"Holding each other with arms wide open": Lessons from queer and disabled peer support practitioners' ethics of lived experience

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Living the Legacy. Compassionate Care. Faith. Discovery

Disclosures & Acknowledgments

SSHRC ≡ CRSH
Social Sciences and Humanities Research Council of Canada
Conseil de recherches en sciences humaines du Canada

CIHR | Canadian Institutes of Health Research
IRSC | Instituts de recherche en santé du Canada

Positionality and Sources of Knowledge

Community
Mad/disability/queer/trans

Bridging
peer support work
service user engagement
community partnership

Institutions
healthcare
social welfare
academia

Outline

In this presentation, I will:

1. Identify the unique features of peer support (PS) ethics

   - History

   - Role

   - Values

2. Describe how PS ethics contribute to health equity

3. Discuss current challenges to PS ethics and efforts to preserve them

Objectives

I hope this presentation helps you:

- Understand and appreciate the unique PS role and values grounded in social movement histories

- Recognize the ways PS ethics can:

  - Address gaps/limitations in healthcare and healthcare ethics

  - Promote social justice

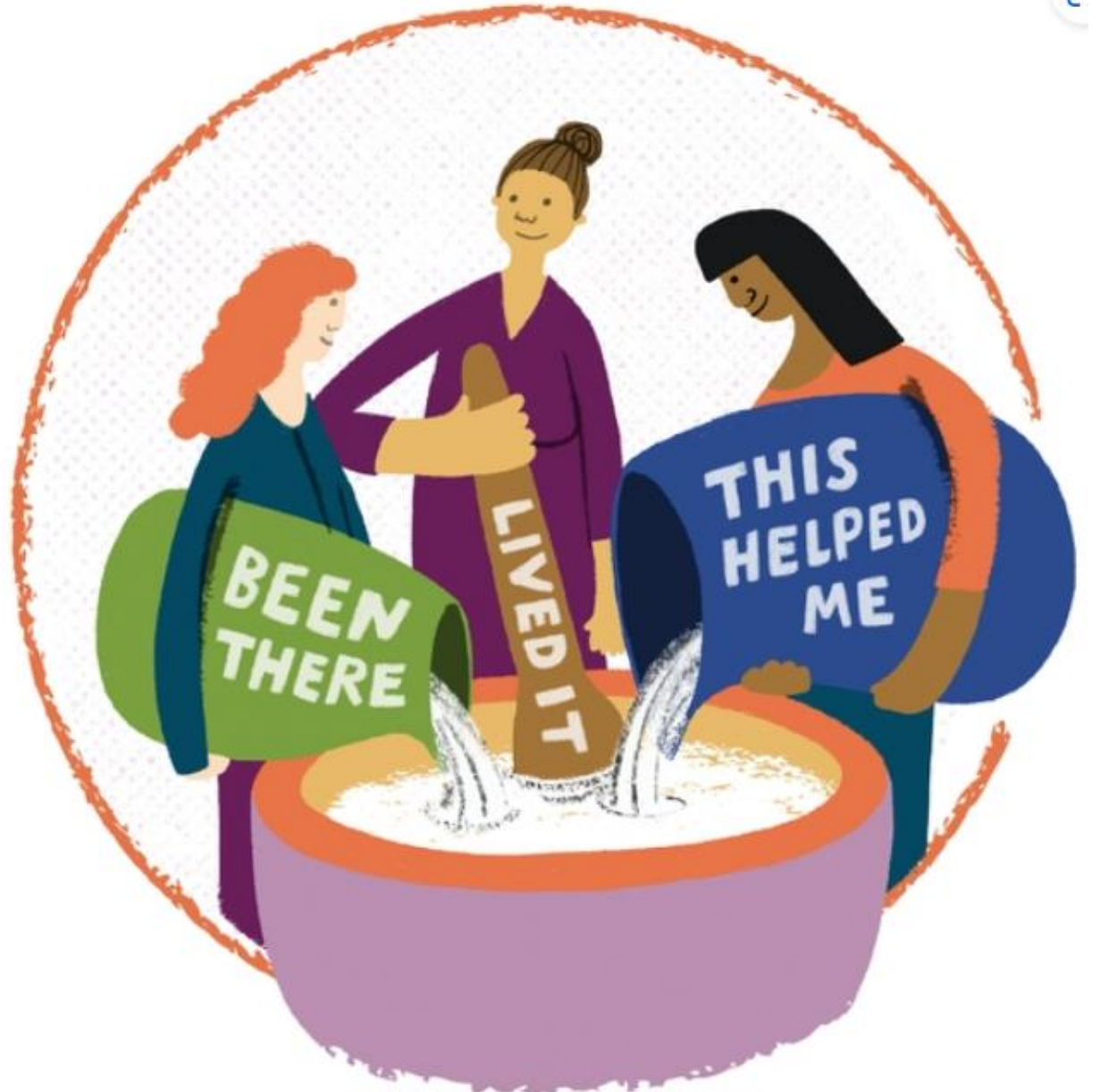- Strengthen relationships and solidarity with PS workers

Main Message: PS Intervenes in Institutionalized Ethics

Definitions

- **Peer support is (broadly):**

  - "a naturally occurring, mutually beneficial support process,

  - where people who share a common experience meet as equals, sharing skills, strengths and hope;

  - learning from each other how to cope, thrive and flourish" (PeerWorks, Ontario)

- **Formalized, structured peer support**

  - "begins when persons with lived [and/or living] experience who have received specialized training,

  - assume unique, designated roles within the mental health system [or other service],

  - to support an individual's expressed wishes" (PeerWorks, Ontario)

  - **Distinct role from family/friends and healthcare professionals**

The Perinatal Peer Support Principles | Maternal Mental Health Alliance

Definitions

	Healthcare Ethics	Peer Support (PS) Ethics
Focus	• Ethical questions arising in the context of healthcare	• Enactment of PS values in everyday practice • In healthcare and beyond
Context	• Formalized into a field and frameworks *in response to severe ethical violations* by professional clinicians and researchers	• Emerging out of social movement traditions in resistance to dominant professional ethics
Creators	• Scholars • Professionals	• Service users
Intended Beneficiaries	• Protect the public	• Empower PS workers

Who is in the room?

- Who has participated in peer support?

- Who is a peer support worker?

- Who has worked with a peer support worker?

- Who has engaged in interprofessional training where peer support values/ethics were discussed?

The "Past": Where Did PS Ethics Come From?

Backdrop: History of Peer Support

- Informal peer support (by many names) has existed for generations as a way of life

- Expansion of Eurocentric models of "health professionals" have shifted:

  - Care from community to "experts"

  - Ethics from community to "experts"

- Social movements of people harmed by this model have been protesting and creating alternatives

- This history grounds PS values and ethics

WHAT IS A MOVEMENT?

A movement is a group of people with a shared purpose who build collective power to create change. It is made up of:

A strong pipeline of leaders

Grassroots people power

Solid partnerships

A shared political goal and plan for the future

With a combination of strategies:

Advocacy
Media reach
Legal action

Protests
Research
...and more!

WHY ARE MOVEMENTS IMPORTANT?

All of the rights we enjoy now have been won by movements throughout history.

What is a movement? [Infographic] - Global Fund for Women

Medical Harms to Disabled and 2SLGBTQIA+ Communities

Pathologization, Elimination, Removal

- 2SLGBTQIA+ identities categorized as a mental disorder

- Coercive psychiatric interventions to convert 2SLGBTQIA+ people to be heterosexual and cisgender

- Institutionalization, involuntary treatment, and associated abuse and dehumanization

- Involuntary sexual sterilization

- Involuntary euthanasia

Protest and Protection

Law

- Legal rights to refuse psychiatric treatment

- Bans on conversation therapy

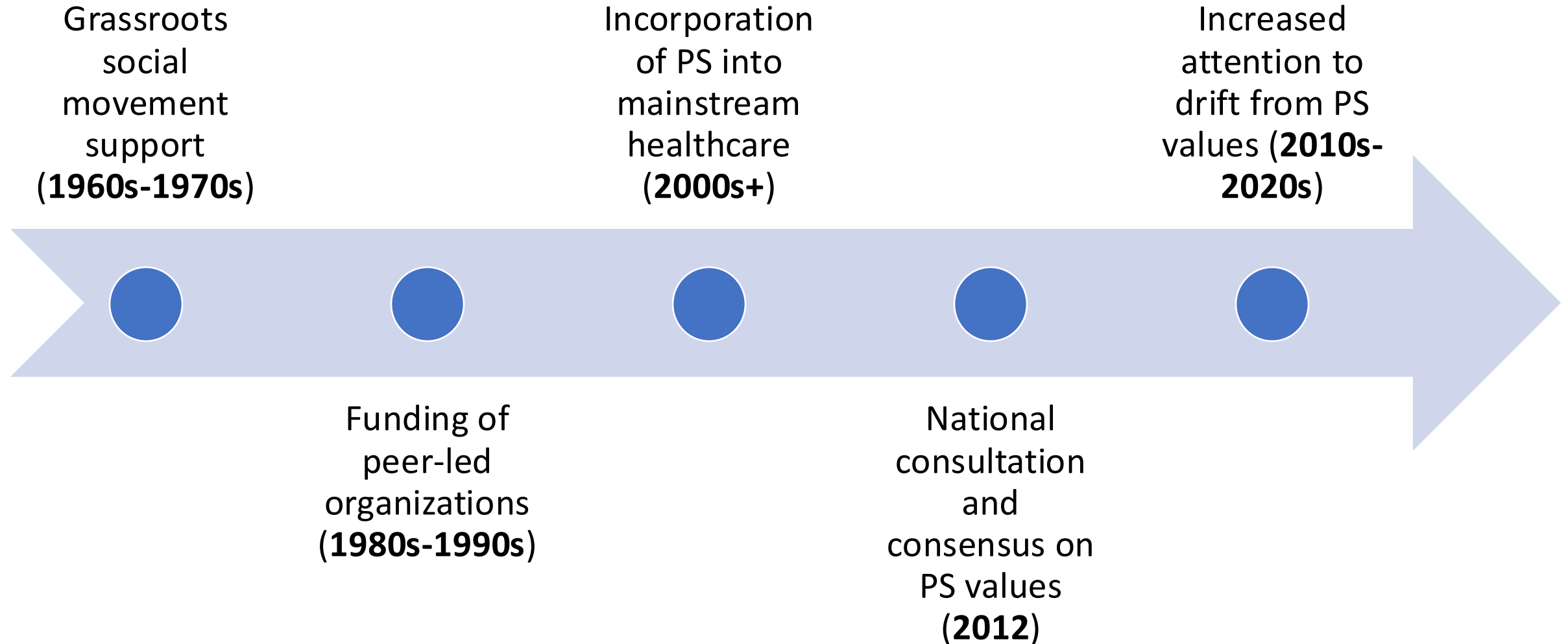- Protections in the criminal code (conversion therapy, sterilization)

Medicine

- De-institutionalization

- Advocacy for identities to be de-pathologized

Community

- Self-help, mutual aid, and peer support initiatives

Trajectory of the Peer Support Role

Grassroots social movement support (**1960s-1970s**)

Incorporation of PS into mainstream healthcare (**2000s+**)

Increased attention to drift from PS values (**2010s-2020s**)

Funding of peer-led organizations (**1980s-1990s**)

National consultation and consensus on PS values (**2012**)

Present: Unique Values and Contribution to Health Equity

Different Foundations

	Healthcare Ethics	PS Ethics
Relationship	• Unequal patient – healthcare professional	• Mutual peer – peer
Goal	• Help and heal • Protect the public • Professionalization	• Learning together
Sources of Knowledge	• Empirical research • Traditions of argumentation • Clinical and academic expertise	• Lived experience • Everyday pragmatic survival strategies
Legal Authority	• To diagnose • Hold in hospital involuntarily • Treat without consent • Find someone legally incapable • Document in the patient record	• None
Professional Concerns	• Risk management • Self-protection from lawsuits	• Disrespectful and/or inequitable workplace conditions contributing to drift from PS values

Comparing Ethics

	Medicine (CMA Code of Ethics)	Nursing (CNA Code of Ethics)	Social Work (CASW Code of Ethics)	Peer Support (Values, PS Canada)
Autonomy	• Respect for persons	• Dignity • Privacy and confidentiality • Respecting informed decision-making	• Dignity and worth of all people • Privacy and confidentiality	• Dignity and respect • **Lifelong learning and personal growth** • **Self-determination**
Beneficence / Nonmaleficence	• Compassion • Honesty • Humility • Inquiry and reflection • Professional integrity, competence, excellence • Prudence • Self-care and peer support	• Accountability • Compassion • Competence • Health and wellbeing • Safety	• Competence • Integrity • Value human relationships	• **Authenticity and trust** • Empathetic and **equal relationships** • Health and wellness • **Hope and recovery** • Integrity
Justice	• Justice	• Justice	• Social justice • Truth and reconciliation	• Social inclusion

PS Values: Self-Determination

	Healthcare Ethics	Peer Support Ethics
Principle	**Autonomy**	**Self-determination**
Inspiration	• Belmont Report (USA) • Beauchamp & Childress' *Principles of Biomedical Ethics* (USA) • Kant (Germany) • John Stuart Mills (UK)	• Social movements • 1966 *International Bill on Human Rights* • Counterculture writing of critical theorists (e.g., Foucault, Goffman)
Interpretation	• Individual's capacity to reason and express a voluntary choice • Informed consent and confidentiality • Negative right (noninterference)	• Empowerment • Liberation from professional control • Resistance to social injustice • Positive right (active support)

PS Values: Shared Power & Mutuality

	Healthcare Ethics	Peer Support Ethics
Principle	**Beneficence & Nonmaleficence**	**Shared power in mutual relationships**
Guidance	• Hippocratic Oath • Professional Codes of Ethics • David Hume, John Stuart Mill, Immanuel Kant • Medical science (diagnosis, prognosis, treatment)	Lived experience of • social movements • medical harm • healing power of equal relationships
Manifestations	• Paternalism • Coercion • Prioritization of safety	• Dignity of risk

• **MUTUALITY IS RECIPROCAL.** We are walking beside someone, rather than in front pulling or behind pushing them.
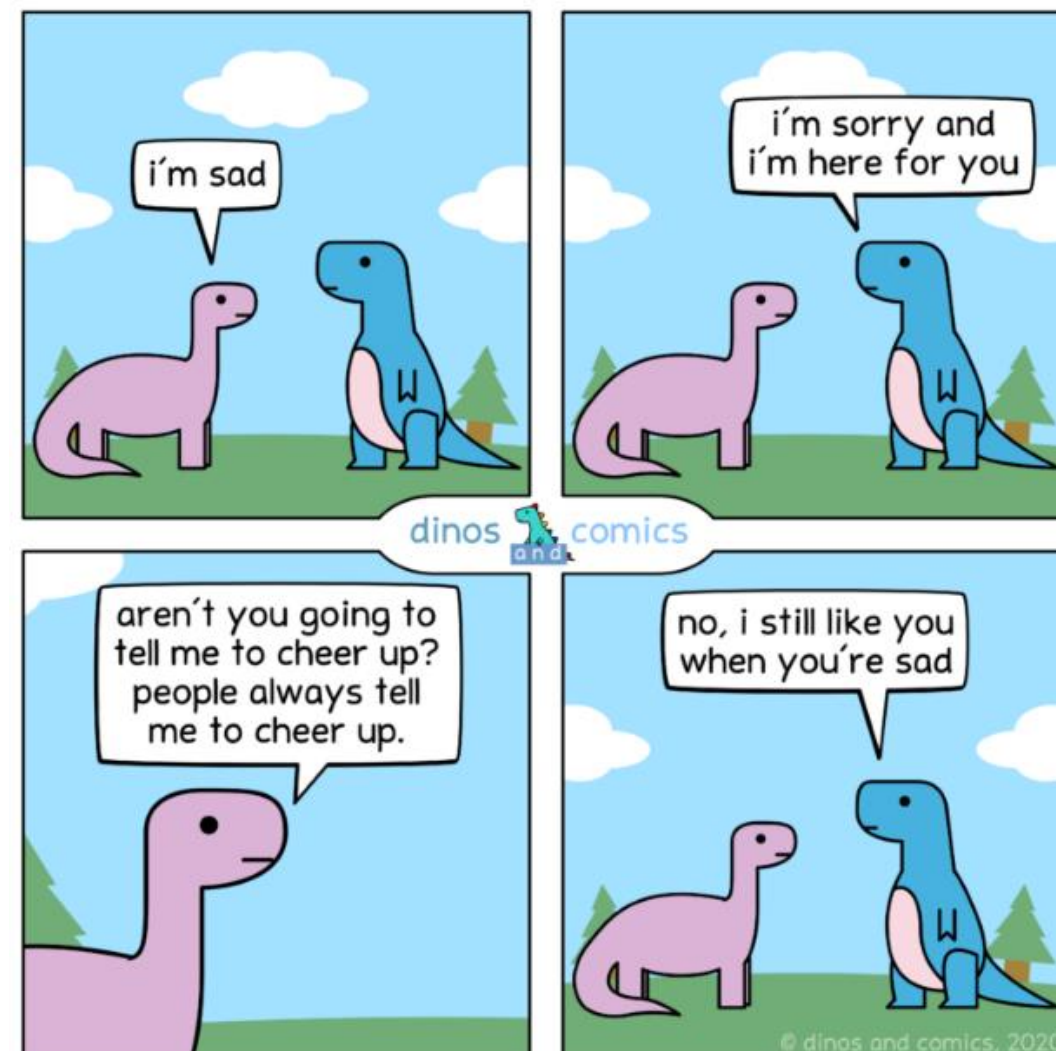
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https://peerconnectbc.ca/wp-content/uploads/Standards-of-Practice_Final.pdf

PS Helps Address Health Disparities

Loneliness epidemic

Trust as a public health issue

Reduced life expectancy

Epistemic injustice

PS Ethics Enhancing Health Equity

PS Ethics	Healthcare Ethics
1. Mutual relationships	• Not discussed – contravenes professional Codes of Ethics • Boundaries
2. Access to and engagement in care	• Patient-initiated discharge against medical advice • "Difficult", "unrepresented", "non-compliant" patients
3. **Supported decision-making**	• Informed consent • Substitute decision-making
4. **Non-coercive support**	• Workplace violence and staff safety • Legal grounds for involuntary treatment and use of restraints

Mutual Relationships

- Non-clinical, non-hierarchical relationships grounded in a genuine interest in shared learning together
- Understanding and validation from sharing of lived experiences
- Community belonging and reduced isolation

"I've heard so many stories of being let down by workers, and workers not being there, and workers not caring, and workers forgetting.

I take the time. I have human relatability. It just opens up a more trusting, engaging, and interchangeable relationship."

(Peer worker cited in Epstein et al., 2023, p. 17)

https://www.facebook.com/thesecurerelationship/photos/being-understood-is-an-attachment-need-to-feel-safe-and-close-to-you-i-need-to-k/792607989661688/?_rdr

"Women [in prisons] often say 'oh you don't know what it is like' and me saying 'actually I do know' makes them open up and trust me in a different way from trusting non-peers."

(Peer worker cited in Faulkner & Kalathil, 2012, p. 22)

Access to and Engagement in Care

- Rebuilding trust in healthcare
- System navigation
- Supporting hope and motivation to engage in treatment
- Understanding unmet needs
- Addressing misunderstanding, poor communication, and stigmatizing attitudes of the care team

"If they don't trust you, that is the end of it. Just forget it. They will come down, get their gear and go. ...So trust is a very big issue in [Needle Syringe Program]."

(Participant 11, as cited in Treloar et al., 2016, p. 142)

https://peerconnectbc.ca/wp-content/uploads/Standards-of-Practice_Final.pdf

Supported Decision-Making

- New self-understandings, empowerment, and enhanced self-confidence
- Journeying alongside as people explore options, values, hopes
- Making more fully informed and voluntary choices

"Autonomous" decision-making → SUPPORTED DECISION MAKING

Capacity is FIXED

Capacity can be DEVELOPED

Capacity is COGNITIVE

Capacity includes SUPPORT

Decisions are made INDEPENDENTLY

Decisions are made WITH SUPPORT

Supported Decision-Making: A Copernican Revolution — Decision Agency

Non-Coercive Support

- Identifying triggers and comfort strategies (preventing 61% of situations in the ED from escalating into workplace violence; Lyver et al., 2025)
- Reducing use of involuntary hospitalization and treatment
- Eliminating use of restraints and seclusion (Atdjian & Huckshorn, 2024)

"If I only had 2 minutes with the peer, this [seclusion event with 6 security guards] could have been prevented."
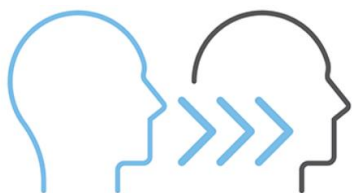
(PS Ethics Discussion Series, March 2025)

https://opentextbc.ca/peersupport/chapter/peer-support-core-values-and-leadership/
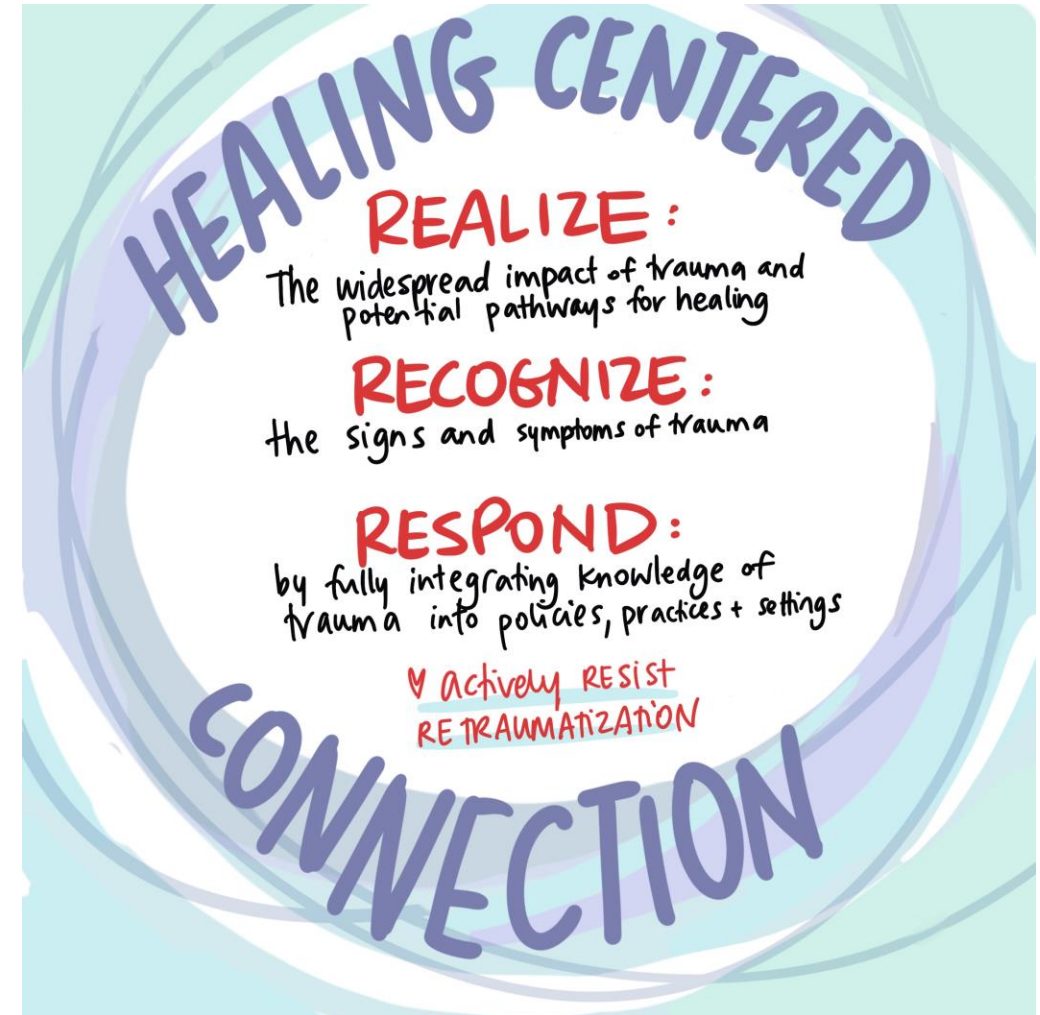
Future: Protecting Unique PS Values and Role

Challenges: Peer Support Drift

Drift into Clinical Roles

Drift into Menial Roles

WHAT PEER SUPPORT IS NOT

"They changed the scope of what peer support really is. At the end of the day, again, I believe peer support is one peer sharing his or her story with another. Now there's that movement that kind of makes people, what I like to refer to as mini clinicians."

(Former peer supporter cited in Adams, 2020, p. 4)

WHAT PEER SUPPORT IS

Peer Support practice aligned with PS values

"I am a harm reduction worker. We were actually literally hired to give knowledge about substance use. Not serve food, not clean toilets. It seems these jobs that nobody else is willing to do fall on peers."

(Participant cited in Epstein et al., 2023, p. 23)

Unpacking Peer Support: An Infographic | CMA

Challenges: Peer Support Drift

Drift from Social Movement Intentions	Drift into Hierarchy	Drift into Causing Harm	Drift into Losing Unique Contribution
• "moving from 'movements' into 'models'" • "Developments that contradicted the movement's initial goals" • "The strategic displacement of a people from the source of their wisdom and power" • No longer "remain[ing] true to their roots"	• Drifting from "a 'we' position" into "services provided by 'us' to 'them'"	• "their roles have included many of the duties that make mental health services oppressive" • "mimicking" and "parodying the system that has dehumanised us"	• Peer supporters "lose the distinctness of their role" • "Defaulting to being like traditional services" • "So fundamentally transformed that the (potential) challenge it poses to dominant power relations is reduced"

Quotations referenced in de Bie, A. & Michetti-Wilson, E. (June 2024). Drift from peer support values and standards: A position statement and call for action. Commissioned by and prepared for the Board of Directors of PeerWorks.

Ensuring PS Remains a Distinct, Values-Based Practice

Invitation for ethicists and interdisciplinary health professionals to attend to learn from peer supporters

I hope this presentation helps you:

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- Recognize the ways PS ethics can:

    - Address gaps/limitations in healthcare and healthcare ethics

    - Promote social justice

- Strengthen relationships and solidarity with PS workers

Thank you!

Please get in touch if you're interested in further conversation or collaboration

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References

- Atdjian, S., & Huckshorn, K. A. (2024). Toward the Cessation of Seclusion and Mechanical Restraint Use in Psychiatric Hospitals: A Call for Regulatory Action. *Psychiatric Services*, *75*(1), 64-71.

- Bocking, J., Ewart, S. B., Happell, B., Platania-Phung, C., Stanton, R., & Scholz, B. (2018). "Here if you need me": Exploring peer support to enhance access to physical health care. *Journal of Mental Health*, *27*(4), 329-335.

- Brooks, H. L., Speed, K. A., Dong, K., Salvalaggio, G., Pauly, B., Taylor, M., & Hyshka, E. (2024). Perspectives of patients who inject drugs on a needle and syringe program at a large acute care hospital. *Plos one*, *19*(2), e0297584.

- Collins, B. M. (2020). Uncharted Territory: Psychosurgery in Western Canada, 1935-1970.

- de Bie, A. & Michetti-Wilson, E. (June 2024). Drift from peer support values and standards: A position statement and call for action. PeerWorks.

- Epstein, G., Harriott, D., Hermanstyne, A., Farah, S., Gold, M., Jennings, L., Nurse, M., Scotton, M., & Walter, J. (2023). *Supporting peer work: Full report.* Working for Change, Toronto Drop-In Network, and George Brown College.

References

- Faulkner, A., & Kalathil, J. (2012). *The freedom to be, the chance to dream: Preserving user-led peer support in mental health*. Together for Mental Wellbeing.

- Fortuna, K. L., Ferron, J., Pratt, S. I., Muralidharan, A., Aschbrenner, K. A., Williams, A. M., ... & Salzer, M. (2019). Unmet needs of people with serious mental illness: perspectives from certified peer specialists. *Psychiatric Quarterly*, *90*, 579-586.

- Lyver, B., Singh, B., Balzer, N., Agnihotri, M., Hulme, J., Chan, K., ... & Schulz-Quach, C. (2025). Exploring the Impact of Workplace Violence in Urban Emergency Departments: A Qualitative Study. *Healthcare*, 13(6).

- Perreault, I. (2011). Psychochirurgie et homosexualité. De quelques cas à l'Hôpital Saint-Jeande-Dieu à la mi-20e siècle [Psychosurgery and homosexuality. Some cases at the SaintJean-de-Dieu Hospital in the mid-20th century]. In P. Corriveau and V. Daoust (Eds.), Régulation sociale des minorités sexuelles. L'inquiétude de la différence (pp. 27-44). Presses de l'Université du Québec.

- "Treating" queerness. STONES: Exploring Kingston's Social History. https://www.stoneskingston.ca/gay-and-lesbian-history/treating-queerness/

- Treloar, C., Rance, J., Yates, K., & Mao, L. (2016). Trust and people who inject drugs: The perspectives of clients and staff of needle syringe programs. *International Journal of Drug Policy*, *27*, 138–145.

- Vilkė, R. (2021). New social movements: Theories and approaches. *Rural Economic Developments and Social Movements: A New Paradigm* (pp. 13-43). Cham: Springer International Publishing.

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Slide 10 images

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- https://www.hlms.ca/wp-content/uploads/40-is-Too-Young-to-Die-paper.pdf

- The Routledge Handbook of Epistemic Injustice - Google Books