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Universal Enhancement

MALA 2019 Annual Conference

To Boldly Go Where Everyone Else Has Gone Before

Session 1

Session 2 (repeat)

May 14, 2019

with Tom Pomeranz, Ed.D.



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Social Justice

Generally refers to the idea of creating a society or institution that is based on the principles of equality and solidarity; that understands and values human rights 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



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Humanization

Generally, individuals with I/DD are:

- **Infantilized by the larger community**
- **Denied opportunities for employment**
- **Prohibited from engaging in informed consent sexual activities**
- **Nurtured to remain unnecessarily dependent**
- **Discouraged from participating in inclusionary community activities**
- **Labelled and referenced with disparaging language.**

By virtue of their outsider status, individuals with I/DD come to be regarded as expendable and vulnerable targets for segregation, denial of opportunity and diminished status.

Humanization refers to those strategies that counteract the destructive conflict dynamics



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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

hopelessness

isolation

rejection

despair

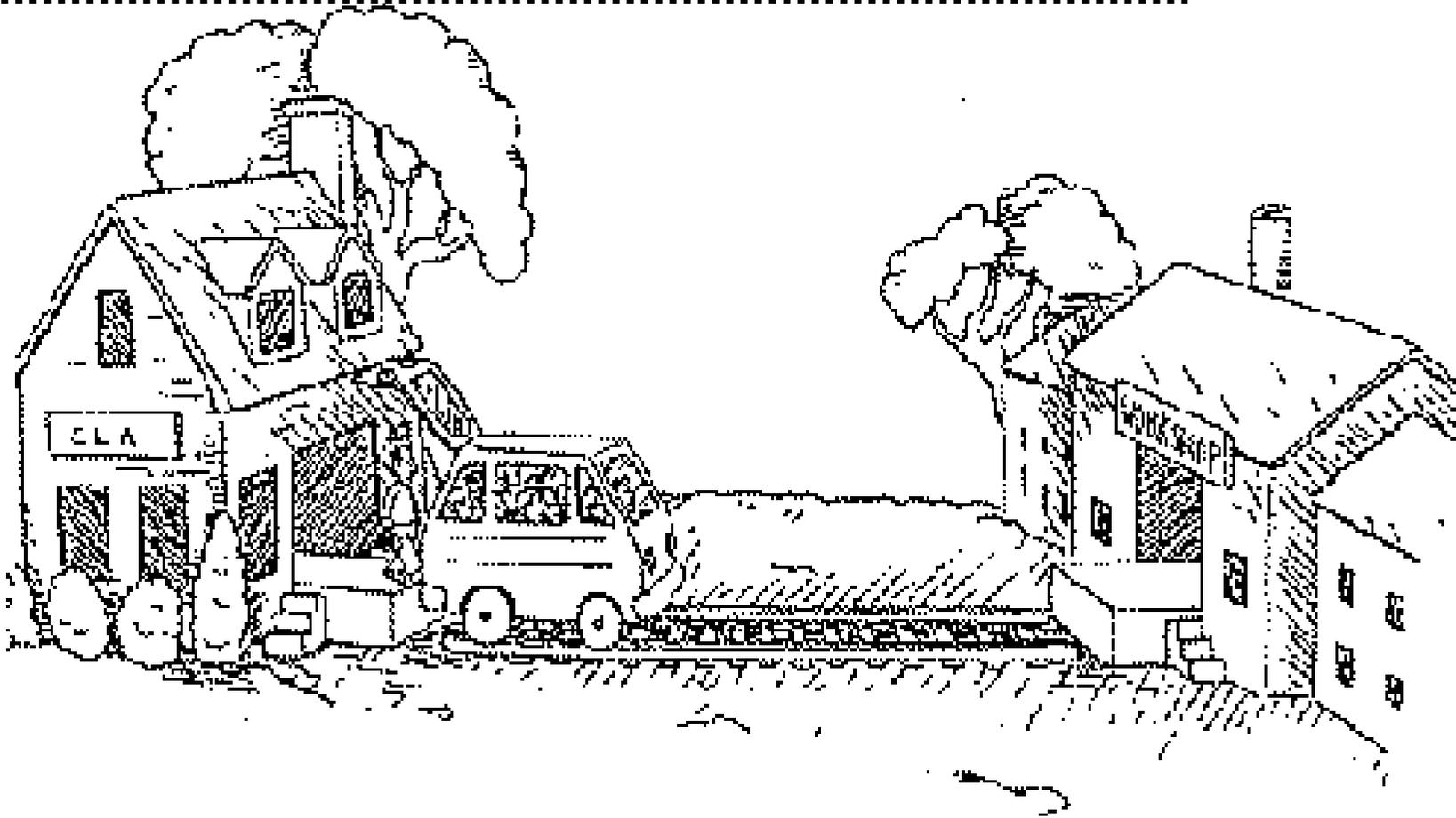
intimidation

failure

prejudice

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Life In The Community



**Would you like to trade
places?**

Reprinted from The Arc of
Berks County Newsletter (June 1998)

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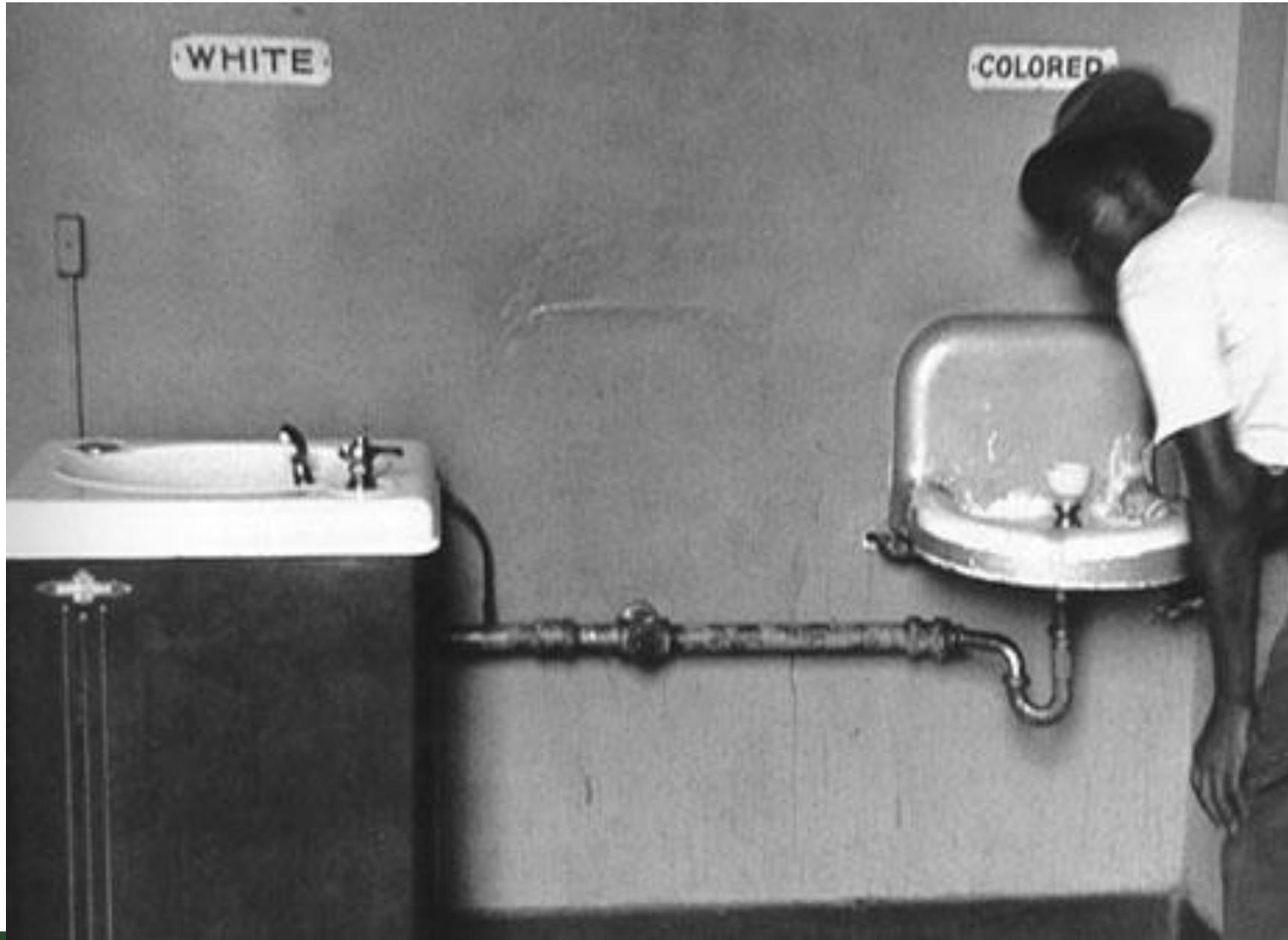
There Is...

**...no
separate
but
equal!**



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It Speaks For Itself



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Which Is Worse?

**African-Americans
had to sit in the
back of the bus.**



**People with
disabilities
couldn't
get on the bus.**

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The Worst Thing

**The worst
thing you can
do to a person
is make them
feel invisible.**

*Toni Morrison, Nobel & Pulitzer Prize
winning American Novelist, Editor,
Professor*



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Civil Rights Workers

IT'S YOUR
WORLD —
CHANGE IT!

DOES THIS DESCRIBE YOUR MISSION?

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Collective Civil Protest

Unlike other disenfranchised groups, in response to their victimization, subjugation and denial of their human rights, individuals with I/DD have not been known to self initiate collective civil protest.

Why?

Perhaps many individuals with I/DD are not aware that they are being subjugated and victimized.

Collective civil protest requires a level of coordination, premeditation, planning and communication necessitating a level of skill and competence that may not be demonstrated.



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Facilitate Quality

**Shift the
paradigm**

or...

**it will
shift you!**



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Thoughts to Provoke

Changing the service system for people with I/DD is a laborious process, for they are absent a political voice.

Site based day programs and group homes are a method to corral and segregate a class of people that society deems too difficult to accommodate.

Many individuals with I/DD lack an identity, a community or a purpose.

We must transition individuals with I/DD from being a victim of the system that supports them to a victor of the system.



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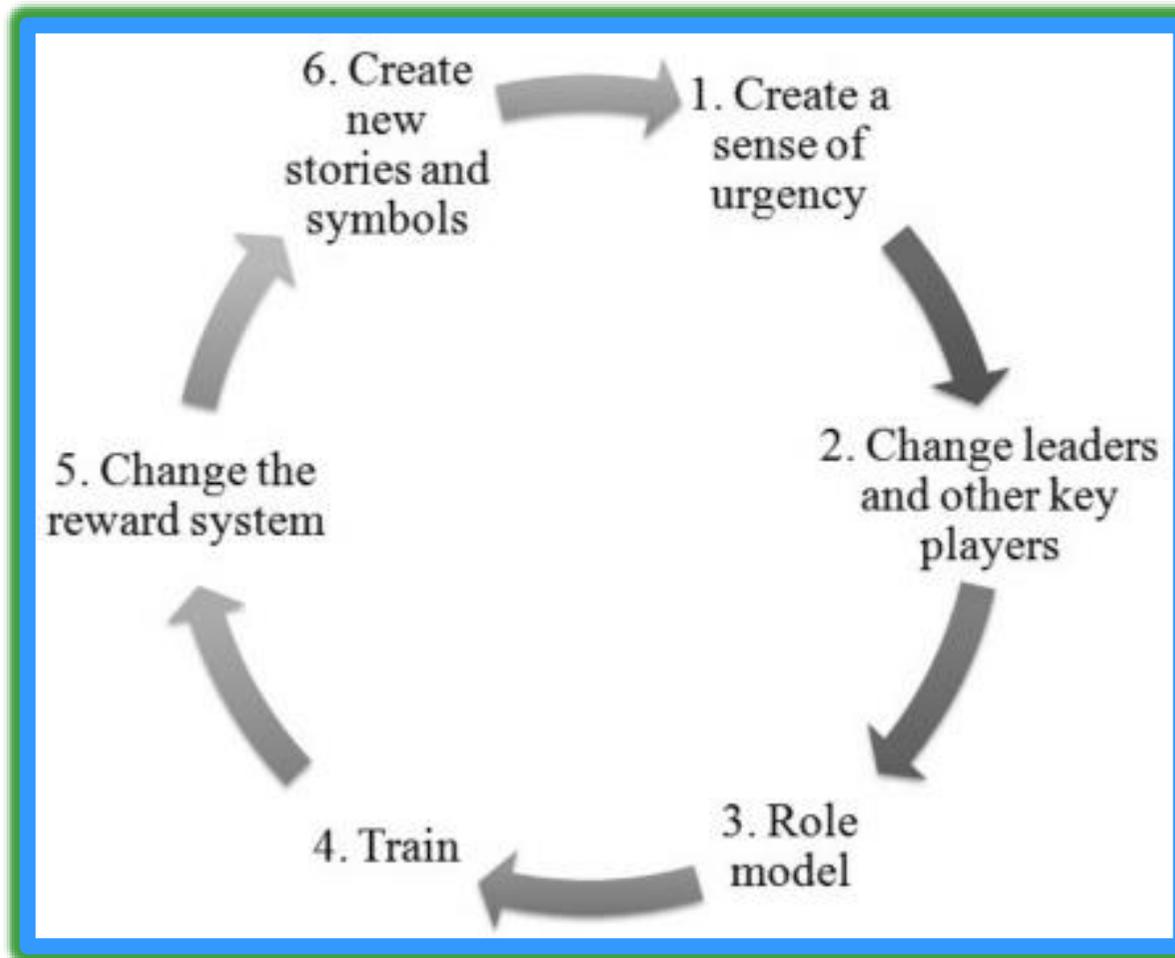
Absurd

If at first the idea
is not absurd, then
there is no hope for
it."

-Albert Einstein

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Effecting a Shift



<http://texasceomagazine.com/departments/people-matters/cultural-shift/>

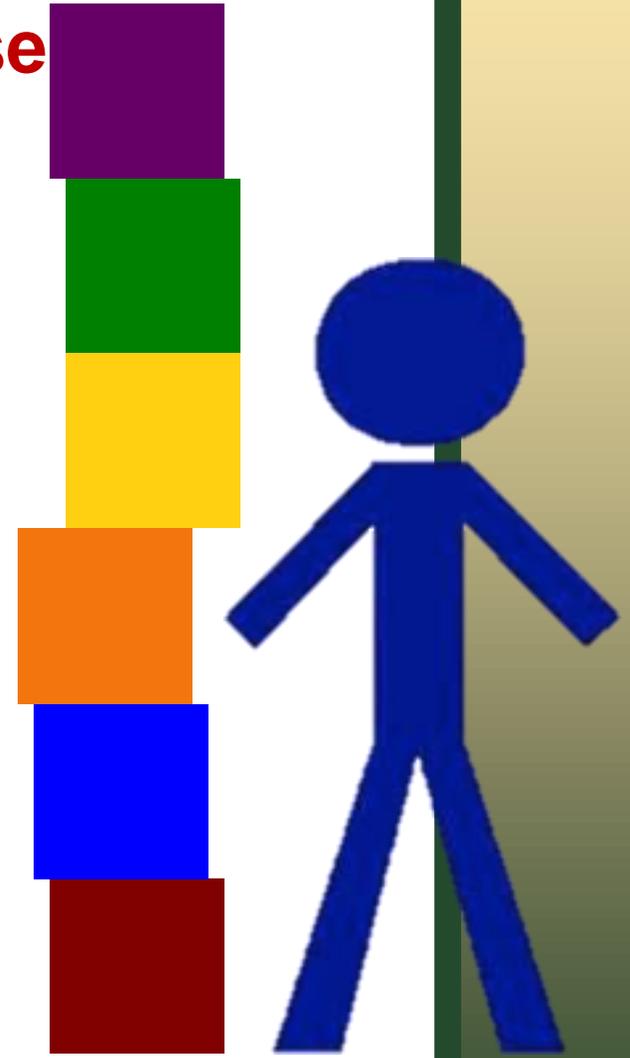
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Obstructionist

Those who continue to be antagonistic to progress and innovation in the field of I/DD are obstructing the quality of life of those supported!

- How should these obstructionist be dealt with?
- Who is responsible to deal with them?
- How much longer should they be allowed to obstruct?

These are not rhetorical questions.



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Inclusive Process

Integration and inclusion of people with disabilities is not an event!

Its success does not result from merely:

Closing Developmental Centers

Placing special needs children in regular classrooms

Eliminating sheltered employment programs

Shutting group homes



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Inclusive Process (cont'd)

Realizing an inclusive and integrated environment is a thoughtful process wherein:

- **Accessibility issues are addressed**
- **Protective oversight needs are met**
- **Staffing needs are allocated**
- **Training of personnel is initiated**
- **Specialized equipment/ materials are obtained**
- **Emotional support is provided for all those impacted**



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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!**

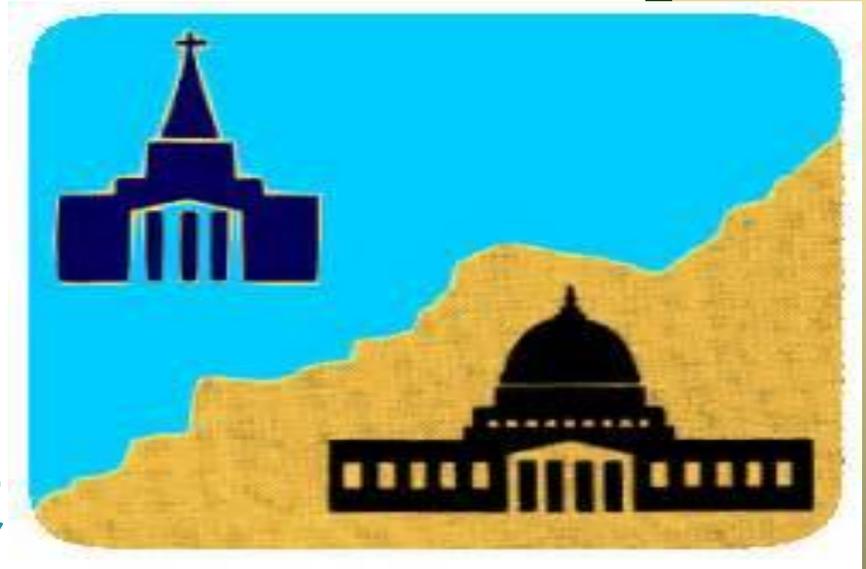


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Radical 'Inclusionists'...

**...their fanaticism continues,
despite the loss of their mission
and vision.**

**As there is a distinct
separation of church
and state, there must
be a separation of social ideology
from social pragmatism.**



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.

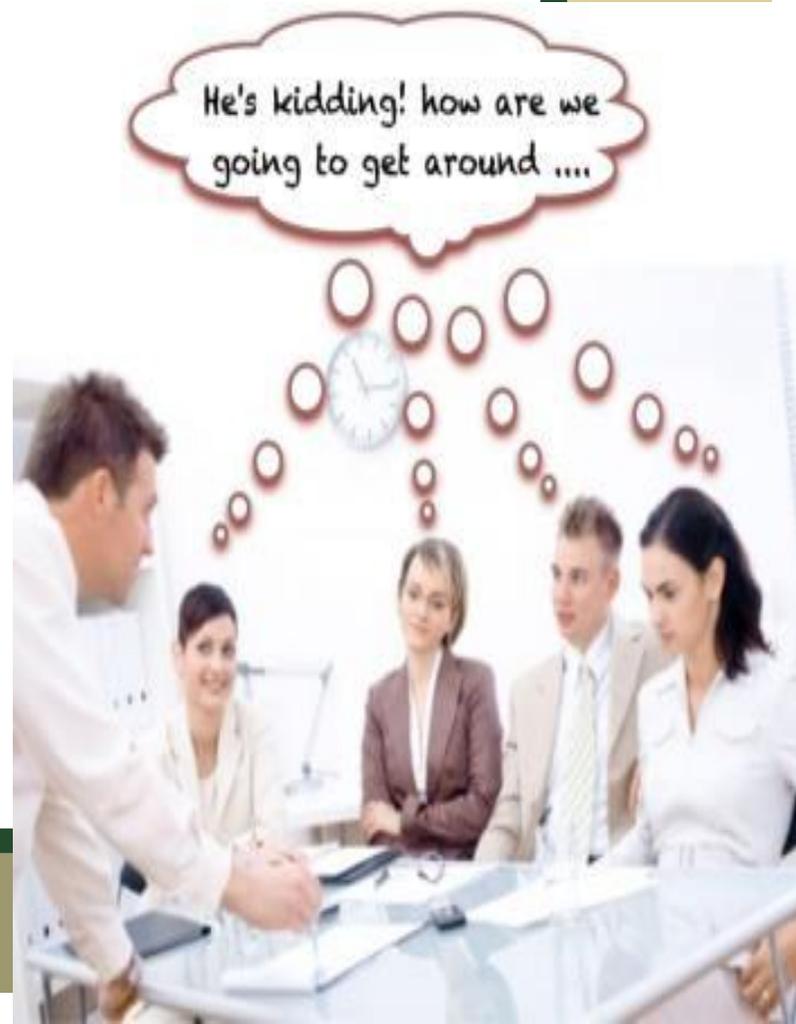
The person **selects** the support agency and the support staff.

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Too Slow

Influences impairing the shift toward supported living:

- **Parents believe their “child” is safer in a congregate setting**
- **Staff fear change in employment role/function**
- **Residents feel secure in their familiar setting and fear the unknown**
- **State Medicaid Plan not developed nor funded to handle “support” services**
- **Providers resistant due to current investment in property**
- **Transition phase from congregate environments to supported living feared too costly to providers and States**
- **State operated congregate settings generate operating revenue for the State**



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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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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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Ask Them to Dance

Integration is being asked to the party

– inclusion is being asked to dance.



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Being In Is Not Enough

IN the Community -

- **Present**
- **Located**
- **There**

OF the Community -

- **Connected to**
- **Having a presence**
- **Assimilated with others**
- **A member of**



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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.



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Thoughts on Inclusion (cont'd)

Inclusion:

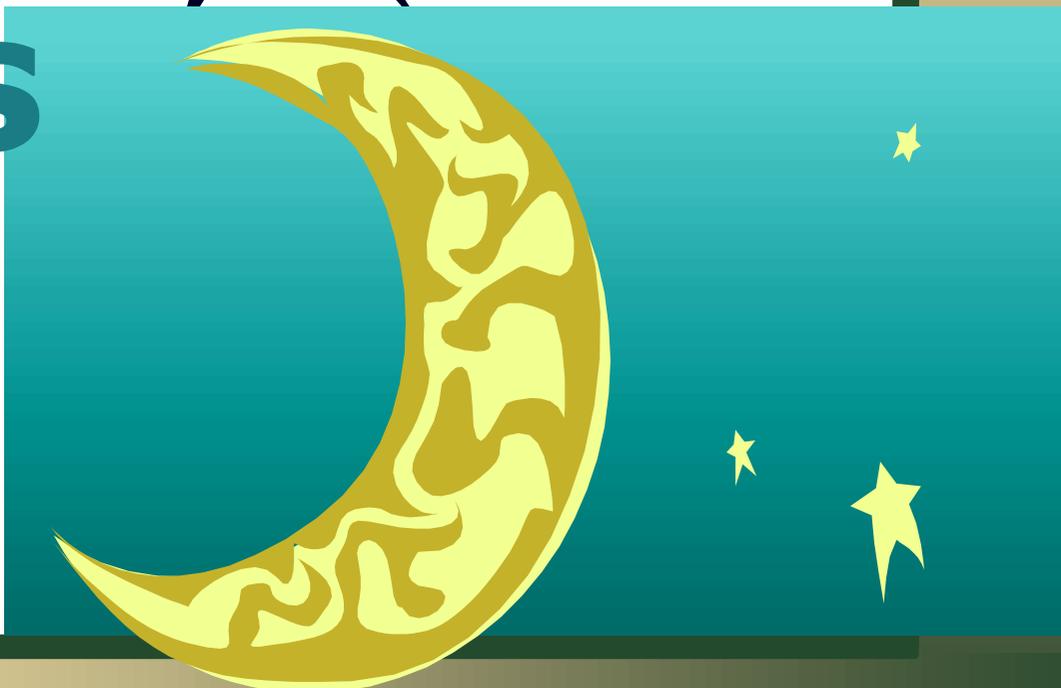
- is not provided by the charitable contributors to the lucky recipient
- is not an intervention delivered to support recipients perceived as passive beneficiaries



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Inclusionary Trek

To boldly
go where
everyone
else has
gone
before.



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Community Network



- Community is a network of people. Members may be geographically distant and vary in numerous 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

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An Enviably 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 Enviably 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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More Life

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



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Life Coaching



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

-- Todd Risley, Ph.D.

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Promotion

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

- Rob Horner, Ph.D



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A Good Community

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

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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.

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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.



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.



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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.



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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.



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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.



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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.



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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.



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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.



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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.



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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.



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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"

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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"

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