

Supported Decision Making

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NAPSA Conference 2016

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Agenda

- Introductions
- What is Supported Decision Making
- Why is Supported Decision Making Important
- How We Can Foster Supported Decision Making



What Is Supported Decision Making?

PERSONS MAKING THEIR OWN DECISIONS
WITH SUPPORT AND ADVICE FROM OTHERS
AS DESIRED OR NEEDED

- Supported decision making means that people with disabilities fully enjoy rights and receive support to exercise rights
- Not substitute decision making but supported decision making

Supported Decision Making

“Gaining autonomy through gaining support”

Dr. Patricia O’Brien

UN Convention On Rights Of People With Disabilities (2006)

“Purpose of the convention is to

Promote

Protect

and

Ensure

the full equal enjoyment of all human rights and
fundamental freedoms by all persons with
disabilities and promote their inherent dignity.”

Margaret Jenny Hatch





*Supported Decision Making –
Rights and Models –Audrey Cole*

Capacity redefined (CACL):

That the understanding of the information relevant to the decision to be made and the appreciation of the reasonably foreseeable consequences of such decision or lack of such decision, may rest either,

within the adult herself or himself, and with decision-making supports and accommodations as needed; or, alternatively,

within the understanding, appreciation and fiduciary duty of the person or persons duly appointed to support the adult in exercising her or his legal capacity



A fundamental principle:-

- *Every person, no matter how severe his or her disability, can maintain control over his or her life solely by means of the commitment that other people are willing to make to that person 's well-being: people should be enabled and supported to maintain that control.*
- That is also the essence of the concept of supported decision making

*Supported Decision Making –
Rights and Models*

- * Rather than “replacing” the person in the decision making process (as does Guardianship)
- Supported Decision Making shifts the focus of the question
 - from the “competency/capacity” of the person
 - to the “competency and integrity” of the decision making process

- In other words, the issue is no longer
“Is this person capable of making decisions?”
- It becomes:
“How do we effectively provide the support this person requires to ensure that only the best and most appropriate decisions are made; that they would be the decisions he or she would make were he or she able to do so; and that they are recognised as being his or her decisions?”

Big vision of Personal Decision Making

- People make their own decisions about the small and big areas of life with advice and assistance from trusted others as is needed/wanted
- People with disabilities fully enjoy rights and receive support to exercise rights to make decisions
- Decisions are informed by: life experiences, cultural practice, and trusted people

Different Forms of Supported Decision Making

- Advocating for oneself with advice
- Use of mainstream measures and supports e.g. lawyers, community information or advocacy organizations
- Formal: supported decision making group, micro board
- Semi-Formal: circle of support
- Informal: Intentionally developed relationships-e.g., family members, friends, service workers, citizen advocates – chosen by the person -- people who the person trusts and has chosen who will provide information, advise, and if need be make decisions with the person's permission

Who Does Supported Decision Making Apply To?

People who are:

- Societally devalued

And

- Impaired in their cognitive ability to make decisions

Definition of Devaluation

The attribution of low, or even no, value to a person or group

By another person or group

On the basis of some characteristic (usually a difference that is perceived as a negative)

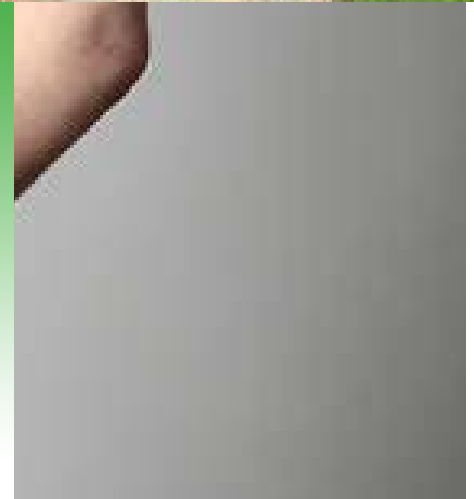


UNIVERSAL NEGATIVE CONSEQUENCES OF DEVALUATION TO DEVALUED PERSONS/GROUPS

Society devalues certain qualities & conditions

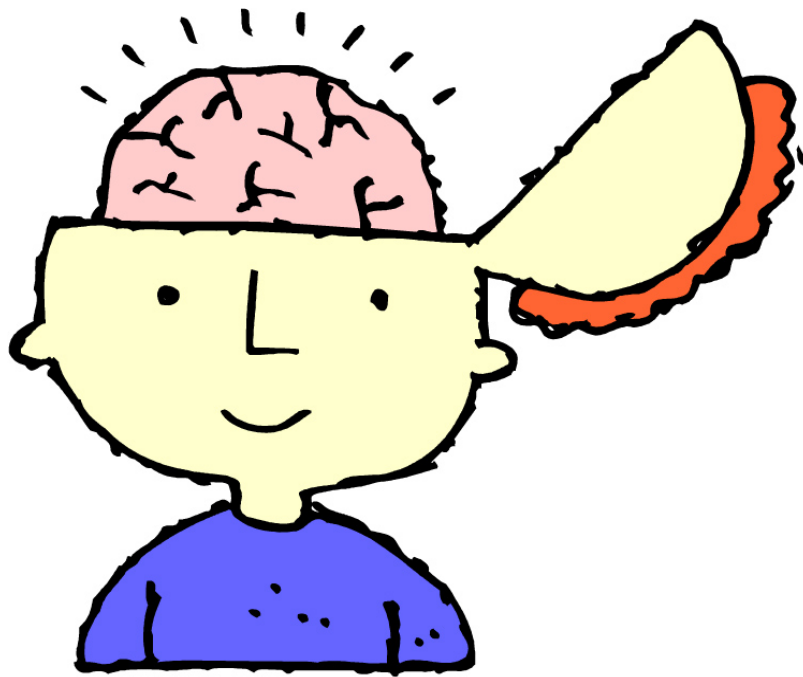
OUR SOCIETY TODAY PLACES HIGH VALUE ON:

- Wealth, material prosperity, material goods
- Health & Beauty of body
- Youth, newness
- Competence, independence, intelligence
- Productivity, achievement
- (Adult) individualism & unrestrained choice
- Hedonistic / sensualistic pleasure









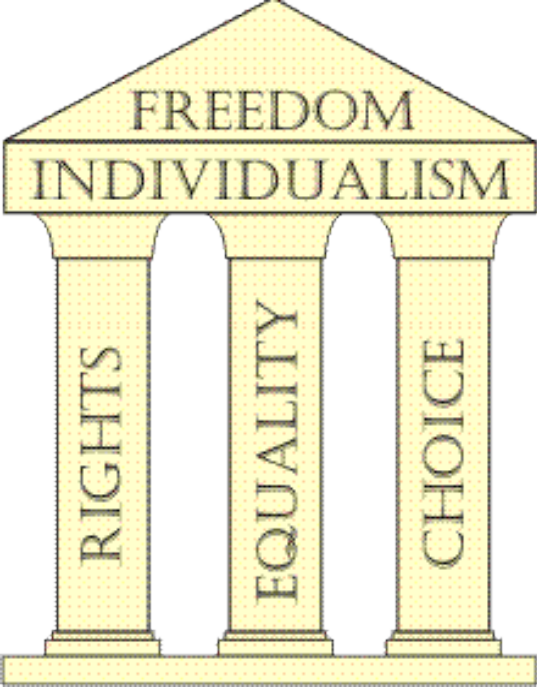


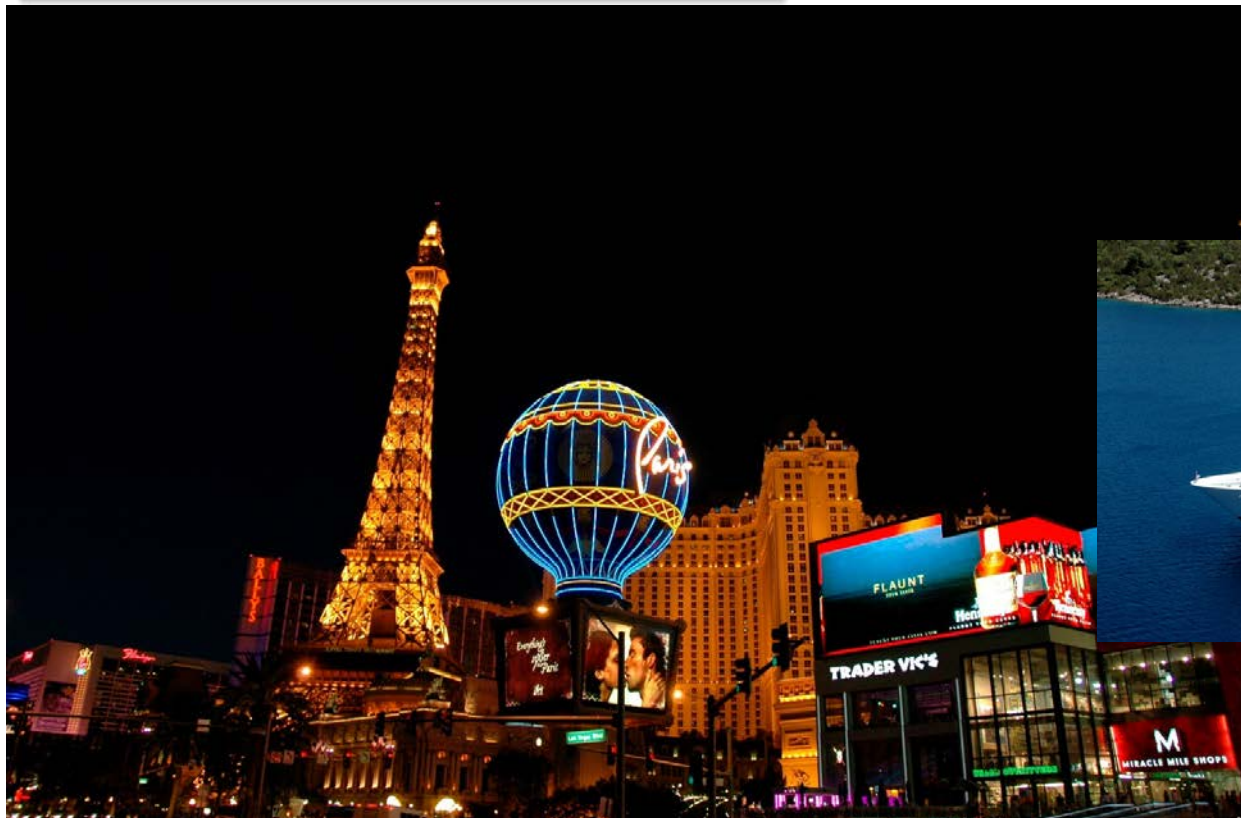
ACHIEVEMENT

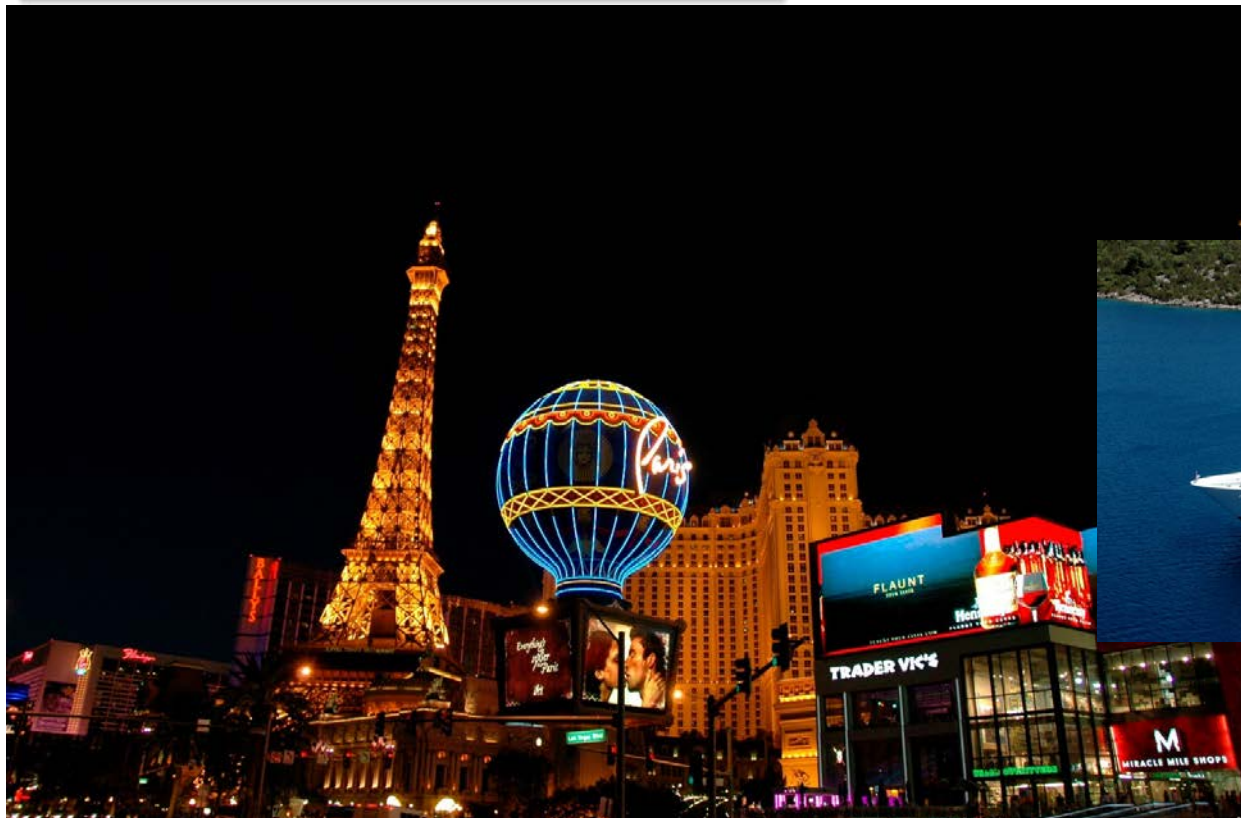
It is hard to fail, but it is worse to have never tried to succeed.

MotivationalTwist.com











GROUPS WIDELY DEVALUED IN WESTERN SOCIETIES

People who are impaired in

- Senses: Vision, Hearing
- Body: Cerebral Palsy, Epilepsy, Paralysis, Severe / Chronic Sickness, Near Death
- Mind: Intellectual Disability, Mental Disorder/ Illness

People who are seen as being very disordered in their conduct or behavior

- Activity Level: Hyperactive, Lethargic
- Sexual Orientation or Conduct
- Self-Destructive, “Substance” Dependent

MINORITY GROUPS WIDELY DEVALUED IN WESTERN SOCIETIES

- Socially rebellious
- Committed crimes
- People who are poor
- People who have few or unwanted skills (e.g., are illiterate)
- People who are unemployed
- People who are rejected for other reasons, for example, due to:
 - Age: Unborn, Newborn, Aged
 - Race, Nationality, Ethnicity
 - Religion



UNIVERSAL NEGATIVE CONSEQUENCES OF DEVALUATION TO DEVALUED PERSONS/GROUPS

Society devalues certain qualities & conditions

- ↳ Persons perceived as identified with these qualities become devalued (i.e., cast into devalued status)
 - ↳ Are then rejected



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 - ↳ Are then rejected
 - ↳ Cast into devalued roles

HISTORICAL ROLE PERCEPTIONS OF INDIVIDUALS OR GROUPS WHO ARE DIFFERENT AND / OR DEVALUED

1. Non-Human

- Pre-Human
- No Longer Human
- Sub-Human: Animal, Vegetable, Object
- “Other”, Alien

2. Menace, Evil, or Object of Dread

3. Waste material

4. Trivial or Object of Ridicule

5. Object of Pity

“When the death of a disabled infant will lead to the birth of another infant with better prospects of a happy life, the total amount of happiness will be greater if the disabled infant is killed. ”

“Killing a disabled infant is not morally equivalent to killing a person. Very often, it is not wrong at all.”

“killing...a chimpanzee is worse than the killing of a human being who, if there is a congenital intellectual disability, is not and never can be a person.”

Peter Singer, Practical Ethics
(third ed. 2011)





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Teddy Bear To “Befriend” Elders



Lancaster News

“A Special Place for Kids”

A place to relate



HISTORICAL ROLE PERCEPTIONS OF INDIVIDUALS OR GROUPS WHO ARE DIFFERENT AND / OR DEVALUED

6. Burden of Charity

7. Child:

- Eternally
- Once Again

8. Ambiguous borderline role of the Holy Innocent

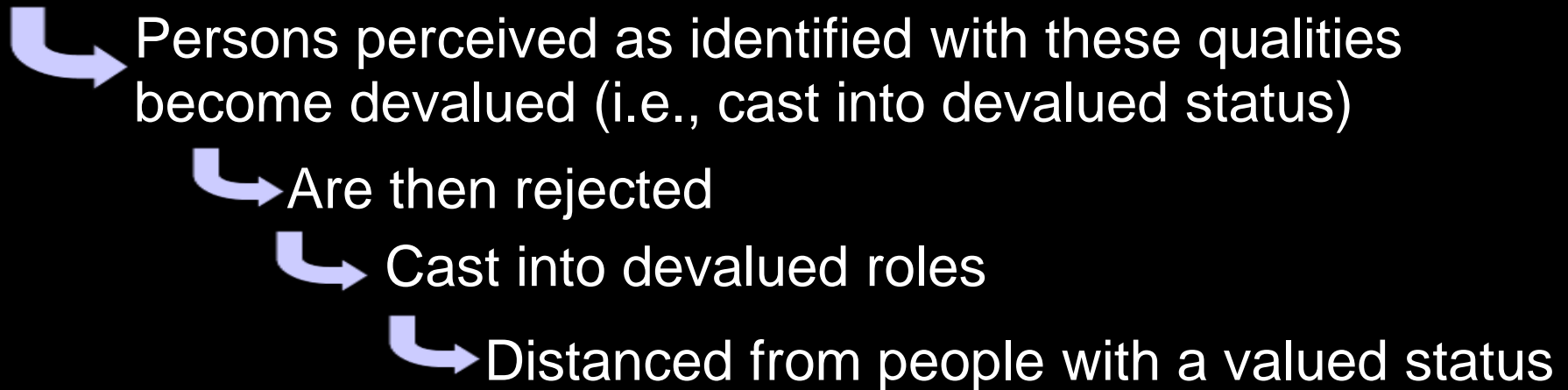
9. Client

10. Sick / Diseased

11. Dying, Already Dead, as Good as Dead, or Better Off Dead

UNIVERSAL NEGATIVE CONSEQUENCES OF DEVALUATION TO DEVALUED PERSONS/GROUPS

Society devalues certain qualities & conditions



ONE OF THE MOST COMMON RESPONSES TO DEVALUED PEOPLE IS DISTANCING, EITHER OF ONESELF, OR OF THE DEVALUED PERSON

A. Physical Distance

1. Physical Exclusion (e.g., architectural barriers)
2. Physical Segregation: Separate Facilities and Groupings, Institutions, Ghettos, Reservations
3. Physical Confinement: Prisons, some Institutions and Nursing Homes
4. Physical Ejection: Banishment, Expulsion,
5. Physical Destruction

ONE OF THE MOST COMMON RESPONSES TO DEVALUED PEOPLE IS DISTANCING, EITHER OF ONESELF, OR OF THE DEVALUED PERSON (cont'd)

B. Social Distance

1. Avoidance of Interactions (e.g., ignoring the presence of people)

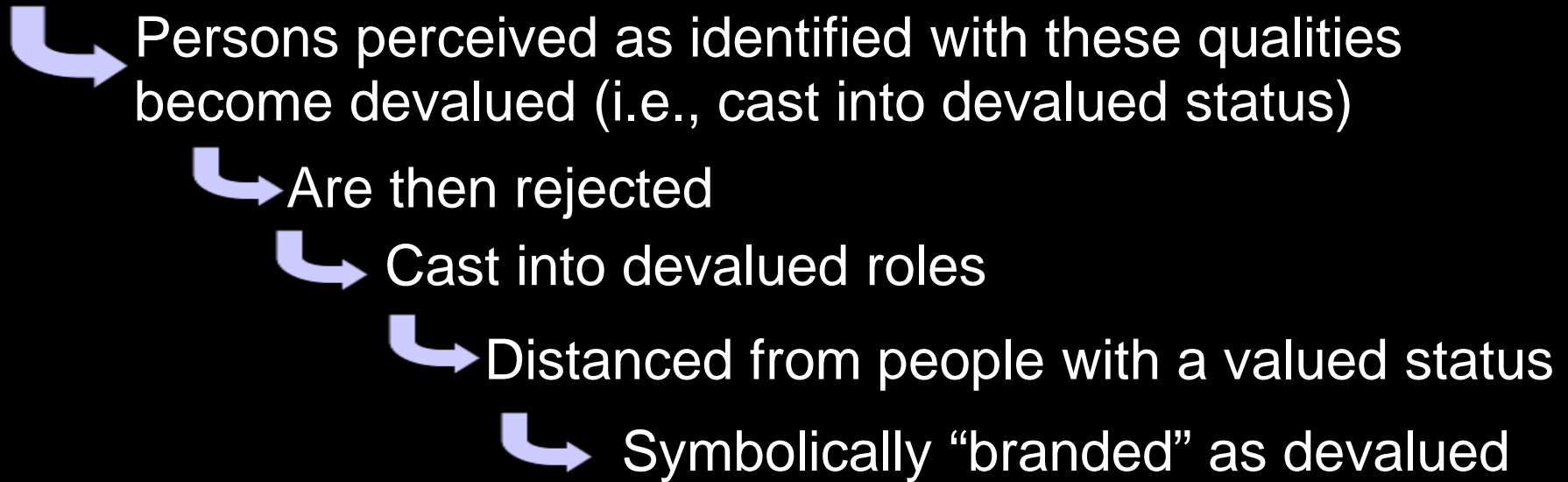
2. Using Language, Negative Imagery or Other Actions that degrade people:

1. Age Degradation

2. Status Degradation (e.g., via impoverishment, brutalization, denial of normative rights)

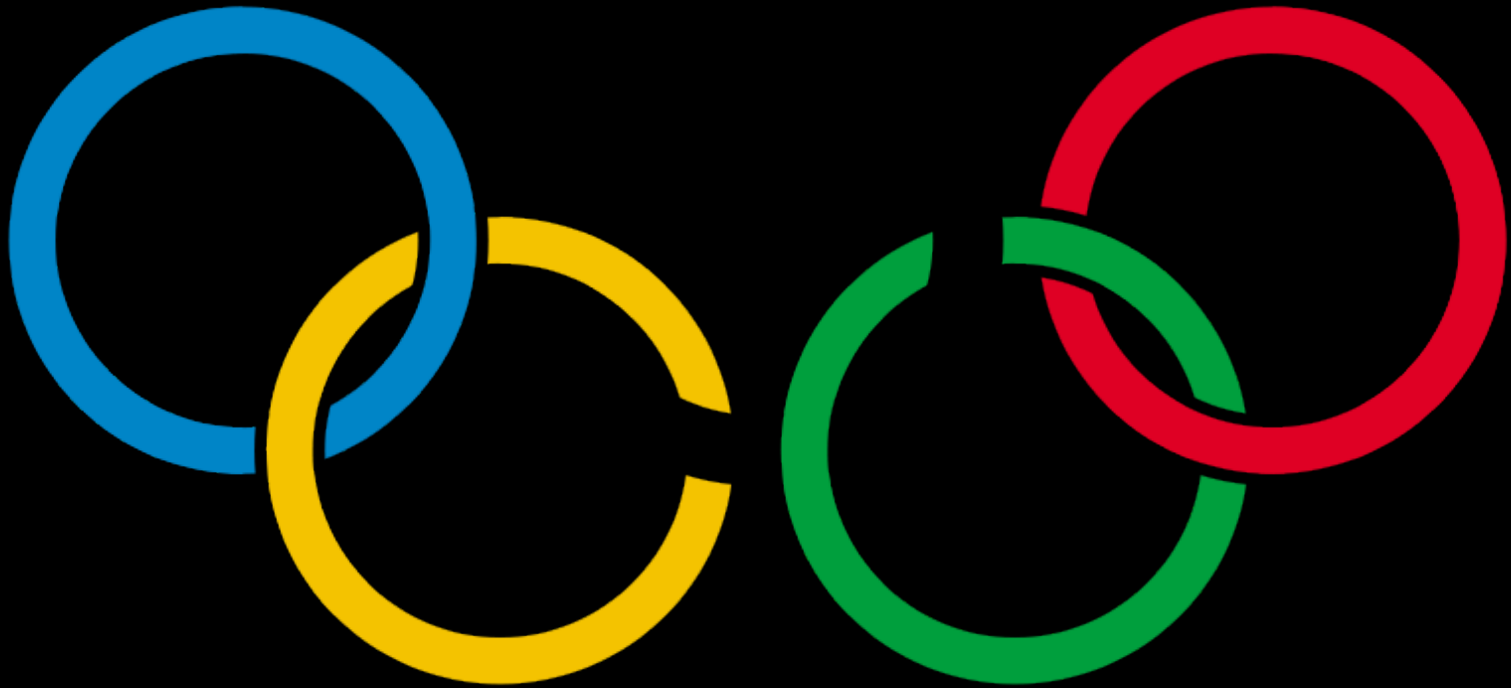
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DARE TO SOAR

"Your attitude, almost always determines your altitude in life."





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Would you drink this?

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people**



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UNIVERSAL NEGATIVE CONSEQUENCES OF DEVALUATION TO DEVALUED PERSONS/GROUPS

Society devalues certain qualities & conditions

- ↳ Persons perceived as identified with these qualities become devalued (i.e., cast into devalued status)
 - ↳ Are then rejected
 - ↳ Cast into devalued roles
 - ↳ Distanced from people with a valued status
 - ↳ Symbolically “branded” as devalued
 - ↳ Subjected to all sorts of discrimination, controlled, abused, subjected to violence and even deathmaking

Why Is Supported Decision Making Important For People Who Are Devalued?

- Your thoughts?

Why supported decision making is important

- Decision making is at the heart of self-determination
- Loss of autonomy is very hurtful
- Our decisions reflect who we are to others
- Most people learn more from decisions they make for themselves than they do from decisions made for them by others
- Supported decision making is a natural, valued and powerful way of making decisions

Why My Daughter and Her Family Chose Supported Decision Making

- Mary wants to make her own decisions. She wants to be in charge yet needs support.
- Mary (like most of us) appreciates (most times) having trusted people in her life who can advise her
- Mary is vulnerable to the negative attitudes and being controlled by others who think they know what is best for her. People who know Mary well, respect her, and have a good relationship with her will do the best job of assisting her to make wise decisions.
- People who know Mary will understand what kind and amount of support to offer her for decision making

- We feel Mary will be “safer” within a circle of support than under guardianship
- People who know Mary well will be able to intuit and interpret for her
- Mary will have access to a circle of people who have experience with decision making

What Can You Do To Promote Supported Decision Making?

- Discussion and sharing of ideas

Concluding Thoughts

- If you don't design your own life plan, chances are you will fall into someone else's plan for you. (Jim Rohn)
- Nothing is more difficult, and therefore more precious, than to be able to decide. (Napoleon Bonaparte)