



COMPENSATING PEOPLE WITH LIVED EXPERIENCE: HIGHLIGHTS FROM THE LITERATURE

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TERMINOLOGY

There is no consensus about which terms are best to refer to people who contribute their deep understandings of lived realities to community organizations.ⁱ

This document will use the prevalent terms “people with lived experience” (PWLE) and “peer” interchangeably, but organizations should always use language that has been chosen by people themselves.² Options include:

- Speaking in ‘First Voice’, an Indigenous concept³
- ‘Person with lived/living experience’ (PWLE)^{4,5}
- ‘Community resident with lived experience’, ‘person with grounded expertise’, ‘expert by experience’^{i,6,7}
- Terms that emphasize a person’s role, e.g., ‘outreach worker’⁸
- ‘Peer’ or ‘peer worker’^{3,9}
- Specific experience-based terms chosen by people themselves, e.g., ‘people who use drugs’¹⁰
- More unique terms chose by people themselves, e.g., ‘partners with lived/living experience’, ‘community champions’^{i,6}



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CONTEXTS OF WORK AND ROLES

The widespread silencing of PWLE means that organizations need to actively challenge dominant power relations to engage peers in meaningful and equitable ways.^{i,11,12} These efforts involve:

- Organizational training, capacity-building, and ongoing transformation^{11,13,14,15}
- Engaging and hiring multiple, diverse, underserved PWLE; e.g., through targeted outreach^{6,7,10,13,14,15,16,17}
- Removing organizational barriers, including barriers to meeting physical needs^{i,7,10,11,18}; cultural^{i,3,13,17,19} and environmental barriers^{13,14,18,19,20}; and literacy^{i,6,7,13,20} and communication-based barriers^{6,14,15,20}
- Trauma-informed approaches to make work more accessible^{1,13-15,21}
- Flexibility in designing bottom-up approaches to work^{1,6,8,13,22}
- Providing new peers with one-to-one support and training^{6,10,11,13,19,23}

Due to societal and organizational barriers, PWLE are engaged across a spectrum of power.^{i,5,6,9,13,23,24} For engagement to be equitable and meaningful, it is optimal for peers to act as partners and leaders in all aspects of decisions that affect their lives.^{6,7,9,10,11,12,13} Both short-term and long-term roles for PWLE in an organization should be co-created upfront.^{9,10,13,19,20} Some possibilities for peer roles include:

- Advocacy, e.g., providing feedback about services^{2,6,9,10,11,16,18}
- Education and awareness, e.g., delivering workshops^{2,6,15,16}
- Direct service provision, e.g., providing peer-to-peer support^{2,8,9,16,25}
- Research, e.g., acting as co-researchers^{13,19,25,26}
- Monitoring and evaluation, e.g., assessing peer engagement practices^{9,13,16,17}



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COMPENSATION

Expecting peers to volunteer does not recognize the value of their contributions and can be exploitative in the context of marginalized lived experiences.^{14,22,26,27,28}

Financial need presents multiple barriers to equitable peer engagement, which can result in the exclusion of peers, and/or require peers to bear unfair burdens in participating.^{i,3,6,8,14,27} To reduce barriers, organizations should provide appropriate direct and indirect forms of compensation for peer work.^{3,8,14,22} Best practices for direct forms of compensation include:

- Adopt a trauma-informed approach: e.g., do not require peers to justify barriers or need^{3,21}
- Center Indigenous experiences and gifting traditions; offer financial and traditional gifts^{3,26}
- Provide financial compensation that is equal to similar professional work^{3,6,11,12,14,28}
- Cover any additional costs the peer may incur as a result of in-town and out-of-town work^{2,6,23,25,26,27}
- Discuss payment upfront, before beginning work^{2,11,13,22,23,25,27}
- Discuss implications of payment for Ontario Works and/or Ontario Disability Support Program upfront, before beginning work^{i,2}
- Provide options for peers to choose when and how they prefer to be paid, and offer to provide receipts^{2,3,25,26}
- Pay peers discreetly, directly, and in cash, unless they request another form of payment^{2,8,13,18,23,25,26}
- Create finance policies, procedures, and a budget specific to peer compensation^{11,13,22,25}
- To maximize an organization's available financial resources: fundraise, partner with other organizations, and advocate for peer compensation in funding requests^{i,12,19,22}



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Organizations can also compensate peers in ways that are not directly financial, including:

- Access to shared resources¹⁹
- Skill-building trainings^{6,7,8}
- Professional growth opportunities, e.g., bridges to employment and/or career pathways in an organization^{i,6,12,28}
- Regular community celebrations and/or socials^{14,19}

LEGAL CONSIDERATIONS

Generally, financial compensation provided in exchange for peer work is considered income according to the Canada Revenue Agency (CRA), the Ontario Disability Support Program (ODSP), and Ontario Works (OW). Discuss the possible implications of payment before a peer consents to provide work.²

Implications of compensating peers for taxes include:

- If the peer is paid for a service they provide, this payment is generally considered taxable income^{29,30,31}
- Reporting requirements will depend on a person's employment status. If they are an employee, payment counts as "employment income"; if they are self-employed, payment counts as "business income"^{29,30,32,33}
- Travel expenses paid for by an organization are not considered taxable income³¹

Implications of peer compensation for ODSP include:

- People receiving income from ODSP must report earnings on a monthly basis; people may want to keep earnings receipts³⁴
- People whose net earnings exceed \$200 per month will have 50% of their net earnings deducted from their ODSP payment in the following month³⁵
- No earnings-related deductions are made if the person is attending full-time secondary or postsecondary school³⁶





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- If they provide proof of earnings, peers may be eligible for the “Work-Related Benefit” (up to \$100) for employment-related costs³⁷
- Peers may want to consult their caseworker before beginning work to learn about exceptions and benefits that might apply to them³⁶

Implications of peer compensation for OW include:

- People receiving income from OW must report earnings on a monthly basis; people may want to keep earnings receipts³⁸
- People whose net earnings exceed \$200 per month will have 50% of their net earnings deducted from their OW payment in the month following³⁹
- Reimbursements for out-of-pocket expenses are not considered income³⁹
- If a peer’s earnings exceed monthly income limits for ODSP and/or OW, organizations may provide compensatory supports in lieu of lost benefits, e.g., bus passes.²⁵

FOUNDATIONAL FRAMING

Due to the risk of tokenism in peer engagement, it is important that organizations create intentional internal and external messaging about their practices for working with and compensating PWLE.^{8,9} The framing below may help organizations to communicate the importance of compensating PWLE equitably for their work:

- Peers provide work that improves the relevance, effectiveness, and accessibility of programs and services^{6,8,10**}
- Compensating peers insufficiently or expecting them to volunteer excludes peers who experience financial barriers from the benefits of engagement



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work, and makes it more likely that only more privileged voices will be heard^{3,6,13}

- Appropriate compensation enables the participation of a wider diversity of peers, which enhances impacts in programs and services^{2,8,25}
- Appropriate compensation helps to build social equity and reduce economic marginalization by recognizing the value and equality of peers' work^{10,23,25}
- Appropriate compensation recognizes the human dignity of PWLE and helps to reduce stigma by shifting from a charity-based view of marginalized people towards a strengths-based view^{1,6,7,10,14,23}
- Appropriate compensation can validate peers' expertise, reduce isolation, and improve capacity, which can reduce some of the impacts to mental health that result from social stigma^{6,13,14,25}



REFERENCES

- ¹ Homer, A. (2019). [Engaging People with Lived/Living Experience](https://bit.ly/2FGOdD3). Retrieved from <https://bit.ly/2FGOdD3>
- ² Becu, A., & Allan, L. (2018). [Peer payment standards for short-term engagements](https://bit.ly/2n9r41z). Retrieved from <https://bit.ly/2n9r41z>
- ³ End Poverty Edmonton (2018). [First Voice inclusion and participation equity protocol](https://bit.ly/2Vid1XR). Retrieved from <https://bit.ly/2Vid1XR>
- ⁴ Centre for Additional and Mental Health (CAMH, 2018). [The involvement of Persons with Lived Experience \(PWLE\) in paid staff roles when implementing Housing First](https://bit.ly/30RByEg). Retrieved from <https://bit.ly/30RByEg>
- ⁵ Vlachoyannacos, E. (2019). [Exploring the role of people with lived experience of poverty in finding solutions to poverty](https://bit.ly/2DyVle8). Retrieved from <https://bit.ly/2DyVle8>
- ⁶ Coleman, S.E., Byrd, K., Scaccia, J.P, Stout, S., Schall, M., Callender, S., ... Mann, Z. (2017). [Engaging community residents with lived experience](https://bit.ly/2PrSkqf). Retrieved from <https://bit.ly/2PrSkqf>
- ⁷ Wilcox, J., Pei, N., Boyer, T., & Johnson, M. (2018). [Case study. Authentic engagement: a learning journey](https://bit.ly/2DNVsag). Retrieved from <https://bit.ly/2DNVsag>
- ⁸ Toronto Community Hep C Program (2018). [Peer manual: a guide and a resource for engaging with clients beyond service provision in a harm reduction setting](https://bit.ly/2Om7GgV). Retrieved from <https://bit.ly/2Om7GgV>
- ⁹ Centre for Additional and Mental Health (CAMH, 2019). [Peer positive toolbox: preparing organizations to better engage people with lived experience through equitable processes](https://bit.ly/2VgRcrG). Retrieved from <https://bit.ly/2VgRcrG>
- ¹⁰ Canadian HIV/AIDS Legal Network (2005). ["Nothing about us without us". Greater meaningful involvement of people who use illegal drugs: a public health, ethical, and human rights imperative](https://bit.ly/2OvORII). Retrieved from <https://bit.ly/2OvORII>
- ¹¹ Belle-Isle, L., Pauly, B., Benoit, C., Hall, B., Lacroix, K., LeBlanc, S., ... Dupuis, G., (2016). [From one ally to another: practice guidelines to better include people who use drugs at your decision-making tables](https://bit.ly/33bxZuv). Retrieved from <https://bit.ly/33bxZuv>
- ¹² Lived Experience Advisory Council (2016). [Nothing about us without us: seven principles for leadership and inclusion of people with lived experience of homelessness](https://bit.ly/2AL5XK0). Retrieved from <https://bit.ly/2AL5XK0>



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- ¹³ Greer, A., Newman, C., Burmeister, C., Burgess, H., Coll, M., Choisl, P., ... Buxton, J. (2017). [Peer engagement principles and best practices: a guide for BC health authorities and other providers](https://bit.ly/30Smuqe). Retrieved from <https://bit.ly/30Smuqe>
- ¹⁴ Hastings-Prince Edward Poverty Roundtable (2017). [Creating community: a tool for engagement](https://bit.ly/31SI6E5). Retrieved from <https://bit.ly/31SI6E5>
- ¹⁵ Paradis, E. (2018). If you build it, they will claim. [Rights-based participation and accountability in Canada's National Housing Strategy](https://bit.ly/31PMHXC). Retrieved from <https://bit.ly/31PMHXC>
- ¹⁶ City of Toronto (2019). [Lived Experience Advisory Group \(LEAG\)](https://bit.ly/2KfGCuw). Retrieved from <https://bit.ly/2KfGCuw>
- ¹⁷ Hamilton Roundtable for Poverty Reduction (2010). [Equity and inclusion policy](https://bit.ly/357tPFz). Retrieved from <https://bit.ly/357tPFz>
- ¹⁸ Region of Waterloo Social Services (2012). [Lived experience as expertise: considerations in the development of advisory groups of people with lived experience of homelessness and/or poverty](https://bit.ly/2LUqsuh). Retrieved from <https://bit.ly/2LUqsuh>
- ¹⁹ Burkett, D. (2009). Social inclusion policy. Hamilton, ON: Hamilton Roundtable for Poverty Reduction.
- ²⁰ LiveStories (2018). [Integrating](https://bit.ly/2AZ0j7n). Retrieved from <https://bit.ly/2AZ0j7n>
- ²¹ Arthur, E., Seymour, A., Dartnall, M., Beltgens, P., Poole, N., Smylie, D., North, N., & Schmidt, R. (2013). [Trauma-informed practice guide](https://bit.ly/1SihzU4). Retrieved from <https://bit.ly/1SihzU4>
- ²² Donnelly, K., Doerge, S., Vandegrift, J., Jubinville-Stafford, M., Blinick, G., Keefe, G., ... Corner, T. (2015). [Resident honorarium: guiding principles and promising practices](https://bit.ly/35grBUH). Retrieved from <https://bit.ly/35grBUH>
- ²³ Saskatoon Poverty Reduction Partnership (2017). [Creating a culture of inclusion](https://bit.ly/31R566h). Retrieved from <https://bit.ly/31R566h>
- ²⁴ Ti, L., Tzemis, D., & Buxton, J. A. (2012). [Engaging people who use drugs in policy and program development: a review of the literature](https://bit.ly/2MhGjIA). *Substance Abuse Treatment, Prevention, and Policy*, 7(47), 1-9. Retrieved from <https://bit.ly/2MhGjIA>
- ²⁵ Greer, A.M., & Buxton, J.A. (2017). [A guide for paying peer research assistants: challenges and opportunities](https://bit.ly/2Oq83am). Retrieved from <https://bit.ly/2Oq83am>
- ²⁶ Cheff (2018). [Compensating research participants: a survey of current practices in Toronto](https://bit.ly/30KudXi). Retrieved from <https://bit.ly/30KudXi>
- ²⁷ The Change Foundation (2015). [Should money come into it? A tool for deciding whether to pay patient-engagement participants](https://bit.ly/2ANP7uc). Retrieved from <https://bit.ly/2ANP7uc>



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- ²⁸ Vancouver Coastal Health (2016). [Peer framework for health-focused peer positions in the downtown eastside](https://tinyurl.com/y4h3rchl). Retrieved from <https://tinyurl.com/y4h3rchl>
- ²⁹ Canadian Council of Christian Charities (2019). [Gifts of appreciation and honorariums](https://bit.ly/30LVIQc). Retrieved from <https://bit.ly/30LVIQc>
- ³⁰ University of Waterloo (2019). [Honorariums](https://tinyurl.com/yxn7y4q8). Retrieved from <https://tinyurl.com/yxn7y4q8>
- ³¹ Government of Canada (2019). [Consolidated federal laws of Canada, Income Tax Act](https://bit.ly/2p0lsuM). Retrieved from <https://bit.ly/2p0lsuM>
- ³² Canada Revenue Agency (2019). [Line 101 – employment income](https://bit.ly/32IFcaU). Retrieved from <https://bit.ly/32IFcaU>
- ³³ Canada Revenue Agency (2019). [T2125 Statement of Business or Professional Activities](https://bit.ly/2MgECEV). Retrieved from <https://bit.ly/2MgECEV>
- ³⁴ Government of Ontario (2018). [As an Ontario Disability Support Program recipient: your responsibilities](https://bit.ly/2Mjsblw). Retrieved from <https://bit.ly/2Mjsblw>
- ³⁵ Government of Ontario (2018). [Treatment of income: when you work and earn money](https://bit.ly/30TJIBA). Retrieved from <https://bit.ly/30TJIBA>
- ³⁶ Government of Ontario (2018). [ODSP: information sheet](https://bit.ly/2MbTl3K). Retrieved from <https://bit.ly/2MbTl3K>
- ³⁷ Government of Ontario (2018). [Employment incentives and benefits: Work-Related Benefit](https://bit.ly/31S3r0w). Retrieved from <https://bit.ly/31S3r0w>
- ³⁸ Government of Ontario (2018). [Ontario Works Directives, 5.1: Income and Exemptions](https://bit.ly/2lsyaK2). Retrieved from <https://bit.ly/2lsyaK2>
- ³⁹ Government of Ontario (2018). [Frequently Asked Questions: income, assets and housing costs under Ontario Works](https://bit.ly/338Mfny). Retrieved from <https://bit.ly/338Mfny>