Assuring Individual Rights:
The Price of Liberty

by

Thomas E. Pomeranz, Ed.D.
Individual Rights...

...refers to the rights of the individual distinct from civil rights legal rights and group rights (or privileges) granted by government and varying with the organization and administration of the government.

...identifies the boundaries of just social interactions, in the presence or absence of government.
Individual Rights... (cont’d)

...are an individuals' moral claim to freedom of action. Such rights may be respected or recognized by others for reasons of reciprocity, contract, pragmatism, or as a moral imperative. Also some theorists believe an individual can forfeit their rights if that individual does not exercise reciprocal respect and restraint.

...are the rights of individuals by virtue of their humanness (e.g. their nature or rational being).

Dictionary by Farlex
Swinging Pendulum

Institutional Period

Professionals know best

Options not offered

Opinions not sought

Denial Of Rights

Universal Enhancement
It Speaks For Itself

Universal Enhancement
Authoritarian – I decide because they are not capable of making the right decision!
<table>
<thead>
<tr>
<th>Choices and Decision-Making</th>
<th>Are Restricted</th>
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Universal Enhancement
Held Hostage

I hope they don’t discharge too many of these residents to the community.

If they do we might be out of a job!

How long must people with intellectual disabilities be used as pawns to assure that others have jobs?
Dirty Little Secret

Under the rock:

- Putting them down at 7 PM
- Skipping baths
- Not reporting med errors
- Sleeping on duty
- Ignoring soiled attends
- Falsifying program records
- Physical abuse

Where is the oversight?
Home Sick?
For people who miss the good ‘ole days at the institution.

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REAL VOMIT: $6.95 PER PINT
   $12.95 PER QUART
   (SPLIT PEA WITH HAM - $2 EXTRA)

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DISINFECTANT BODY MIST,
   $12.90
ONE LITTLE SQUIRT AND YOU'RE RIGHT BACK IN O.T.

SURPRISE TV!

This TV will switch channels randomly at variable intervals and turn on and off at all hours unpredictably. No controls!

SHCHAMBERS
The GAG
Regret

Regret is a prison, difficult to escape.

Why did I do that?!
Banana Republic

We appoint you King and Queen.

Client Councils are forms of “mock” self-governance, commonly established in large congregate settings/institutions.

To assure the oppressed remain docile oppressors nurture Banana Republics.

Universal Enhancement
The Greatest of Sacrifices

The loss of liberty is the price of care
Self – Determination:
The power or ability to make a decision for oneself without influence from outside; Collins English Dictionary

Determination of one’s own fate or course of action without compulsion; Based on Wordnet 3.0

It is the belief that people with disabilities have the right and ability to choose and control their own quality of life, their own goals and dreams and what service they need to obtain these. State of Hawaii, Self – determination Booklet
Self – determination is not a program! It is an attitude!
The punishment of prison is denial of self – determination!
Swinging Pendulum

Institutional Period

Professionals know best
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Denial Of Rights

Institutional Reform Period

Individual rights vs. right thing
Poor quality in name of rights
In jeopardy in name of rights

Rights At All Costs

Universal Enhancement
Quality

Don’t excuse poor quality in the name of:

Decision Making
Self-Determination
Individual Rights
Self Expression

How do we assure quality supports without the imposition of unnecessary control?

Universal Enhancement
Avoiding Accountability

I know he looks ridiculous, but it’s his right to dress the way he wants.

The pretense of rights allows the “Rightist” to avoid accountability, exposing their inability to teach others how to make choices.
Where’s Your Focus?

We are focused more on rights, than doing the right thing!

Universal Enhancement
Find A Balance

Authoritarian – I decide because they are not capable of making the right decision!

Laissez Faire – It is their right! They can do as they please!
Radical “Rightsist”
Let it be known that there are those who would sacrifice an individual’s well being, health and happiness to avoid the imposition of restrictions.

Stand up to these Radical Rightsists!
When the organization’s philosophy is “we don’t restrict rights”, RECOGNIZE that when people are in jeopardy, failure to restrict rights may be a denial of rights!
Find A Balance

Authoritarian – I decide because they are not capable of making the right decision!

Laissez Faire – It is their right! They can do as they please!

These represent two personality extremes that may mask the staff/family struggles to deal with their own issues.
How You Define It

Individual Rights are like pornography. It’s a matter of geography.

- Prohibition of informed consensual sex
- Denial of employment
- Imposition of rigid schedules
- Restriction on freedom of movement
- Insensitive behavior management programs
- Limited/no options

Universal Enhancement
One can only gain liberty when one is willing to be responsible for their actions.
Their Rights!

Don’t just emphasize their rights; Focus on what you can do to support individuals in being responsible adults!
Disability is too often used as a cover for:

- Sexual impropriety
- Theft
- Fraud
- Lying
- Aggression
- Property destruction
- Illegal drug use

We must promote a culture of personal responsibility among those we support!
Why...

...are rights denied?

(check the correct response)

- Mean-spirited
- Malevolent
- Vitriolic
- Ignorant

Universal Enhancement
Restricting Rights

Should rights be abridged by virtue of receiving services?
Questionable Restrictions

Options, spontaneity and opportunities are frequently restricted because...

• Rules and policies mandate it
• Individuals are seen as children
• The agency is risk intolerant
• Staff must maintain control
• The agency attorney said so!

Stop the questionable restrictions!
House Rules
When do house rules infringe on the rights of the individuals?
You may not...
• Have a pet
• Consume alcohol
• Have food in your bedroom
• Leave your home without supervision
• Have friends in your home without permission
• Use the telephone after 10 PM
• Watch TV after 10 PM on week nights
House Rules (cont’d)

You may not...

• Use vulgarity
• Use the property of others without their permission
• Leave the home without informing staff
• Refuse to do your assigned home chores
• Smoke in non smoking areas
• Disturb others with your radio or TV
• Be impolite
Just Felt Like It

Are there occasions when you...
- wear no underwear under your clothes?
- eat dinner in bed?
- eat dessert first?
- watch TV at 2:00 AM?
- sleep on your living room floor?
- eat cold pizza for breakfast?

These are freedoms of expression that we all take for granted.

Do those you support have these freedoms?
Extending or restricting rights is a political tight rope. No matter the response opposition will arise from:

- Family
- Guardian/conservator
- Protection and Advocacy
- Licensing
- Accreditation
- Media
- Funding authorities
- Staff
- Medicaid
- Administration/management
Political Tightrope (cont’d)

Courts
Academia
Case Managers/Service Coordinators
Human Rights Committees
Clinicians
Ombudsman
Board of Directors
Elected Officials
Legal Counsel
The Support Recipient
Neighbors

Who Do You Listen To?
Celibacy

When individuals can provide informed consent for sexual expression, why should they be...

denied  deterred  precluded
prohibited  dissuaded  refrained
restricted  prevented  intimidated

...from such expression by virtue of their diagnosis or need to receive supports?

Must those we support be required to take a Vow of Celibacy?

Universal Enhancement
Regulatory Focus
Free from:
- Abuse
- Neglect
- Intrusion
- Subjugation
- Boredom
- Deprivation

Universal Enhancement
Universal Enhancement Focus

Free to:

• Form relationships
• Choose residence
• Schedule routines
• Select housemates
• Employ support staff
• Express dreams and desires
Where Are They?

When will Human Rights Committees take a stand to declare that being denied an opportunity to:

- choose what food you eat
- determine who you live with
- decide where you live
- select your support staff
- determine your daily schedule
- engage in spontaneous activities
- have a consensual sexual relationship...

is a denial of basic human rights?
Restricting Rights

Should rights be abridged by virtue of receiving services?

or

Should rights be abridged as a result of one’s conduct?

Universal Enhancement
Self - Advocate
To speak, plead or argue in favor of [something or someone that benefits oneself] ; one that argues for a cause; a supporter.
Speak Out

Self-advocacy may be misinterpreted as...
acting out
non compliance
defiance
oppositional behavior
stubbornness

...when expressed by people with intellectual or other developmental disabilities.
Warning Signs

THIS IS A WHEELCHAIR - NOT A HEARING AID

TOO MANY PEDESTRIANS - SO LITTLE TIME

IF YOU PAT ME ON THE HEAD ONE MORE TIME ILL BREAK YOU LEGS
Self Advocate Wheelchair

Universal Enhancement
Teaching Self Advocacy

**IMPERATIVE:** Teach the people we support to be effective self advocates!

“please don’t talk to me as if I’m a child”
“please don’t touch me like I’m a child”
“please don’t assist me without my permission”
“please don’t talk about me as though I’m not here”
“please don’t ask others what I want”

“Ethel, please don’t grab my walker without asking me first.”
Civil Rights

The furtherance of civil rights must be bannered by those who are subjugated and marginalized. Why must people with developmental disabilities be limited to self-advocate, when acts of protest are needed?

We want to choose where we live!
We want to choose with whom we live!
Guidelines for Choice and Decision-making:

1. Provide people options.
2. The more capable and competent the person, the larger the set of options that can be provided.
Provide Options

How do you provide bounded options to individuals requiring pervasive supports?

Soap
Food spices
Make up
Clothing
Jewelry

Toothpaste
Bath Time
Shampoo
Cologne/perfume
Pillow firmness

How would you feel if you were denied options for these aspects of your life?
Guidelines for Choice and Decision-making:

- Provide people options
  - The more capable and competent the person, the larger the set of options that can be provided
- Bound people’s options - limit options that can result in injury or death
Heat-related death is under investigation

By Douglas A. Campbell
Inquirer Staff Writer

William Philipscheck, the 40-year-old mentally disabled man who died of a heat-related illness Thursday, had chosen not have air conditioning, according to an official of the company paid by the state to teach him “daily-living skills.”

Philipscheck, a client of the state Division of Developmental Disabilities, spent Wednesday on a state work crew picking up trash in Atco. He died of hyperthermia at 1:40 a.m. Thursday at Underwood-Memorial Hospital in Woodbury after his body temperature reached 106 degrees.

Yesterday, Camden County Prosecutor Edward F. Borden Jr. had taken over the investigation of Philipscheck’s death. Officials at Underwood-Memorial Hospital, the county medical examiner’s office and state Division of Developmental Disabilities referred all questions to the prosecutor.

Norman Reim, a spokesman in the state Department of Human Services, said his agency issued a directive yesterday “throughout our system statewide...to take special care of clients because of the extreme heat.” The Division of Developmental Disabilities is part of the Department of Human Services.

Reim said Philipscheck Associates Inc., of Gloucester City, which runs the Brooklawn apartment complex where Philipscheck lived, was responsible for providing medical aid to the man.

Betsy Snyder, Philipscheck’s assistant executive director, said yesterday that Philipscheck had been “monitored regularly throughout the night” by the company’s staff the evening before his death.

Snyder confirmed statements by other residents of the company’s four-unit Georgetown Square complex that Philipscheck’s apartment unit had no air conditioning.

The Georgetown Square complex

Residents interviewed Thursday said that Philipscheck was lying on a stone front step at the complex at 6 p.m. Tuesday, only able to mumble. When a Kelsch caretaker was notified, according to resident Stacey Bowe, the caretaker said Philipscheck was simply looking for attention.

Snyder said that Kelsch had talked with staff members and taken written reports from them.

She said that staff monitoring of residents involves “helping them with daily-living skills, if needed.”

Snyder said Philipscheck “has been with our agency for a number of years” in two programs.

Reim, the spokesman for DHS, said that on Wednesday, Philipscheck had gone to his state-sponsored job, which he had been doing since the mid-1980s. Reim said the job that day involved gathering trash in Atco.

Reim said the state’s clients are paid for their work. “They were taking breaks” during the work day, Reim said of Philipscheck’s crew.

Borden said his investigators are looking into “all the facts and circumstances” surrounding Philipscheck’s death.

Inquirer Staff Writer Larry Lewis contributed to this article.

Bill (Philipscheck) was an individual who decided he did not want the air conditioning.
Covenant

When we commit to provide supports, a covenant is formed. Though not in writing, a contract is consummated:

Do No Harm

The imposition of restrictions arises not from the individual’s diagnosis, but from our covenant.
People with disabilities have a right to the same boundaries that define appropriate behavior for all individuals.

JUST SAY NO TO:
- Obsessively shaking hands
- Telling strangers that they love them
- Asking strangers for money
- Speaking excessively loud
- Inappropriate hugging
Quintessential Rights
Perhaps the most important right of the people we support is to be viewed with dignity and respect; thus they are more likely to be treated with dignity and respect!
She’s 45 Years Old

She likes it when I:
Hold her hand while walking
Speak to her in childlike intonation
Give her children's toys to play with
Pat her on the head

Infantilize her, eroding her dignity and respect

Universal Enhancement
Respecting Rights

We must create a climate that communicates *respect* and *value*. **Individualization** of personal space - the person is unique, possessing things of value. **Age appropriate** items - regardless of ability, the person deserves the respect extended to all adults. **Meaningful work** – engaging in activities of meaning and making valued contributions.

All are effective strategies for promoting individual rights.
Establishing Boundaries

When addressing difficult rights’ issues that impact quality of life, you might consider wearing three hats.

Clergy: There are ethical factors that must be considered.
Consider setting limitations if one’s choices are seen as unethical or degrading.

- Wearing provocative or revealing clothing
- Using offensive language in public
- Exposing others to offensive magazines
- Lying to avoid consequences
Establishing Boundaries

When addressing difficult rights’ issues that impact quality of life, you might consider wearing three hats.

Clergy: There are ethical factors that must be considered.
Police: There are legal factors that must be considered.
Legal Factors

The options of individuals may need to be bounded, if their behavior violates the law.

- Making harassing telephone calls
- Going into neighborhood homes uninvited
- Buying cigarettes or liquor for minors
- Taking candy from a grocery store
Establishing Boundaries

When addressing difficult rights’ issues that impact quality of life, you might consider wearing three hats.

Clergy: There are ethical factors that must be considered.
Police: There are legal factors that must be considered.
Ombudsman: There are personal wishes that must be considered.
Ombudsman
One that investigates reported complaints, reports findings, and helps to achieve equitable settlements.
Rights of Individuals with Disabilities

You have the right to:

Wear your own clothes and to choose them

To keep your own things in a private place that you can access whenever you want

See your friends, family, girlfriends or boyfriends every day

Use the telephone privately to make or get calls

To have paper, stamps and envelopes for writing letters

To mail and receive letters that are not opened

To say “NO” to anybody trying to change the way you act by hurting you or upsetting you
Rights of Individuals with Disabilities (cont’d)

You have the right to:

How you want to spend your free time and with whom

Services that help you live, work, and play in the most normal way possible

Keep and spend your own money on the things that you want and to keep and use your own things

Be treated well and with respect

Spend time alone or alone with a friend/s

Go to school

Be involved in a religion if you wish to be
Rights of Individuals with Disabilities (cont’d)

You have the right to:
See a doctor as soon as you need to
Meet people and take part in your community activities
Exercise and have fun
Say “NO” to things that will put you in danger
Make choices about where you live, with whom you live, the way you spend your time and with whom you spend it
Say “NO” to drugs, being tied or held down, or being forced to be alone unless it is necessary to protect you or someone else

Other rights as provided by law or regulation

Adapted from Capitol People First Consumer Rights Poster; Mayer-Johnson Company
Guardianship Defined

Guardianship for physically or intellectually disabled persons has, in recent decades, been understood to facilitate the independence and self reliance of the ward. They are limited as much as reasonable in order to allow wards to exercise as much control over their lives while maintaining as much dignity and self reliance as possible. The desires of the wards are given primary consideration. Also wards are allowed to do as much of their care giving as possible.

The guardian will be granted only those powers necessary to accomplish for the ward what the ward cannot accomplish independently.
Guardian’s Responsibility

Many guardians and providers are confused—guardian’s are not bestowed unlimited rights by the court. They are delegated duties and responsibilities!
Guardianship

What laws give legal guardians the authority to determine whether a:

- 40 year old woman with intellectual disabilities may shave her legs?
- 53 year old man with intellectual disabilities and cerebral palsy may display a Playboy Bunny poster on his bedroom wall?
- 47 year old woman who requires pervasive supports may wear make up and jewelry?
- 34 year old man with autism may attend a church service with a friend of a different religion?

Some “wards” will not be able to experience life (emancipated) until ….
In grim reality, Polly Spare is President of Voice of the Retarded (VOR), a group of parents who once dumped their kids in institutions and today grease political wheels to keep them there. Allied with unions representing workers at DD centers, VOR is well-heeled and very influential. Its *amicus* brief in the *Olmstead* case said, “The safety and constant monitoring provided by an institutions presents one care option envisioned by the ADA.”

Reprinted from”THE GAG”
Bad Choices

Making bad choices may lead to the ability to make good choices.

Bad choices:
- Staying up after midnight on a work night
- Not using suntan lotion at the pool
- Leaving your purse unattended
- Not brushing your teeth on a regular basis

We learn through our MISTAKES.
Informed Consent

• An informed consent can be said to have been given based upon a clear appreciation and understanding of the facts, implications and future consequences of an action.
• In order to give informed consent, the individual concerned must have adequate reasoning facilities and be in possession of all relevant facts at the time consent is given.
• In cases where an individuals is provided insufficient information to form a reasoned decision, serious ethical issues arise.

Wikipedia
Reasonable Risks

Individuals make good choices by making many choices - some of which are bad.

*Risk adverse systems limit opportunities... is your system risk adverse?*
Decisional Capacity

There are three abilities that influence one’s decisional capacity:

- to understand the consequences of the choice
- to analyze the options that are consistent with one’s preferences
- to communicate preferences to others or independently act upon them to make a choice
Informed Consent Challenges

How can people be assisted in making informed consent decisions when they have:

- Cognitive impairment?
- Psychiatric illness?
- Lack of relevant experiences?
Making Choices

- Empowers the individual; increases individual sense of control
- Leads to a sense of self efficacy, i.e., effort will produce a positive result and increase self esteem
- Increase communication and self expression
- Internal model for a positive alternative behavior that is a substitute for “acting out”
Bounded Choice
A concept which advocates identifying limits imposed on individual choices as a result of ability, societal norms and/or available resources.

Universal Enhancement
Imposing Boundaries

The time and intensity of support is a significant factor in determining how intrusive we are.

- **Limited Imposition of Boundaries**
  - 2 hours per day

- **Pervasive Imposition of Boundaries**
  - 24 hours per day

In limiting:

- *Cigarettes smoked*
- *Cash carried*
- *Calories consumed*
- *Alone time*
- *Bedtime*
- *Sexual expression*
High Risk Choices

Some choices may involve significant risk to the individual, others or property. A choice would be considered “high risk” if it could lead to imminent or probable harm or to a consequence which violates the norms of the agency or the majority of individuals in the environment.
High Risk Choices (cont’d)

The choice of individuals may need to be limited if the choice:

- May result in severe and/or immediate negative consequences to the individual or others
- Will lead to imminent or very probable near-term physical or psychological harm to the individual making the choice
- Will physically harm another individual
High Risk Choices (cont’d)

Demonstrates a severe disregard for the dignity or security of other individuals

Will result in probable ridicule or isolation of the individual making the choice

Will result in serious property damage
High Risk Choices (cont’d)

Examples of individual choices which may involve high risk include:

An individual with poorly controlled diabetes chooses to be diet non-compliant, resulting in repeated hospitalizations.

An individual with a personality disorder hits and spits at other residents and staff.

A confused individual who likes to smoke in his/her apartment has tried to put cigarettes out on articles other than an ashtray.
Low Risk Choices

Most choices have results which involve little risk or have an impact which is relatively inconsequential. Where risk is involved in such situations:

- The risks are tolerable
- The party making the decision understands the consequences
- The party making the decision has the resources (e.g. personal or financial) to deal with the consequences
- Mutually agreeable action is easily negotiated and would be commonly considered acceptable
Low Risk Choices (cont’d)

Most individual preferences involve little risk of negative consequences. Examples of such choices would include:

- To not take a shower as regularly as expected
- To have chocolate rather than vanilla ice cream
- To refuse to take medication for constipation
- To skip breakfast in the dining room and instead have milk and cereal or toast in the individual’s apartment
- To wear three sweaters at one time
A concept which advocates a formal process of negotiating a plan to address decisions or preferences, to decrease the probability of poor individual outcomes or of putting others at risk for adverse consequences.
Managed Risk

When there is a high probability that a choice will result in harm to an individual and/or others, an obligation exists to:

Be pro-active in identifying the cause for concern

Provide information about the possible consequences of his/her choice

Negotiate an agreement that will minimize the possible risk while still respecting the individual’s preference

Document the process of negotiation and the decisions made
Managed Risk (cont’d)

Managed Risk Agreements should be negotiated with the individual and/or designated agent(s), and should address the following items in writing:

- The cause for concern
- The probable consequences of the choice
- What the individual wants
- Possible alternatives to the individual’s current preference/action
- The final agreement reached by all involved parties
Managed Risk Agreement

The rationale for and structure of a Managed Risk Agreement:

Cause: History of making annoying and harassing telephone calls

Consequence: Violation of law; punishment

Wants: Unrestricted phone use (e.g. no one monitoring, to call mother and two friends anytime)

Alternative: Block all numbers but those identified; no time limitations; individual will pay for separate line
A concept which advocates establishing mutual expectations about exercising control and assuming a degree of responsibility for the results of decision-making.
Shared Responsibility

Shared responsibility requires give and take:

- Walking to the park unsupervised
- Spending the night with the opposite sex
- Consuming alcohol
- Gambling
- Getting a tattoo
- Learning to drive
- Obtaining a credit card

Identify the provider’s risks and the individual’s responsibilities.
Implementing Choice

Learn to assess the degree to which choices, if executed, are likely to result in undesirable outcomes, such as:

- Unwarranted burden
- Violation of societal or personal norms

Concepts in Community Living
Implementing Choice (cont’d)

Learn to distinguish between normal negotiation of services/intervention and the need for a formal “managed care agreement”.

- The severity of any negative consequences
- The immediacy of any negative consequences
- The impact of any negative consequences
Implementing Choice (cont’d)

Learn to distinguish between “enabling” and “preventing” when responsibility can’t be shared equally, and identify when each of these roles is appropriate.

Achieve support/collaboration
Deny or remove the opportunity
Implementing Choice (cont’d)

Learn to assess the likelihood that the individual is a fully informed decision maker.

- Situation-specific competency
- Delineation of options with attendant benefits and risks
Implementing Choice (cont’d)

Learn to evaluate accurately the sources of concern and how to mediate them.

- Threat to the well-being of the individual or to the professional doctrine of “best interest”
- Threat to the well-being of the individual or the provider’s image
- Threat to the well-being of the individual or to the stereotypical patronizing view of individuals who are elderly or have a disability