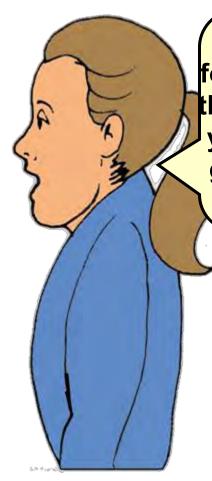
An ability to interpret the silent communication of body posturing and facial expressions - enhances one's ability to be perceptive

Respect

Responsive Encouraging Sensitive Perceptive Expediting

Expediting





Would you like for me to help call the optometrist so you can get your glasses repaired this afternoon?

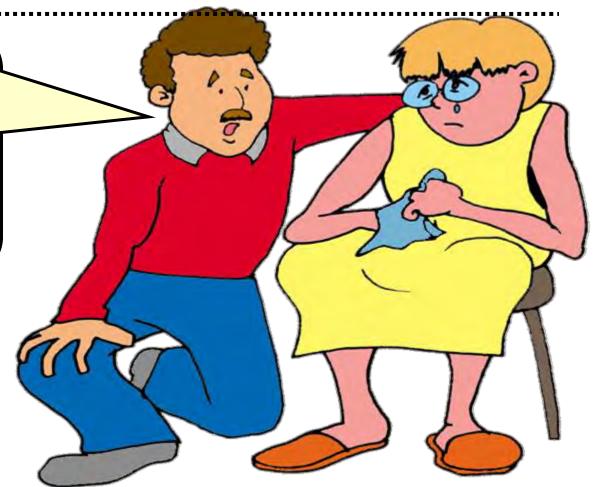
Responding to the needs of others - as you would wish for others to respond to your needs

Respect

Responsive **Encouraging** Sensitive Perceptive **Expediting** Caring

Caring

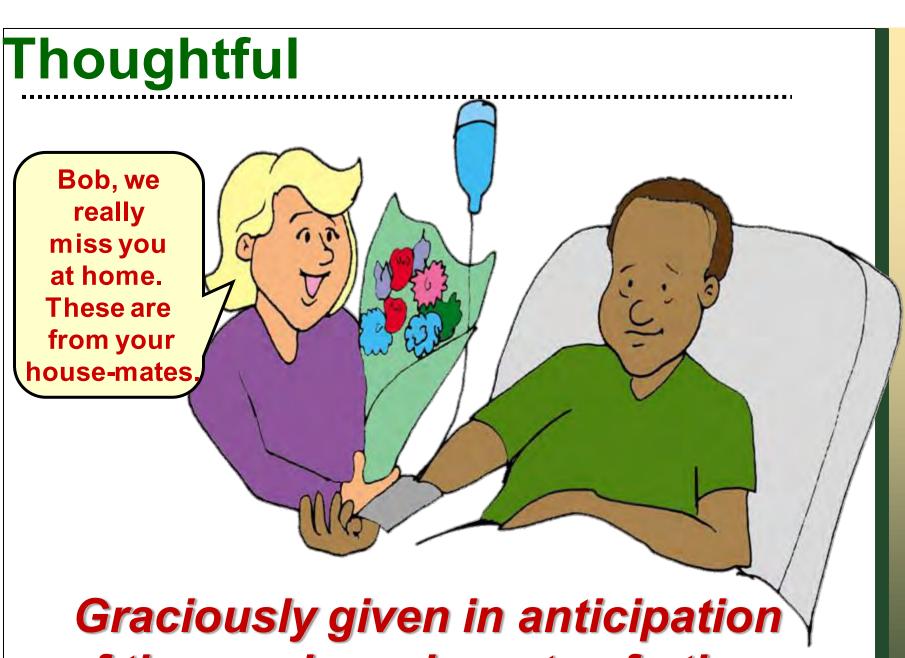
Susan, why are you crying?
Would you like to talk about what is bothering you?



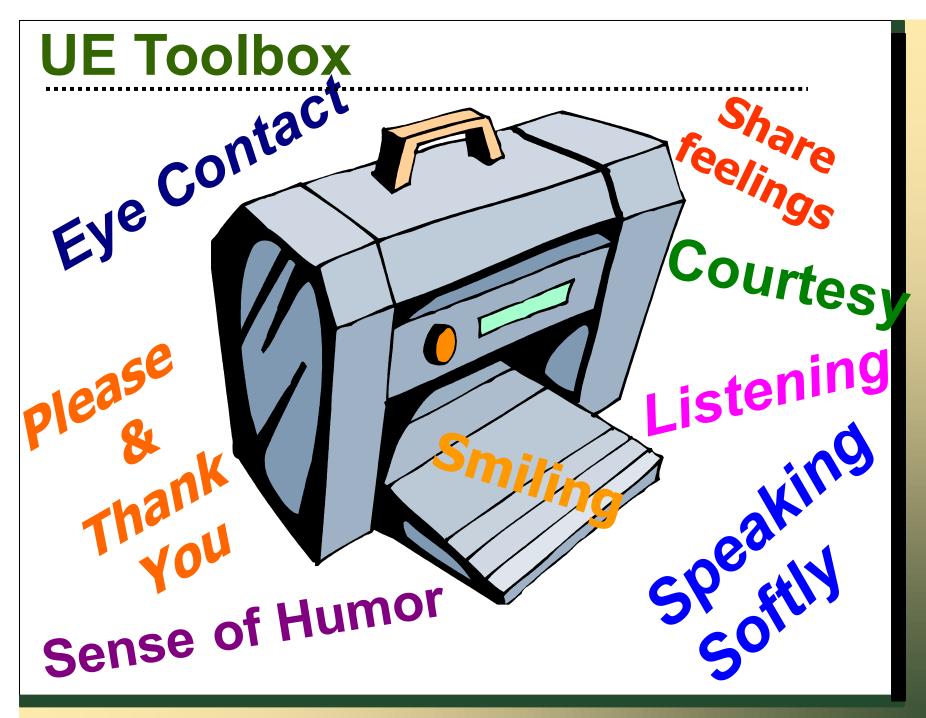
A recognition that caring <u>about</u> others is a bonding activity. Caring <u>for</u> nurtures dependency and learned helplessness.

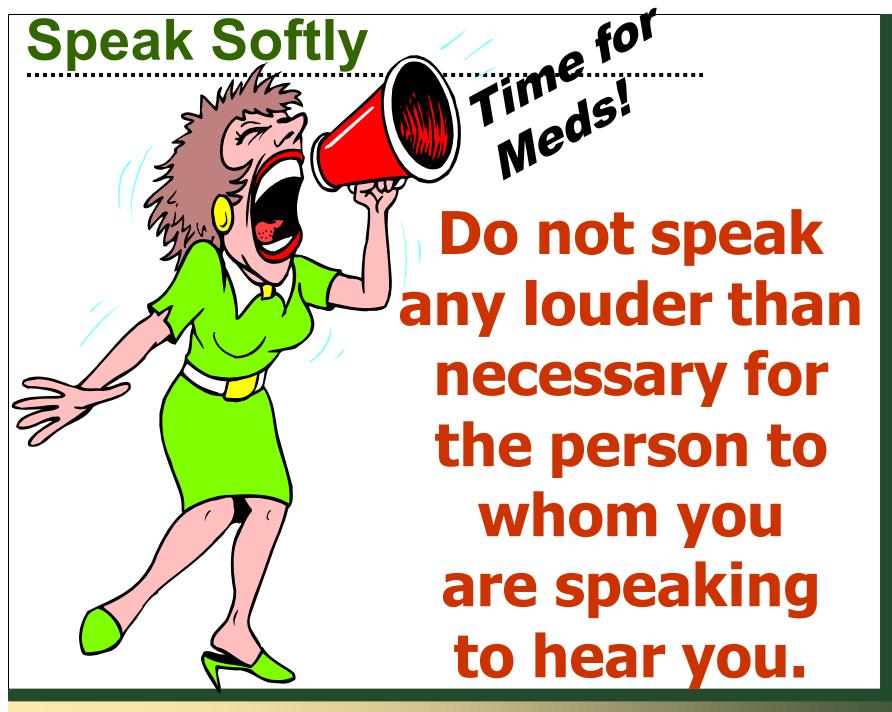
Respect

Responsive **Encouraging** Sensitive **Perceptive Expediting Caring Thoughtful**



of the needs and wants of others





Move Furniture Not People



WHOA!

Never assist anyone in moving without their permission!

Request Permission



Never assist anyone in moving without their permission!

Corrective Feedback



Corrective feedback should always be given quietly. It is nobody's business other than the person with whom you are sharing the feedback.

Being a Good Listener Listener's Code: Never Pass Up **The Opportunity To Be Silent Definition of Listening:**

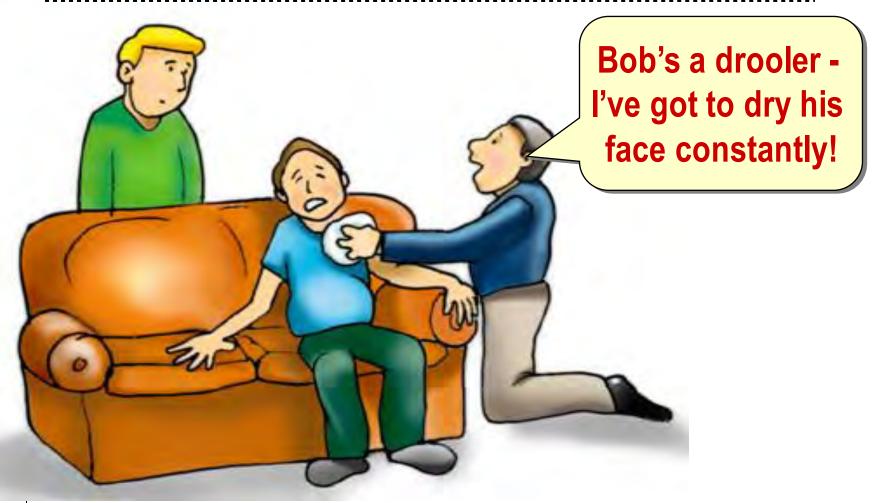
Quiet

Be Sensitive

belittle is to be little.



Talk With - Not About

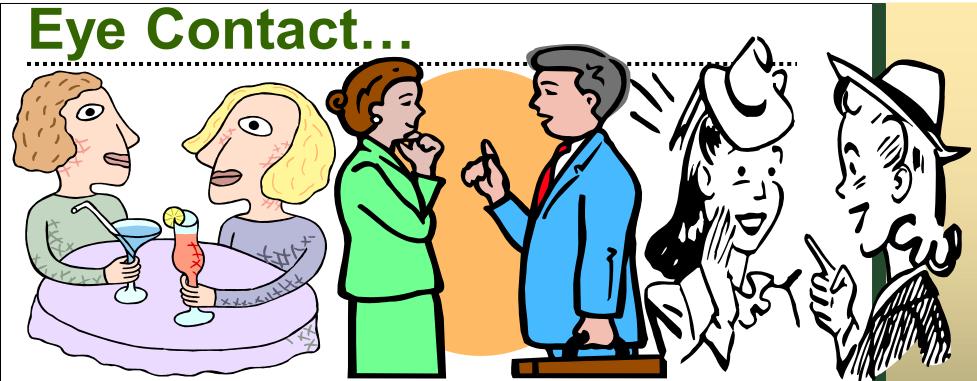


Do not talk about individuals in front of them!

Speak To Me

Don't "talk for" people when they cannot communicate; talk "to them" to relay the communication to others.





Is the way in which you give others an emotional hug

Says that I trust you - I can be

Says that I trust you - I can be vulnerable

Communicates that I listen - what you say is important



Smile

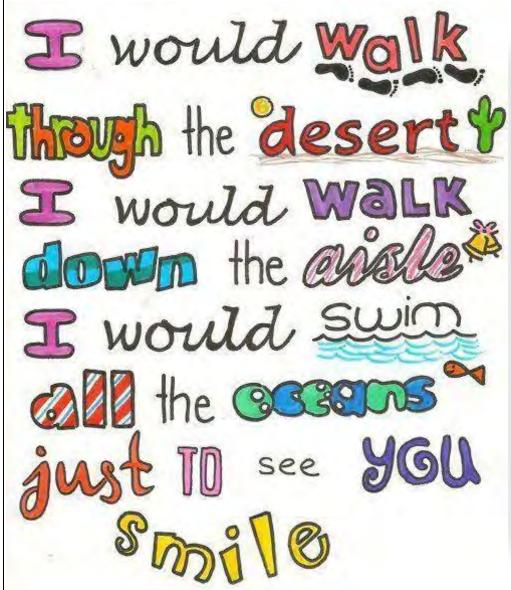
"Every time you smile at someone, it is an act of of love, a gift to that person, a beautiful thing."

-Mother Teresa



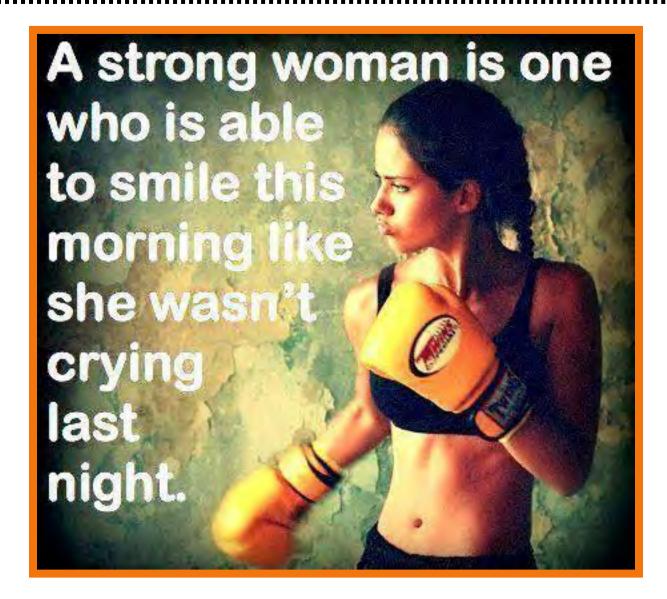
Smile (cont'd) If you cant find the right words for certain situations just give a smile. Words have the potential to confuse. but a smile convinces..

Smile (cont'd)





Smile (cont'd)





Smile (cont'd)

You've got to take the good with the bad, smile with the sad, love what you've got, and remember what you had. Always forgive, but never forget. Learn from mistakes, but never regret.

Smile (cont'd)



Smile
it's the second
best thing
you can do
with your lips.

Respect Responsive **Encouraging** Sensitive **Perceptive Expediting** Caring **Thoughtful**

It must start with respecting yourself!

Do's

Top Ten Things You Should Do When You Support Us

☐ Forget the records: Get to know US as people

SABE Conference - Providence, RI, September, 2000



Do's (cont'd)

Top Ten Things You Should Do When You Support Us

- ☐ Forget the records: Get to know
 US as People
- ☐ Listen and Hear our voice:
 We've got a lot to say

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Hear Our Voices

How do you hear the voices of people who lack language and speech?

Be sensitive to:

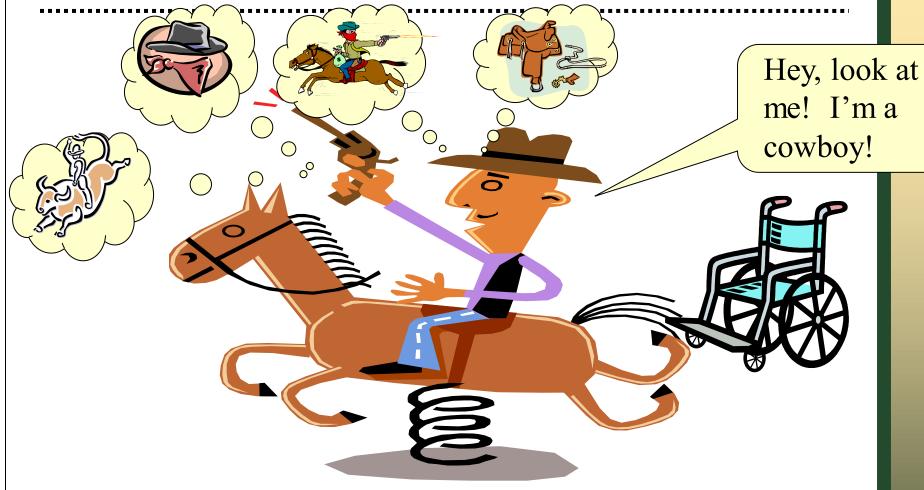
- Frown or smile
- Head up or head down
- Attentive eyes or eyes not engaged
- Silent or boisterous
- Hands outstretched or hands retracted, etc.



Do'S (cont'd) **Top Ten Things You Should Do When You Support Us** Forget the records: Get to know US as People ☐ Listen and Hear our voice: We've got a lot to say Treat us like you want to be treated Ask us how we feel about stuff Make your goal to help us accomplish ours Take time to explain things Put yourself in our shoes - walk our walk Tell us the truth

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Tell Us The Truth



How can this man with profound intellectual disabilities be supported in realizing his "dreams" in socially acceptable ways?

Tell Us the Truth (cont'd)

When you tell me the truth, please make it a thoughtful process – deception is insincere.

- •Explain the truth to me in a way that I can understand
- Focus on emphasizing the possibilities
- •Do not nurture/encourage seemingly unrealistic goals
- •Do not protect me from my feelings I have a right to them
- •Do not make me the last to be informed if it's about me shouldn't I know first?

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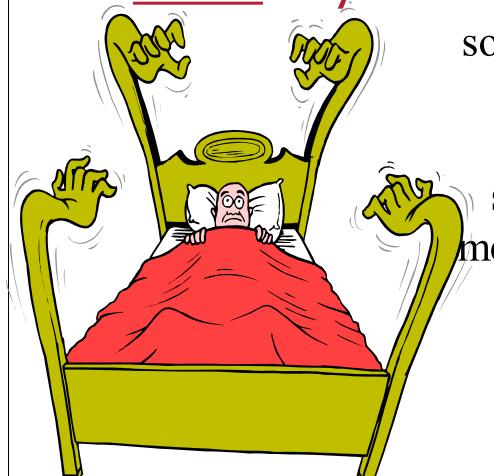
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A Regulatory Nightmare

"I have a dream.

Dr. Martin Luther King, JR.

He didn't say:



"I have a dream, that someday everyone will have - a behavior management plan, seasonably adjusted menus, skill acquisition objectives, interdisciplinary assessments and a discharge plan."

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Blue Ribbon Staff

Sensitive and effective Support Staff, their supervisors and clinical staff who serve as their resources need "fire in their bellies." Check those characteristics depicting how you present yourself to the individuals you support:

Energetic
Happy
Motivated
Inspired
Excited
Enthusiastic

Fincouraging
Proud
Self Confident
Willing
A leader
Determined

Blue Ribbon Staff (cont'd.)

or...

- □ Tired □ Reluctant
- Depressed
 Inflexible
- Discouraged Angry
- ☐ Indifferent ☐ Passive/Aggressive
- Spent
 Needy
- Pessimistic Cranky

Which staff would you prefer to have supporting you?

Don'ts

Top Ten Things You Shouldn't Do When You Support Us:

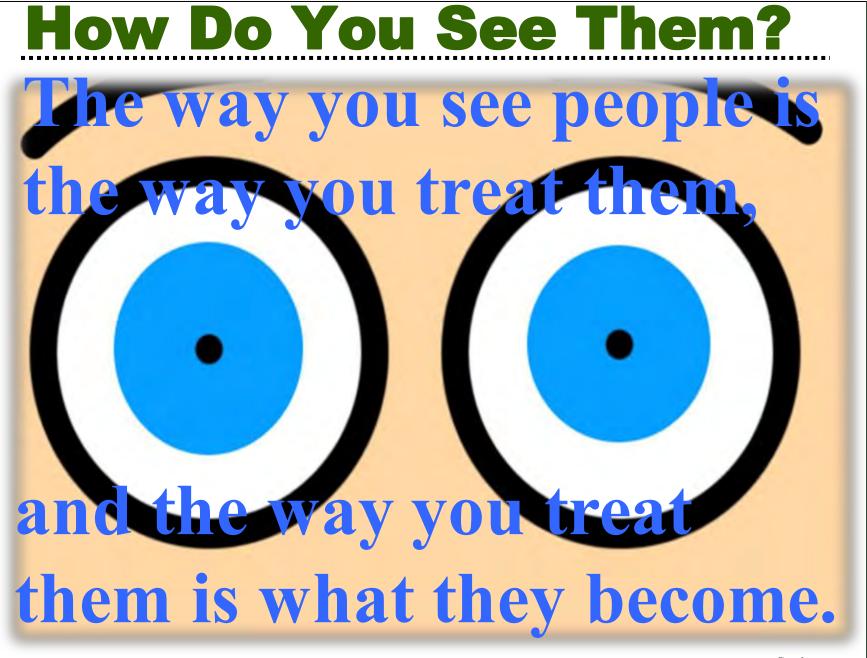
- □ Don't think we don't think
- ☐ Don't change your tone of voice when you see us
- □ Don't touch our property without asking us
- Never ask someone else what we want ASK US!
- □ Don't make decisions for us
- ☐ Don't have meetings about us without us
- Don't talk to us in an authoritative way
- □ Don't discount our abilities
- ☐ Don't think that we are all the same
- □ Don't patronize us

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Hurt People

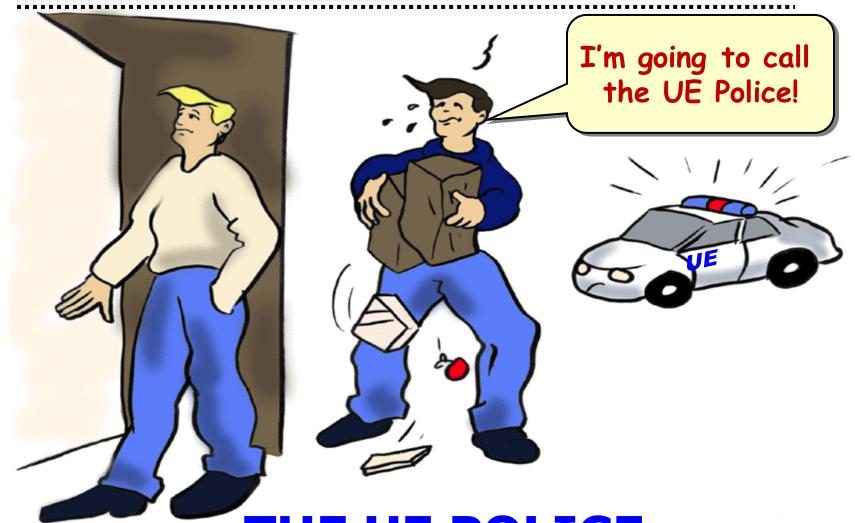
Hurt people hurt people. That's how pain patterns gets passed on, generation after generation after generation. Break the chain today. Meet anger with sympathy, contempt with compassion, cruelty with kindness. Greet grimaces with smiles. Forgive and forget about finding fault. Love is the weapon of the future.

- Yehuda Berg -



Goethe

Universal Enhancement Police



THE UE POLICE
Enforcers of Dignity and Respect

Respect Responsive **Encouraging** Sensitive **Perceptive Expediting** Caring **Thoughtful**

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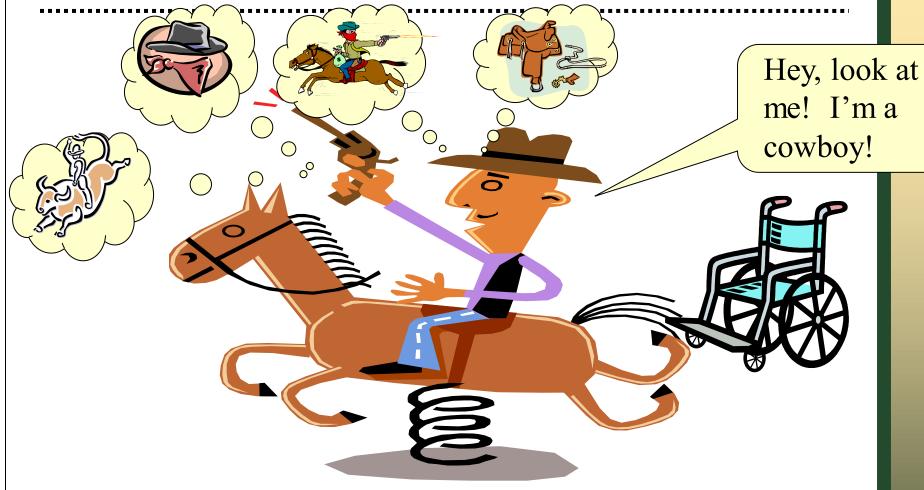
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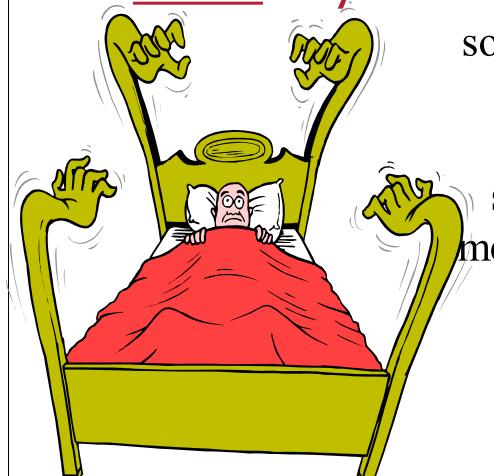
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- Yehuda Berg -

Who Are We? What Are

They?

We insist We have talents

We defend ourselves We change our minds

We are "caregivers" They are clients We like things

They tantrum They have splinter skills

They are noncompliant

They are disoriented

They fixate on objects

Vho Are We? What Are They?(cont'd)

We make friends We take a break We have hobbies We persevere We love people

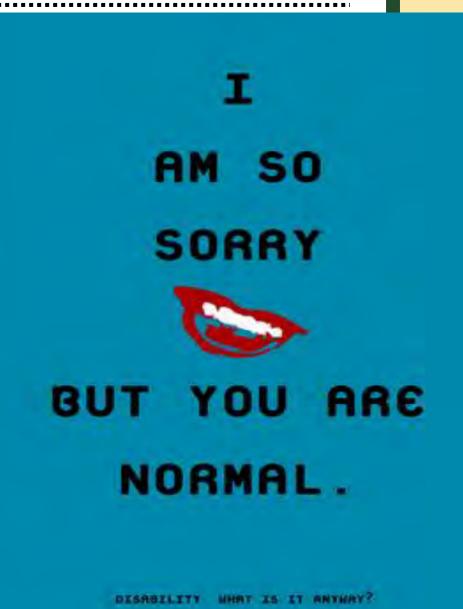
They seek attention They go off task They self-stim They perseverate They develop

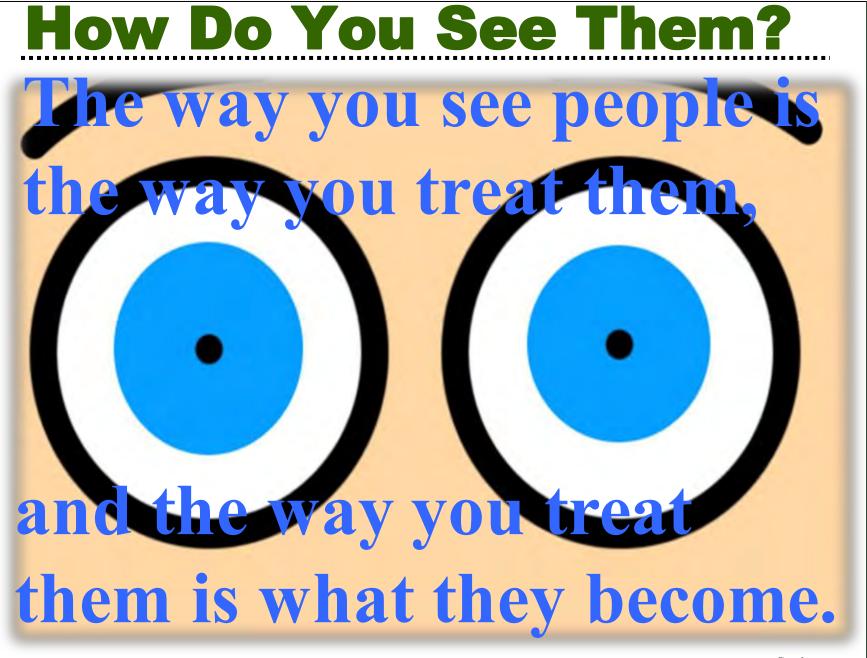


Mayer Shevin

I Am So Sorry....

A different perspective!





Goethe

Accessible Settings...

necessitate that the NEEDS of people with disabilities are specifically considered, and products, services and facilities are built or modified so that they can be used by people of all abilities.

Barriers cause handicaps, not disabilities

Do Not Forget!



If the setting inhibits or prevents participation, how can those we support have a life if they do not participate in it?

Universal Design...

...incorporates many accessibility code requirements and stresses innovative solutions to facilitate daily living and independence, especially for people who have, are or will be experiencing changes in their

mobility and/or sight and hearing.

...environments are designed to readily accommodate people who differ in height, size, strength and mobility.

...is a leading – edge design concept that strives to accommodate human functional diversity and the future change in how people perform their activities of daily living.

Susan Mack, OTR/L, CAPS, Ultimate Home Design March/April 2006

Not Accessible



Two of the people living in this home use wheelchairs. Guess who will do their laundry?

Keep It Simple

The complexity of this sophisticated washer and dryer is a challenge for a person of average intelligence.





No Cost Accessibility

Creative approaches to accessibility



Threshold



Promote Self-Determination

Consider these options:

modify the environment — accessibility provide adaptive equipment teach skill acquisition provide personal assistance

The best approach for maximizing selfdetermination is influenced by numerous

factors:

individual preference technology cost stigma time available personnel

Accessibility

Does your organization promote supported routines by facilitating accessibility?

Modified toothbrush handles

Raised electrical outlets Long-handle dust pans

Lowered counter tops

Front load washers

Front mounted garbage disposal switches

Wash mitts

Touch lamps Lowered

closet bars

Lowered thermostats

Front control ovens/stoves

Accessible Living











Closet Organizer

Maximize access for those individuals who use wheelchairs



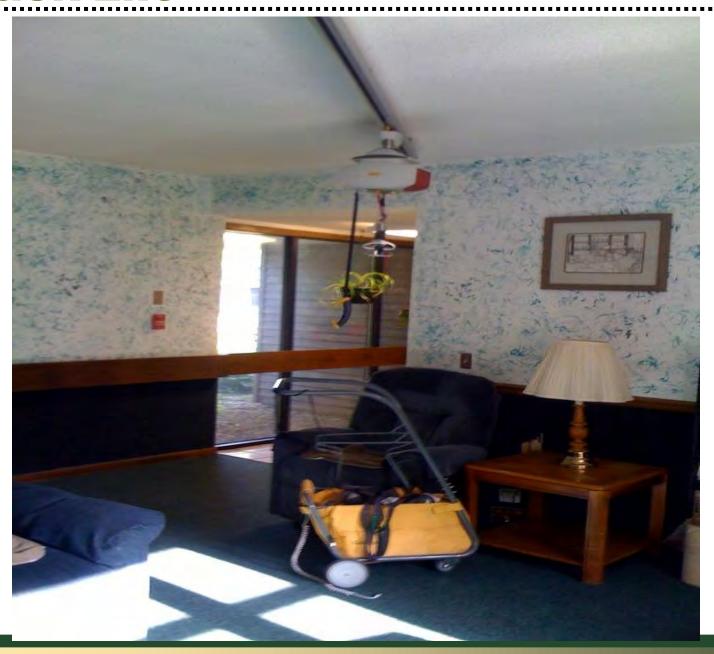
Accesible Privacy



Accessible Privacy (cont'd)



Track Lift



Modified Walker



Don't Ignore the ObviousSometimes what you're searching for does not really require searching. It's right in front of

Sometimes the best answer is the most obvious one. Often, when something seems too simple or unsophisticated, it is exactly the right approach.



you.

Don't Ignore the Obvious



Here's the obvious solution...what was the dilemma?

Cereal Dispenser

Assures options -Dispenses with one hand



Appliance Cart

Assistive device for moving items between the kitchen and dining room.



Modified Container



Easy To Grasp...

...and it's off the shelf!



Adapted Lotion Holder



Integrated Day (Cont'd)



Community integration refers to assimilating and welcoming people with disabilities into the larger community

Community integration enables persons with disabilities to fully participate in life at the same level as nondisabled people



Integrated Day (Cont'd)

Successful Community integration

integration gives people with disabilities a strong community presence without reducing them to their disability level



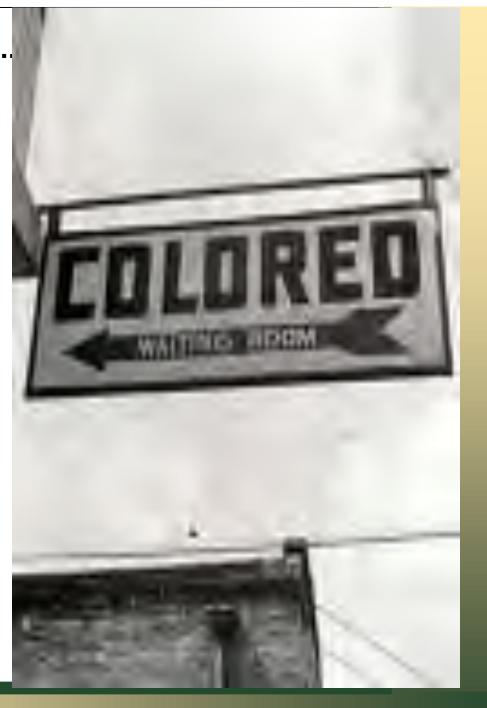


Community integration

is the foundation for community engagement promoting individuals with disabilities to play a meaningful role in the deliberations, discussions, decision making and /or implementation of projects or programs affecting them

There Is...

...no separate but equal!



Social Justice

Generally refers to the idea of creating a society or institution that is based on the principles of <u>equality</u> and <u>solidarity</u>; that understands and values <u>human rights</u> and that recognizes the dignity of every human being. Wikipedia The fair and proper administration of laws conforming to the natural law that all persons, irrespective of ethnic origin, gender, possessions, race, religion, etc. are to be treated equally and without prejudice www.businessdictionary.com

From a simple point of view, social justice is equivalent to social fairness. It is a phrase that refers to giving what is rightly due to an individual or group, team or community. It works on the universal principle that guides people in knowing what is right and what is wrong. www.socialjusticedefinition.com

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?



Grouping

Considerations

Individual competence is obscured by aggregating individuals by their disability.

Grouping amplifies the disability common to each individual in the group.

Assembling individuals with disabilities by those holding power over them i.e. support staff, managers, families, volunteers, etc., is commonly justified by "that is their choice".

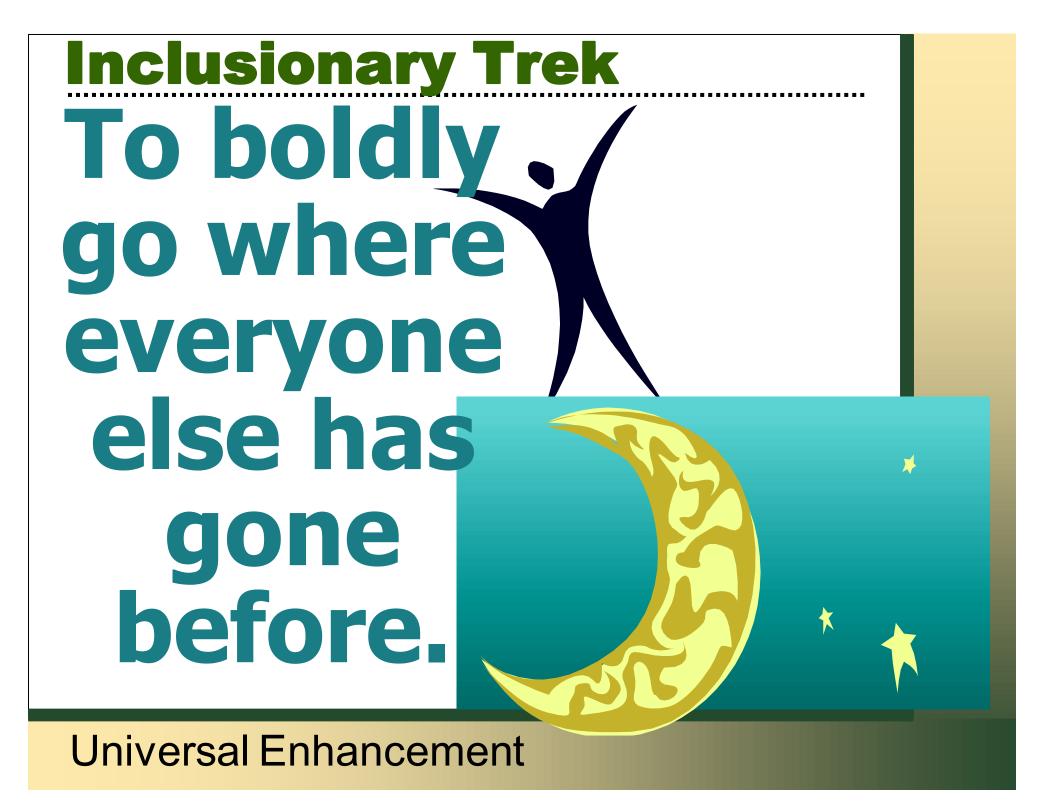
Is being grouped with individuals of the same disability a choice when no viable option is presented to mingle and interact with a diversity of people?

Grouping (cont'd)

Consequences

When an individual's disability is the determining influence for grouping, it limits opportunities to develop the myriad of relationships realized through integrated educational, employment, leisure and volunteer activities.







Community

"The community is not there to find

it has to be BUILT."

--John O'Brien







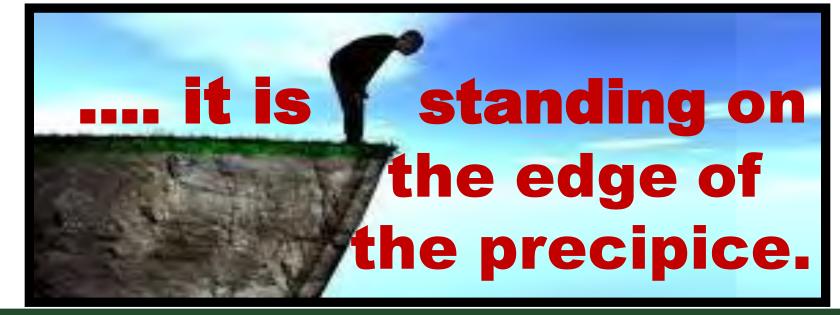






Placement List

Being a priority on a "placement list" is not seeing the *light* at the end of the tunnel,



Community Integration

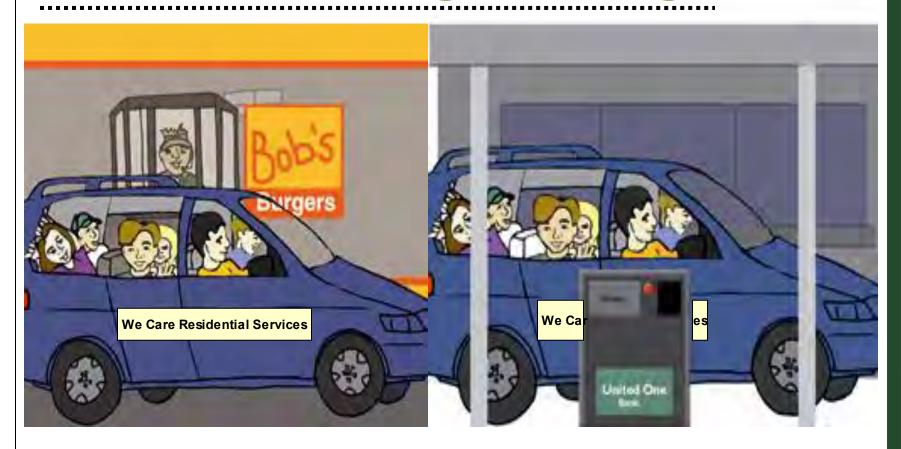
Integration (noun) 1: The act or process or an instance of integrating: As an incorporation as equals into society or an

organization of individuals or different groups (as races)

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

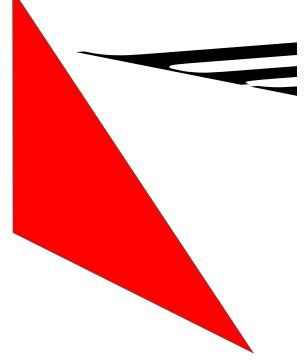


Drive Through Integration



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

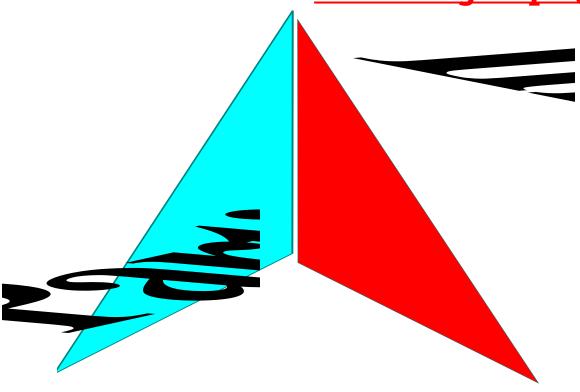
Participation (noun) 1: The act of participating 2: The state of being related to a larger whole



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

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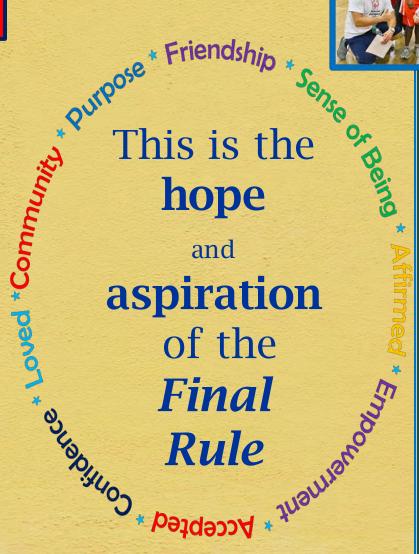
ncusion (cont'd)

Principles of Social



- Enhancing opportunities
- Accessing resources
- Giving a voice
- Respecting rights





Relationship vs Friendship

Relationship: a connection, association, or involvement. The way in which two or more people, groups, countries, etc., talk to, behave toward and deal with each other, the way in which two or more people are connected.

Merriam-Webster

Friendship: is a relationship of mutual affection between two or more people. Friendship is a stronger form of interpersonal bond than an association. Characteristics of friendship include: sympathy, empathy, honesty, altruism, compassion and understanding.

Wikipedia

Intimacy

What would your life be like without an intimate relationship?

Intimate: marked by close acquaintance, cherished, dearest,

devoted, warm friendship, relating to or indicative of one's deepest nature. Wikipedia



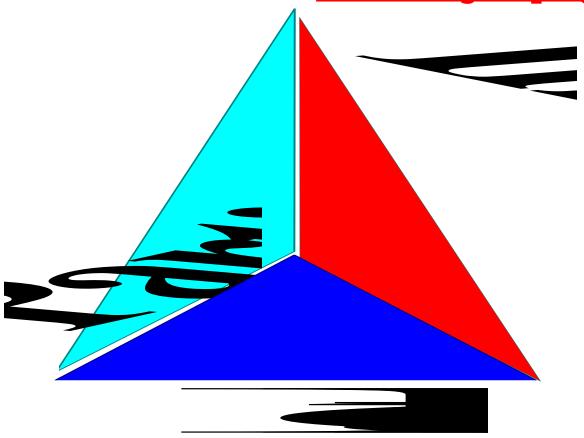
cutcaster.com - 90/520/54

Aristotle on Friends

No one would choose a friendless existence on condition of having all the other things in the world.

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

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



nclusive Environments (cont'd



•Provides the individual the confidence to request the needed modification/s followed by careful consideration of the request/s

• Provides the individual with accommodation with a goal to enable the individual an opportunity to fully participate and

•Approaches the provision of accommodation as doing all it can to ensure access and inclusion rather than focusing on what regulation requires

Thoughts On Inclusion

Inclusion:

 is not merely overcoming and achieving, but must rise to the status of existing and being. often labeled as naive, and reviled by social conservatives, is cast in a similar light as the social movements of gay rights, anti-racism and feminists.



Thoughts on Inclusion (cont'd)

Inclusion:

- •is not provided by the charitable contributors to the lucky recipient
- •is not an intervention delivered to support recipients perceived as passive beneficiaries



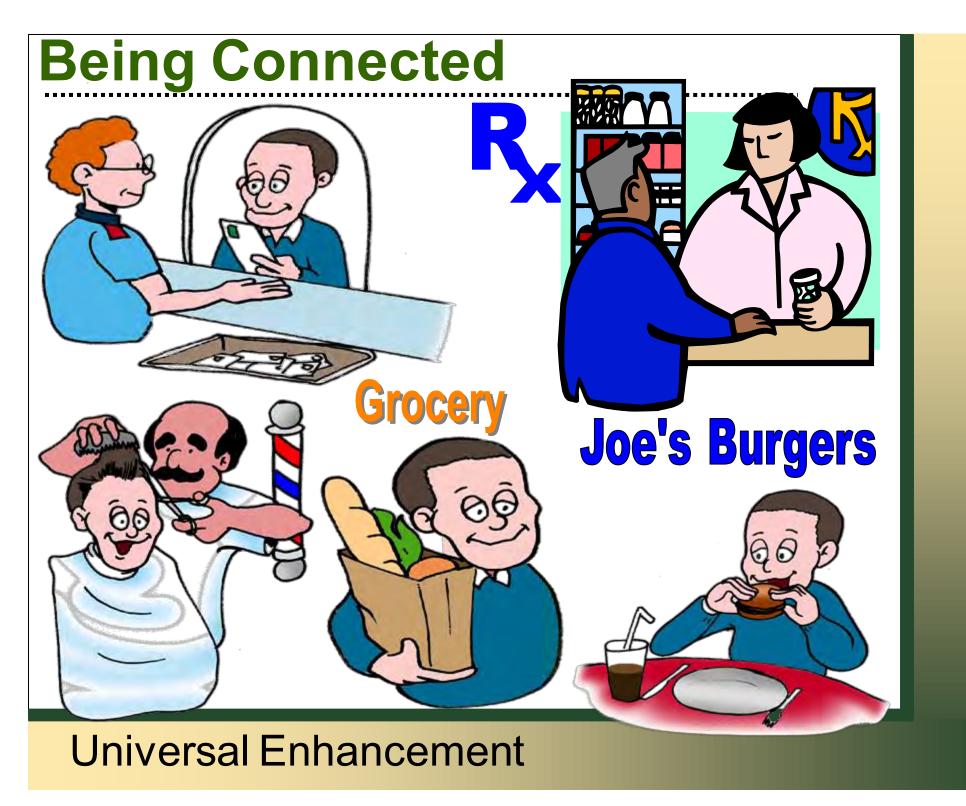
" Inclusion?

Is someone doing inclusion If people were



segregated, we would not be "doing inclusion."

Support an inclusionary life!



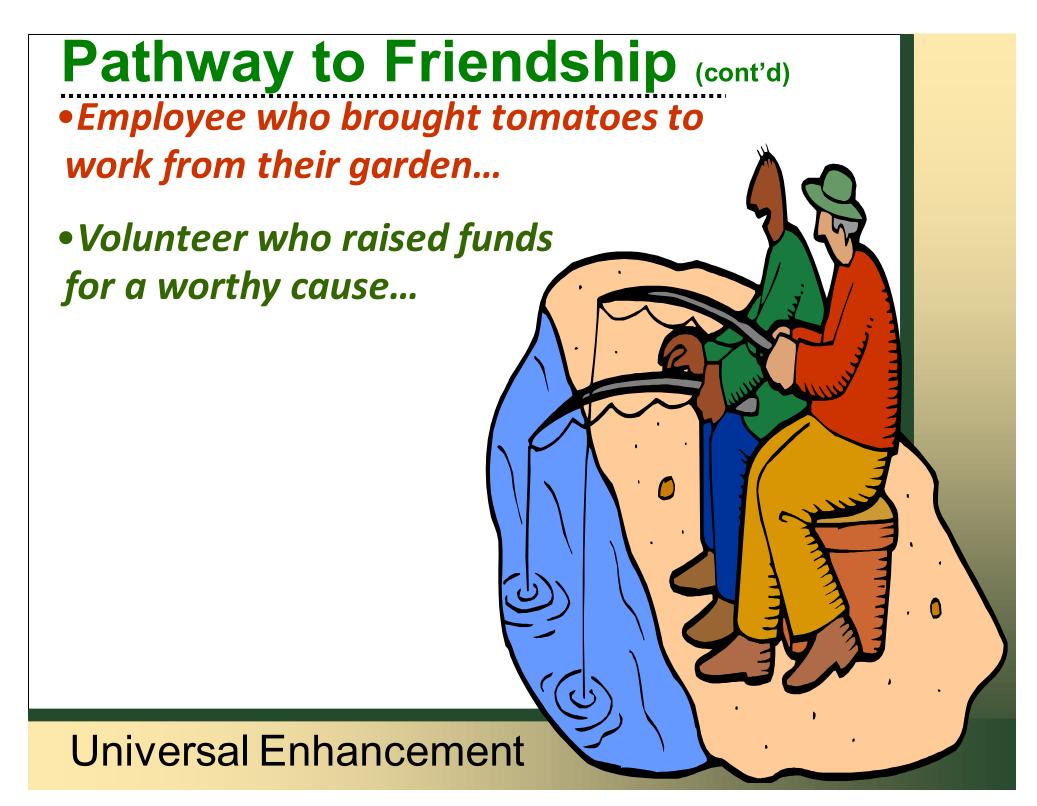
Pathway to Friendship

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 (an):

• Parishioner who collects the tithe....

• Camper who won first place in diving at the Girl/Boy Scout Camp...

• Church member who joins the choir...



Volunteering....

is an essential life activity is a demonstration of appreciation enhances sense of self facilitates relationships increases skill acquisition promotes adult status enhances QOL through meaningful engagement

Encourage Volunteering!



st And 2nd Place



The place where one lives, the focus of one's domestic attention; Free Merriam Webster The place where you want to be at the end of a rough day. It's where you feel comfortable and at ease. Yahoo Answer

2nd Place - Work

The place where one is employed or labor is expended.

It's where an activity is conducted to exert strength or

faculties to do or perform something.



3rd 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





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." Wolf Wolfensberger

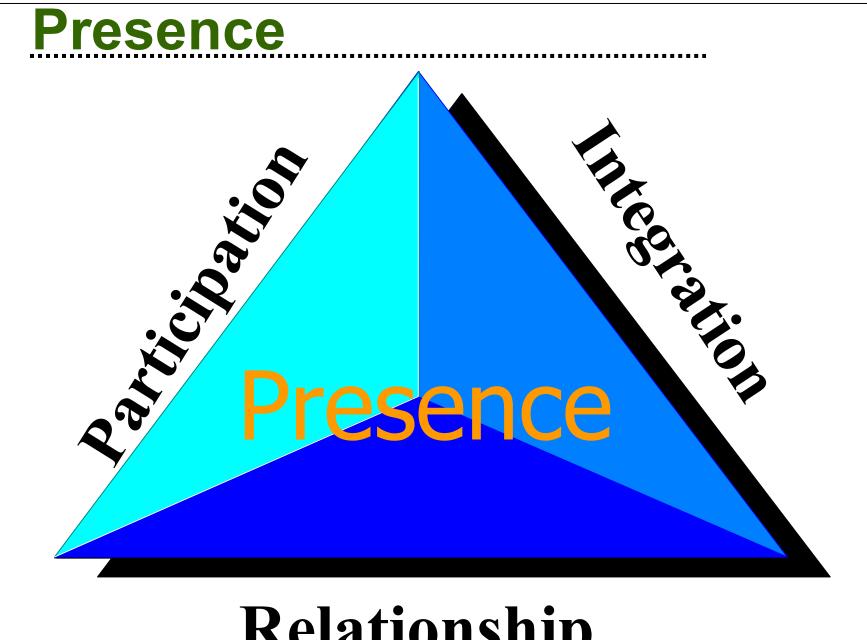


How do we assist people to obtain socially valued roles?

Ask Them to Dance Integration is being asked to the party inclusion is ' being asked

Universal Enhancement

to dance.



Relationship

Inclusive Environments

•Values the "disability" as part of a range of diversity that is fundamental to the human condition – the presence of the disability is not seen as a detriment

Sees individuals, not stereotypes



Nurtures an environment that promotes effective communication about needs without an assumption of accommodation

Is more than merely accessible

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

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' 1.)

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



Community Network



Community is a network of people. Members may be geographically distant and <u>vary in numerous</u> characteristics; politically, sexual orientation, professionally, nationality, religion, etc.

- Despite those differences a bond is nurtured, a connectivity, a common cause to celebrate
- Group members gather on a regular basis, behavioral patterns and nuances of a culture form.
- The term community is the blending of the prefix "com" meaning with and the root word "unity".

 Inspired by Al Condeluce

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.

Come One Come All

We are looking for bowlers and or teams for our fall leagues.

Men's Leagues

Monday 6:15pm

Tuesday 6:15pm

Wednesday 6:15pm

Friday 6:15pm

Ladies Leagues

Monday 6:30pm

Tuesday 6:15pm

Wednesday 6:15pm

Mixed Leagues

Monday 6:15pm

Tuesday 6:15pm

Saturday 6:30pm

Sunday 6:15pm

Seniors and Daytime Ladies

Tuesday Noon (seniors)

Thursday 9am (seniors

Mondays 9:30am (ladies)

Wed. 9am and Noon (ladies)

Thursday 9:30am (ladies)

So why is it we continue to form "special" Bowling

Leagues???

If interested please inquire at the front desk.