Sexuality, Ethics, and Intellectual Disability: The Path to the Present and Roads to the Future

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Quick Exercise:

- Write down the most ‘edgy’, ‘embarrassing’, or ‘fulfilling’ sexual experience (real or imagined) that you have ever had. Take some time to think about it.

- Now – share it with the group of people around you and see what they think about your choices.

JUST KIDDING…NOT SERIOUSLY…OK – You can stop now…TMI…

BUT – CONSIDER THE FACT THAT WE ASK MANY OF THE PEOPLE WE SUPPORT TO DO JUST THAT – **ALL THE TIME**

- What would this do to your own concepts of sex/privacy/'appropriate'?

Goals and Objectives

- A brief history of sexuality in ID services in the US
- Current concerns regarding abuse and educational efforts
- Ethical Considerations
- 'Healthy Sexuality' → Healthy Systems
- Dignity of Risk/Duty of Care
- Example vignettes – small group discussions

History

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How did we get here and where are we going?

HISTORY

Since the 1800s and continuing to today, perspectives on sexuality have played a key role in the formation of our systems of supports for people with intellectual disability (ID).

(Scheerenberger, 1983; Trent, 1994)

"The past is never dead…it's not even past" – William Faulkner

HISTORY

"[O]ur culture's inability or refusal to deal with very real sexual needs of [people with ID] has been the primary impediment to every farsighted ideological proposal since Wilbur's advocacy of community placement in the 1850s" (Conway, 1976, p. 62).

Students→Wards→Threat to Society → Society as a Threat to 'Them' → Advocacy/Human Rights → Risk

In American historical context:

- "Because of the negative history experienced by people with disabilities, it is not possible to discuss any sexual behavior of persons with a disability without also discussion the environment in which they live or have lived " (Hingsburger & Tough, 2002, p. 10).
- 1850-1900
  - Not a lot of focus on sexuality
  - Training schools
- 1900-1950
  - Eugenical sterilization
  - People with I/DD as 'posing a risk'
  - The Menace of the Feebleminded – eliminate the problem

In American historical context…

- 1950-1970s
  - Institutionalization – out of sight, out of mind
  - People with I/DD as 'at risk'
  - Eliminate sexuality via segregation and aversive conditioning
- 1970s-1980s
  - An increasing focus on education and the role of environment
- 1980-1990
  - Rights based approach
  - Self Advocacy movement
  - Deinstitutionalization

In American historical context…

- 1990s-2000s
  - Moral panic and the second wave of 'the menace'
- 2010s →
  - The intersection of Rights and Risk;
  - We can see elements of all the previous eras:
    - Roadblocks to relationships;
    - What if…?
    - Emotional isolation;
    - Education yes, but little opportunity.
- 2020s?
  - Well, that depends on us

Current Concerns

Harm – Education - Staff

Abuse/Harm

- Young people with disabilities are at increased risk of encountering sexual abuse than their peers without disability. This risk is further increased (4x) when a child has intellectual disability.

- "[B]etween 39 and 68% of female children and 16 and 30% of male children with a disability will be sexually abused before they are 18 years old" (Mahoney & Poling, 2011).
  - Perpetrators are more likely to be in a position of providing care/education.

- "Several recent studies indicate that people with IDD experience much higher rates of non-consensual sexual encounters than non-disabled individuals, with worldwide incidence ranging from 44% in children with IDD to 83% in adults with IDD" (Stein & Dillenburger, 2017).

Education

- "Children with ID **typically are not engaged in sexuality education until later than their typically developing peers, if at all**. Their sexuality education is often centered on fear of perpetration and is not comprehensive in covering what is appropriate or healthy in a relationship" (Martinello, 2014)

- "In conclusion, **there is a need to draw up educational programmes,** differentiated according to gender and adapted to their reality, which include contents related with sexual health, sexual abuse and condom use" (Gil-Llario, 2018, p. 72)

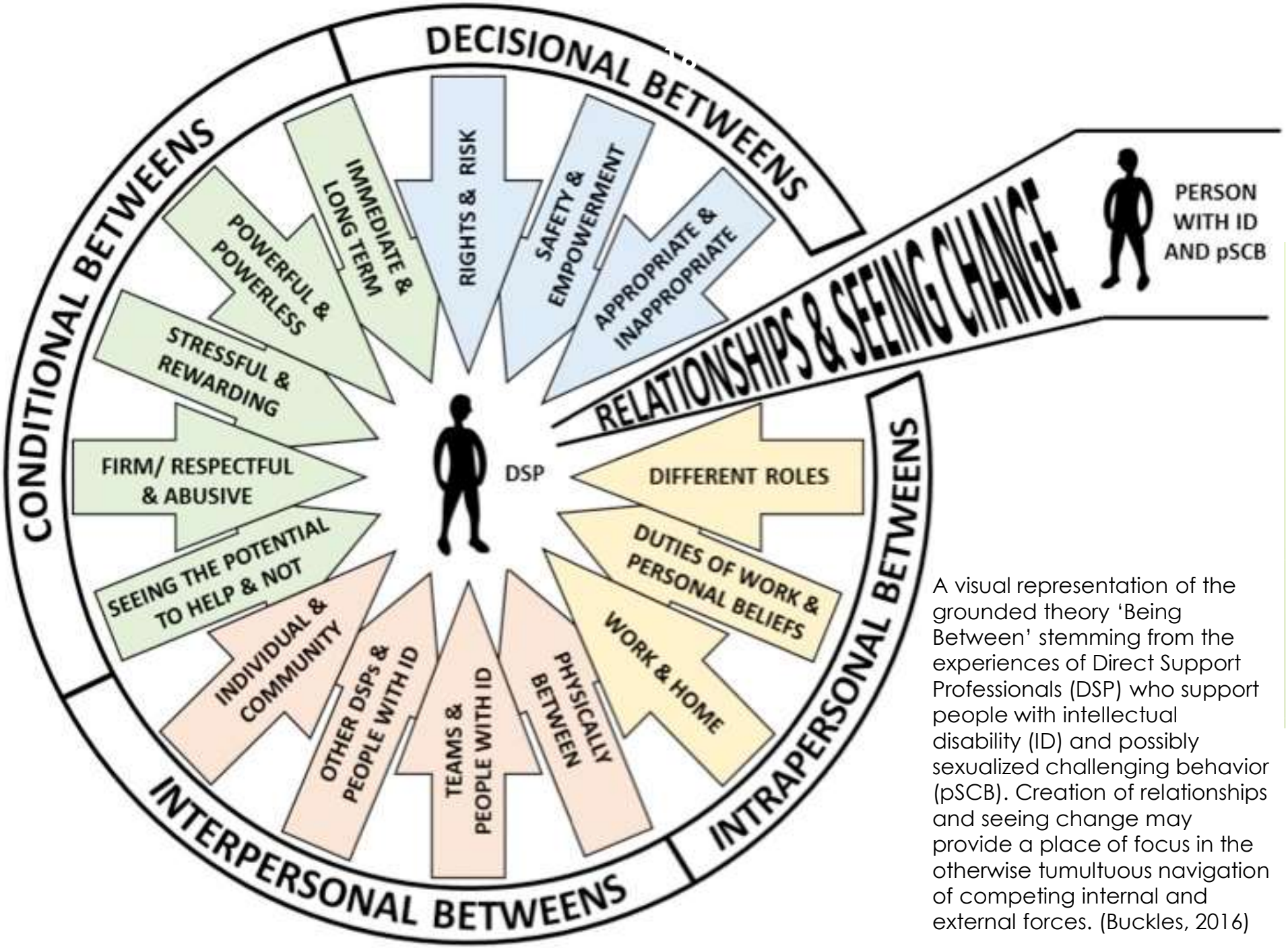
Education

- Medina-Rico et al. (2018)
  - Adolescents with ID – less knowledge of mechanism and contraception
  - "less than half had knowledge about laws against sexual abuse" (p. 234).
  - "Only 53-56% of people with severe to moderate ID respectively receive sex education" (p. 235).
  - Role of support networks:
    - Parents/family, physicians, educational system, direct support professionals

Staff

Whether staff members like it or not, whether they acknowledge it or not, they are enormously powerful in the lives of people with [intellectual disability]. Powerful in terms of the physical environments that are provided in day and residential service; powerful in terms of the social environments they create; powerful in the spoken and unspoken feedback they give about client aspirations and behaviour; and powerful in offering models of adult men and women with adult lifestyles making adult choices.

(Craft & Brown, 1993, p. 3)



A visual representation of the grounded theory 'Being Between' stemming from the experiences of Direct Support Professionals (DSP) who support people with intellectual disability (ID) and possibly sexualized challenging behavior (pSCB). Creation of relationships and seeing change may provide a place of focus in the otherwise tumultuous navigation of competing internal and external forces. (Buckles, 2016)

Ethical Considerations

Ethics

"It can be easy to feel an urgent need to use whatever means are necessary to reduce risks as quickly as possible.

It can be easy for professionals to lose sight of just how much power they hold over the people in their charge.

Finally, it can be easy to believe that one is not capable of causing harm to people in our care or custody" (Prescott, 2014, p. 1).

IN SHORT – IF THE JOB FEELS EASY, WE'RE PROBABLY DOING IT WRONG

Ethics

- "It is unethical for therapists to take away one behavior without replacing it with another" (Hingsburger & Tough, 2002, p. 8)
  - If your only goal is 'eliminate' or 'reduce' have you actually *done* anything?

- "Our energies are better put to eliminating the *need* for difficult behavior than in trying simplistically to eliminate the behavior itself" (Lovett, 1996, p. 94).

Ethics

- Autonomy
- Beneficence
- Fidelity

Healthy Sexuality
–
Healthy Systems

What do we mean when we say 'sexuality'?

- HYGIENE
- ANATOMY/PHYSIOLOGY
- PERSONAL SAFETY
- FREINDSHIPS
- PREFERENCE/FANTASY
- LOVING RELATIONSHIPS

- AND YES, INTERCOURSE

What do we mean when we say 'healthy'?

- Is it *just* about prevention? (harm, disease, pregnancy)
- What about pleasure?
- The 'privacy trap'
  - Policies may state that sexual activity is allowed 'in private areas'…but
  - 'On the ground' practice often provides no *actual* privacy.
    - Leads to: misinterpretation, 'trouble', and 'leaky boundaries'

Healthy Sexuality

"People with developmental disabilities can develop healthy sexual relationships if they live in healthy systems"

(Hingsburger & Tough, 2002, p. 8).

- We are 'the system'
- Are we 'healthy'?

HEALTHY SYSTEMS
What we *can* control

"It would be cruel to work with people with disabilities to incorporate sexuality and eroticism into their sense of self and their expectations and [then] leave them in the very system that forced them to divorce themselves from their sexuality in the first place" (Hingsburger & Tough, 2002, p. 10).

HEALTHY SYSTEMS 4 Essential Components

(Hingsburger & Tough, 2002)

- **1 - Clear Policy**
  - At agency and system levels
  - "Good agency policies do not just spell out what is forbidden, but also what is allowed" (p. 10).
- **2 - Education**
  - Tailored for all stakeholders
  - "Raising the subject can lead to shouts of denial and disapproval and threats of litigation. Not raising the subject though, simply continues the damage caused by denial" (p. 10).

HEALTHY SYSTEMS 4 Essential Components

(Hingsburger & Tough, 2002)

- **3 – Encouragement of self-advocacy**
  - Negotiation vs. advocacy
    - "'Help to advocate' does not mean 'be the advocate for'" (p. 11).
    - The difference between advocating *for* and advocating *with*…
- **4 – Relationship training**
  - "It is more than social skills training. It is teaching about personal safety…and loving relationships" (p. 12).

Dignity of Risk

-

Duty of Care

Dignity of Risk and Duty of Care

"[V]irtually total avoidance of risk has been built into the lives of [people with ID] by limiting their spheres of behavior and interactions in the community, jobs, recreation, relationships with the opposite sex etc. **Such overprotection endangers the [individual's] human dignity and tends to keep him [or her] from experiencing the risk-taking of ordinary life which is necessary for normal human growth and development**"

(Perske, 1972, p. 24).

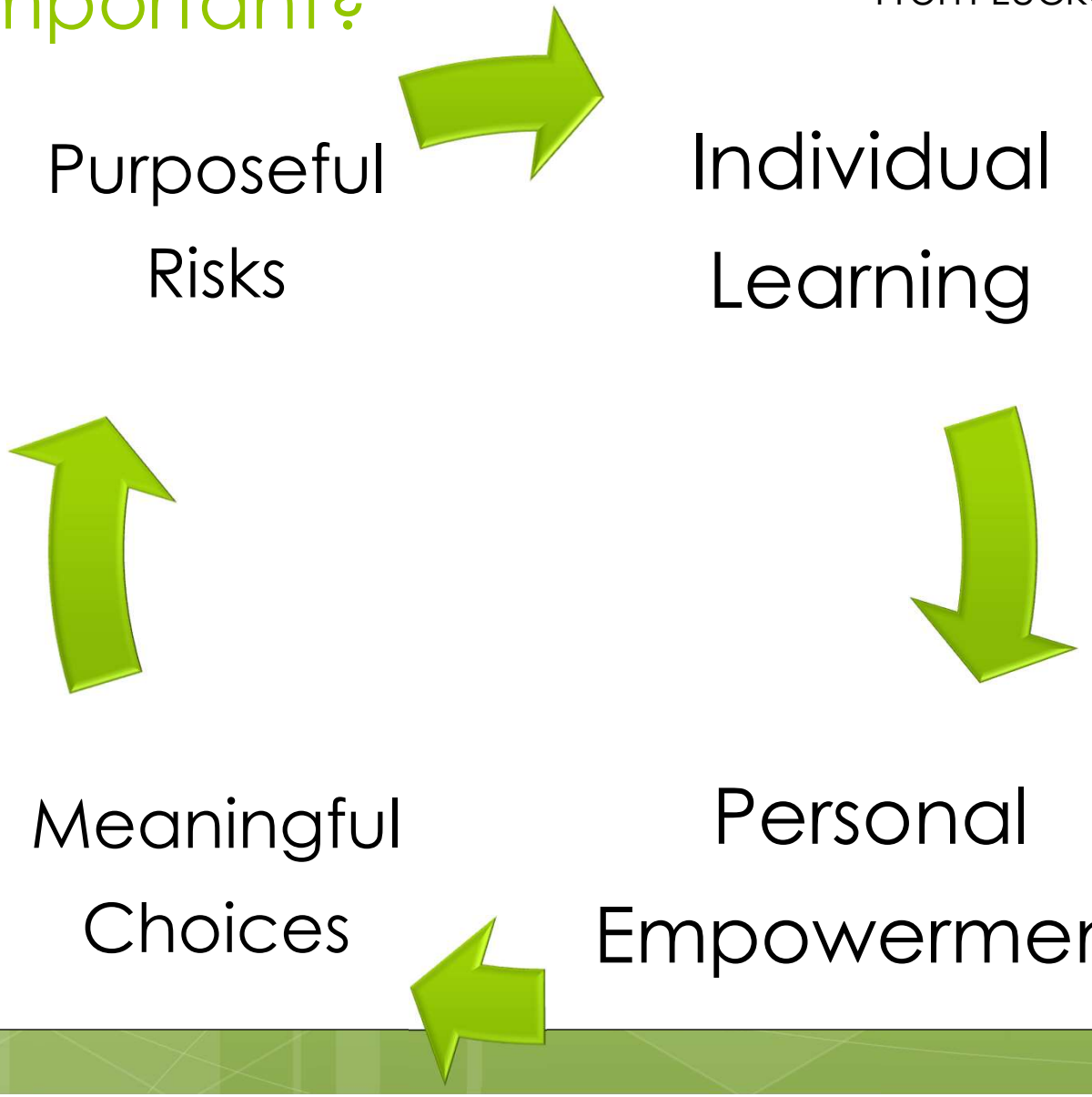
At its root, these conversations are about…

"the tension between safety and empowerment"

(Alaszewski & Alaszewski, 2002, p. 62)

D of R– Why is it important?

From Luckasson, 2006



Dignity of Risk + Duty of Care
A Conceptual Model

Sailing The Seven 'C's of Risk/Care Decisions

CONSIDERATION

CONSULTATION

CREATIVITY
(Compromise)

CONSENSUS

CONSENT (Informed)
…An ongoing process…

"No action without information ~ No information without action."

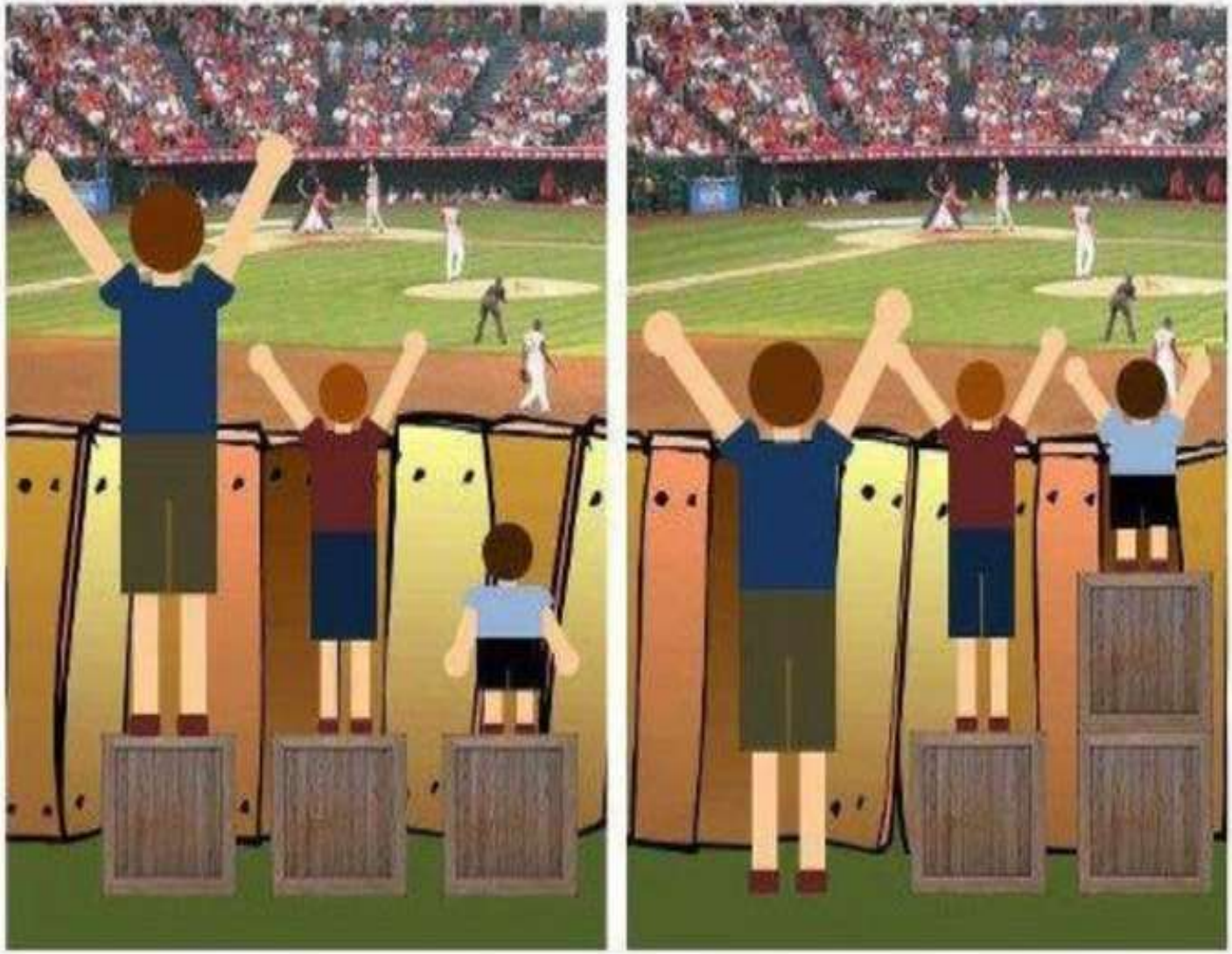
DOCUMENTATION THROUGHOUT

Our role?

- SUPPORT THE SUPPORTS
  - It's a lot easier to see the forest for the trees when you're not the one doing the hiking…
  - DSPs and families…at the crossroads of risk and rights
  - We can add to the C's (Consider, Consult, Consensus, Creativity, Consent)
    - Model **CALMNESS**
    - Encourage **COLLABORATION**
- CHECK FOR PROGRESS/FOLLOW THROUGH
  - It is difficult to keep momentum.
  - Small movements are still movement.
    - Frame as partial success rather than partial failure

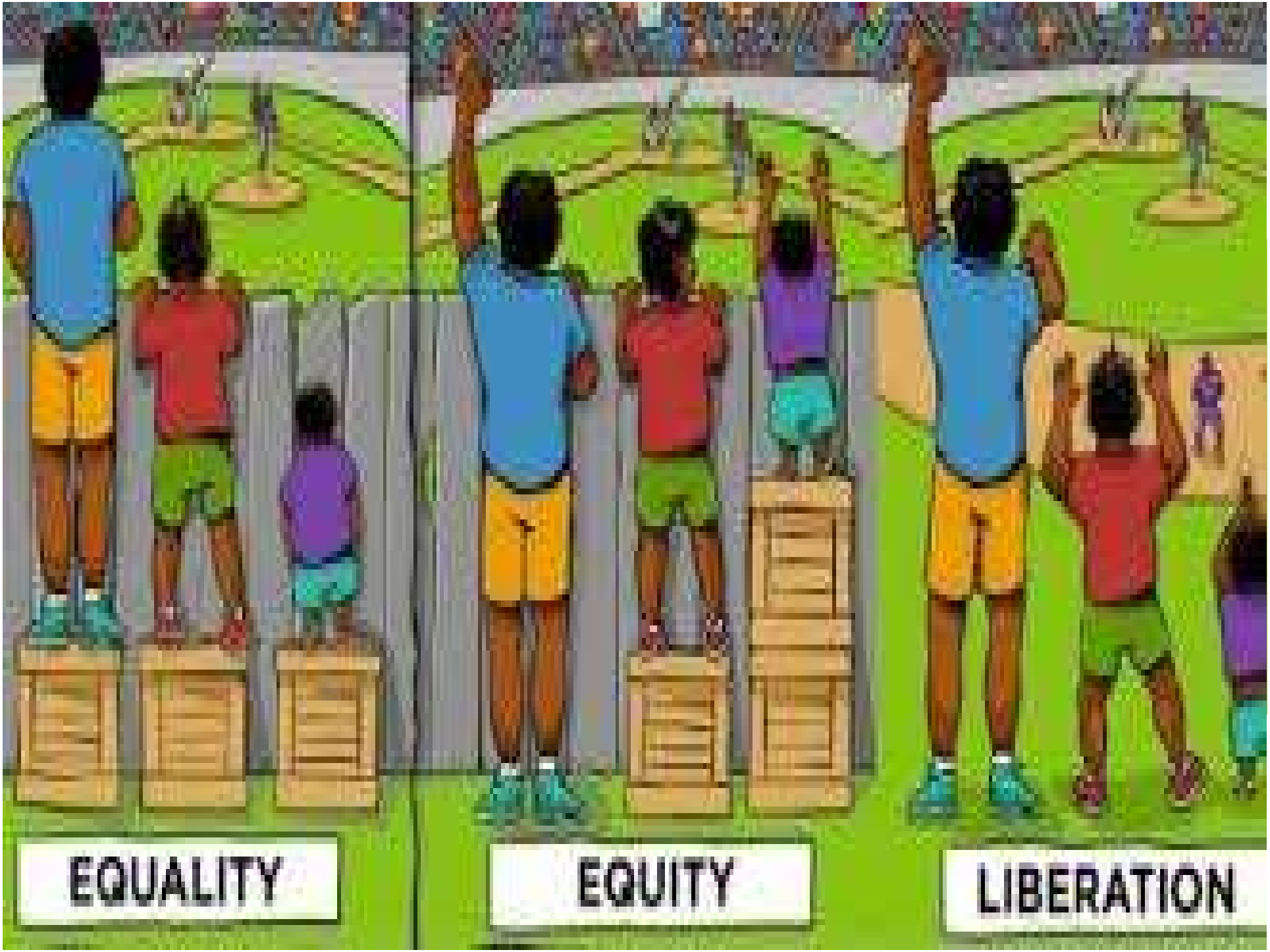
Vignettes and Discussion

Equality is not always Justice



This is EQUALITY

This is JUSTICE


EQUALITY
EQUITY
LIBERATION

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