

The **POLITICS** of SERVICE USER LABOUR



LUCY COSTA
LISA WALTER



TO ALL THE SERVICE USER/SURVIVORS
WHO HAVE WORKED FOR FREE
IN ASYLUMS, PRISONS, LONG-TERM CARE FACILITIES,
RESEARCH PROJECTS, ADVISORIES,
PEER SUPPORT, AND ENDLESS FOCUS GROUPS

the *POLITICS* of service user labour

**by Lucy costa
& Lisa walter**

Citation information: Costa, L., Walter, L., Aird, A. (2022)
The Politics of Service User Labour. (The Empowerment
Council: Toronto.)

who's responsible for this zine-thing?



Lucy Costa (author) is an advocate in the service user/survivor community doing advocacy, research and education for over twenty years in Toronto. Toronto is covered by the Toronto Purchase, Treaty No. 13 of 1805 with the Mississaugas of the Credit.

"I wanted to broach the topic of service user labour (in all its various forms), because there are a lot of good, bad, spoken and unspoken things that are happening in respect to employment, and engagement practices. Likewise, I have had positive and negative experiences working alongside service users/survivors."



Lisa Walter (editor/graphic designer) is a multi-disciplinary artist and social change educator based in Winnipeg, in Treaty 1 territory/Winnipeg (Manitoba, Canada).

"I've had some less-than-positive experiences as a peer supporter (paid and unpaid) and working in a variety of psychiatry-instigated projects and committees, in Toronto and in Winnipeg. The problems I encountered were complex and their systemic causes obscured. I think it's important to dig into what's happening, and why, because it seems to be pervasive. Service user/survivors can have more of an impact on the labour landscape when we have a shared understanding of the issues."



Big shout out to Ali Aird who assisted with research and writing for this project



what is this zine about?

The Politics of Service User Labour talks about issues that concern service users/survivors who perform different kinds of labour (paid and unpaid) in the mental health sector. These issues are part of the legacy of patient labour in the psychiatric system. Though there have been improvements in employment and inclusion opportunities over the years, problems remain. We still need to work together to advance working conditions, wages, and benefits for service users/survivors.

Service user labour is political. Everything that happens in relation to it, whether in paid or volunteer work, has social and economic contexts. It's grounded in a long history of institutional power.

So while this zine looks into problems that affect individuals who do this work, we also raise issues that affect our community as a whole. We also delve into messy topics like how service user/survivors can be complicit in upholding oppressive practices when they participate in the system, and the need for accountability. This stuff is challenging and

messy, but also really important for creating better, more equitable labour and inclusion practices.



Trackwomen at the Baltimore & Ohio Railroad Company, 1943.
(National Archives Identifier 522888)

In each section, we examine a topic or group of topics and pose questions for people doing service user labour to think about. We also ask questions to guide reflection by service users on labour issues that impact our communities.

There are a couple of issues we don't delve into. We wanted to write about employment/volunteer work and police record checks of people who have mental health histories, but that's a complex topic beyond the scope of this zine. Troubling aspects of the peer movement, including peer employment, have already been written about a fair bit. Likewise, statistical employment rates for people with disabilities are a subject of ongoing study and discussion. We're leaving those matters aside.

Zines have been a way of collectively taking action in our communities for decades. This zine is a work in progress – we've gathered up what we've learned and the questions that remain, and are handing it over to you. Our intention is to fuel more exploration and discussion and, most importantly, action that will make life better for our communities.



INCOMPREHENSIBLE

The topics we cover include:

1. Why service user labour is political:
 - The historical context
 - The economic context
2. Identity-based labour and working conditions:
 - Why linking labour to identity is problematic
 - Ambiguous definitions of labour
 - Precarious labour
 - Labour fragmentation
 - Emotional labour
 - How this relates to the economic context
3. Messy stuff: Complicity and accountability
 - The potential for complicity in service user labour
 - Honorariums
 - Entitlement versus accommodation
 - Community accountability
 - Service user/survivor organization accountability
4. Where do we go from here..?



Before we dive in...

Before we dive into the nitty-gritty, there's some important background stuff we want to put on the table.

TERMINOLOGY

While we assume you have a passing familiarity with mental health systems, it's worth clarifying certain terms.

What do we mean by labour, exactly?

According to the most general definition, *labour* is work. More specifically, it is any activity that contributes to the production of goods or services. Labour is not the same as *employment*, in which a worker is paid and has a formal agreement with their employer. 'Labour' is a more general term, and it applies to traditional employment and unpaid work arrangements.



Examples of unpaid labour include caregiving, volunteering, and internships. In these situations, labourers contribute to the production of goods or services without receiving money for their efforts.



What is a service user? What is lived experience?

Service user is one of many terms used today by those who have had contact with the psychiatric system, or other healthcare system. *Lived experience*, in this context, is the experience of having had mental health and/or substance use issues; the acronym *PWLE* refers to a person (or people) with lived experience. Sometimes 'service user' and 'person with lived experience' are used interchangeably, but not all people with lived experience are service users.

What is service user labour?

Service user labour refers to work (paid and unpaid) performed by people who are recruited, in part, on the basis of their identity as service users and having lived experience of mental health and/or substance use issues. We refer to this as *identity-based labour*.



HOW WE GOT HERE: WHY THIS LABOUR HAS ALWAYS BEEN POLITICAL

How and why things are the way they are now is complicated, but there are a couple of ways of thinking about them that we want to highlight.

The historical context

Understanding the history of psychiatric patient labour, and how it has evolved up to the present day, helps us appreciate present day challenges for service users.

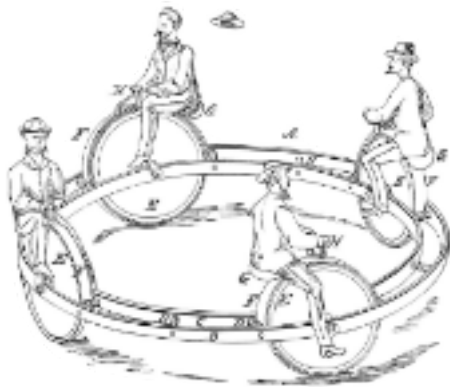


What we now call service user labour goes back a long way. Psychiatric patients (who were once called “feeble minded”) have always worked in psychiatric hospitals, even in the days of insane asylums. Inhumane wages were paid to people with

intellectual disabilities who worked in institutions and sheltered workshops. Black male patients were used in hospitals for physical labour – this was considered a “natural” form of work because Black men were supposedly accustomed to demanding manual labour.

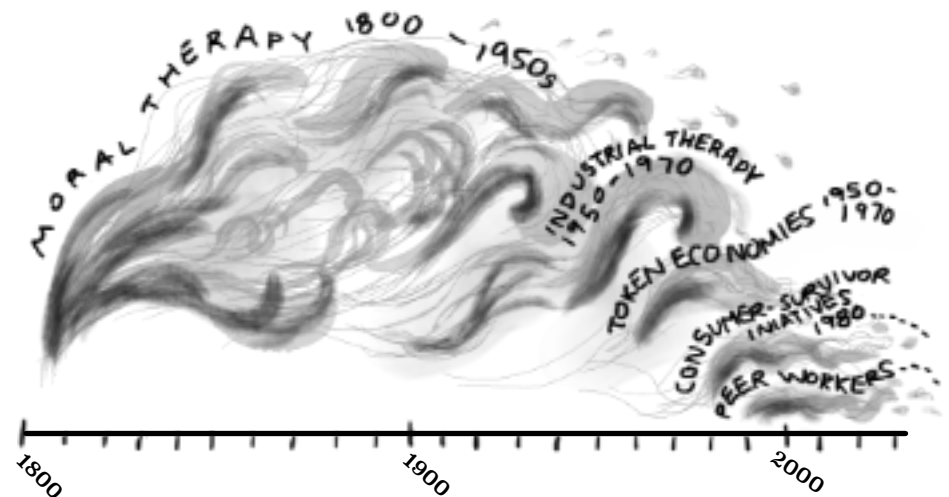
Sometimes this labour was called “therapy.” Work by patients, like that of building the 10-foot high brick wall that surrounds a Toronto psychiatric hospital, was promoted as being therapeutic; the workers didn’t get paid. Patients’ labour was embedded in the visible and invisible workforce that kept hospitals running.

Patients are still used today to perform labour that keeps hospitals going and makes them relevant. They’re used in things like focus groups, committees, and projects initiated by psychiatry. These kinds of projects are meant to give the appearance of including patients in running hospitals, but they are more like empty gestures of inclusion rather than meaningful inclusion.



Examples of patient labour:

- Moral Therapy (1800 – 1950)
- Industrial Therapy (1950 – 1970)
- Token Economies: systems whereby a patient’s “improvement” was rewarded with tokens used to purchase privileges (1960s -1970s mostly, but still operative today in some sites)
- Consumer/survivor initiatives and social enterprises (1980s to present day)
- Peer workers (1990s - to present day)



The economic context: psychiatric institutional economies

They say money makes the world go around. Figuring out how it does that, and for whom, is the subject of economics.

Economics, in very basic terms, is the study of how wealth moves around within a region or system – how it’s made, consumed, and transferred. Understanding how money moves around within healthcare systems – healthcare economies – can tell us a lot about how they are set up and operated, and what the priorities are.

Because healthcare economies – or, for our purposes, psychiatric institutional economies – are dependent on government financing, they will always be interested in “value for dollar.” They want to get the best health outcome for the least amount of money invested. Funders want to know how services may be made more effective and efficient. In the past ten years, they have placed increasing importance in finding out from patients how services might be improved. There is frequently a difference, though, between how clinical staff define value for dollar and how patients define it.

Currently, there is a wide range of service user labour and employment schemes. They include:

Volunteer work:

- no honorarium or reimbursement for expenses, but may have other incentives for participation such as gift cards, free food, or public recognition; or
- expenses reimbursed but no honorarium; or
- honorarium and expenses reimbursed;

Employment:

- may be temporary, casual, contract, or permanent.



Any of these activities might have additional perceived bonuses; for example, that they will improve one’s resumé.

This spectrum of labour and compensation arrangements is not consistent with the real world labour market. In many ways, it’s like its own invisible “lived experience economy.” It often flies under the radar, is at the disposal of sector interests, and is not necessarily aligned with service users’ employment equity goals. It’s difficult, if not impossible, to know what the consequences of these arrangements are, or how this kind of labour improves the lives of service users as a whole.

Some service user labour is valuable to the psychiatric institutional economy because it supports the institution’s clinical agenda. Labour that empowers service users, that gives them control of services, or makes room for critical thinking or questioning is not usually valued or supported. As well, some hospital staff tend to see service user labour as inherently healing or inspirational; it doesn’t need to be compensated, because the benefit is that it’s therapeutic. This adds to the confusion and exploitation of service users, especially when some feel that working for little or no pay is a way of “giving back” to the system.

Typically, service users working in the system see themselves as part of a committee, a department, or a project. When we step back and look at the work we do in relation to a much larger system – an economic system – we start to see that there are larger forces at play.



identity-based labour and working conditions

In this section, we examine issues that relate to working in mental health and psychiatric systems. They affect service user workers' experiences of work, regardless of the kind of volunteer/employment relationship they have with an organization. Because many people are now doing work with organizations based on their supposed lived experience, these issues have implications for our communities.

IDENTITY-BASED LABOUR

In service user labour, work is linked to identity. Our experiences of psychiatric systems become a commodity or a credential – a feature in our contributions to the psychiatric institutional economy. Over the years, there have been growing questions and concerns about lived experience as a factor in the labour market. What does it do or not do?

For instance, a person with lived experience is typically someone who has personally dealt with mental health or substance use concerns. However, in some circumstances, a family member or relative might be seen as having "lived experience" merely by virtue of knowing someone who has interacted with the system. We believe that there is a significant distinction between a family member and someone who has experienced psychiatric treatment themselves. Yet there are situations where a family member takes opportunities that are better suited to service users (e.g., leading a patient engagement project, or sitting on the board of directors of a mental health organization).



Identity-based labour presents a unique set of challenges related to equity, tokenization, and representation. The nature of service user labour makes it difficult to identify and confront these challenges. Employee confidentiality, poorly-defined roles, and isolation in the workplace are just a few of these barriers. Deciphering when identity matters or when job skills matter gets muddled when there are no rules or rights around lived experience.

For racialized service user workers, there's sometimes the added layer of being brought in to supposedly represent an entire group of people. In the absence of actual antiracism and anti-colonialism work, this kind of tokenizing is particularly offensive.



Some more things to think about...

Questions for you:

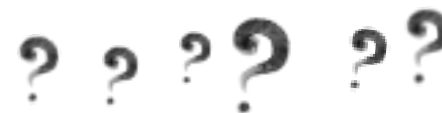
- *Do you feel that your knowledge is valued as much as that of colleagues without lived experience – by your supervisor? by your colleagues?*
- *Can your colleagues confidently describe the lived experience-related work you do?*
- *Is it public knowledge which of your colleagues have lived experience, and what kind of experience they have – e.g., mental health issues, hospitalization, homelessness, family member or caregiver, etc.? Is lived experience anonymous or confidential? Who profits from this?*

Questions for service user communities:

- *Does labour requiring lived experience promote education or growth for service users?*



- *What happens when we turn personal experience into labour, either paid or unpaid?*
- *Whose lived experience counts, and whose doesn't?*
- *Whose lived experience is visible, and whose is invisible?*
- *Who's deciding these things, who benefits, and what (if any) mechanisms exist for accountability?*



AMBIGUOUS DEFINITIONS OF LABOUR

In identity-based labour, whether paid or unpaid, it is often unclear how much of a worker's role is defined by the labour they perform, and how much by their identity. How a worker is expected to draw on their lived experience is often not made explicit.

This ambiguity creates opportunities for tokenization, favouritism, and selective hiring. It also justifies complacency in situations where a service user accepts payment just for being who they are, while performing little or no labour. When we accept an invitation to participate but don't contribute anything, we can become complicit in these empty gestures of inclusion – projects that signal inclusion but limit meaningful participation.





Some more things to think about...

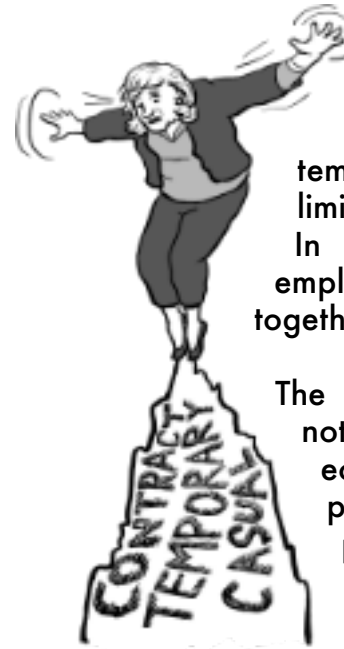
Questions for you:

- *During hiring and recruitment, is the employer clear about what they mean by lived experience in the context of a job? In the job description, do they say what lived experience-related skills and abilities they're looking for?*
- *How does having lived experience specifically contribute to a work or volunteer role? Is it drawn upon and valued? How is this demonstrated?*
- *How is lived experience, as a factor in your duties, assessed in performance evaluations? How does it factor into opportunities for advancement?*
- *How does work that draws on lived experience contribute to an organization? How does it address equity issues?*

Questions for service user communities:



- *How can we know how meaningful it is when an organization promotes the involvement of people with lived experience or peers?*
- *What kind of accountability is there for organizations that promote service user involvement in funding applications? Are there guidelines for funders to evaluate what kind of involvement is more than just a gesture?*



-- BUT WAIT, THERE'S MORE!

Precarious labour

Service user labour is often part-time, temporary, or on contract, in roles with limited opportunity for career advancement. In the absence of secure and ongoing employment, service users frequently patch together multiple part-time jobs.

The instability this creates becomes more noticeably problematic in moments of economic instability (during the Covid-19 pandemic, for example). Shifting budget priorities leave contract and part-time employees vulnerable to layoffs, and non-traditional employment arrangements can make workers ineligible for financial assistance.

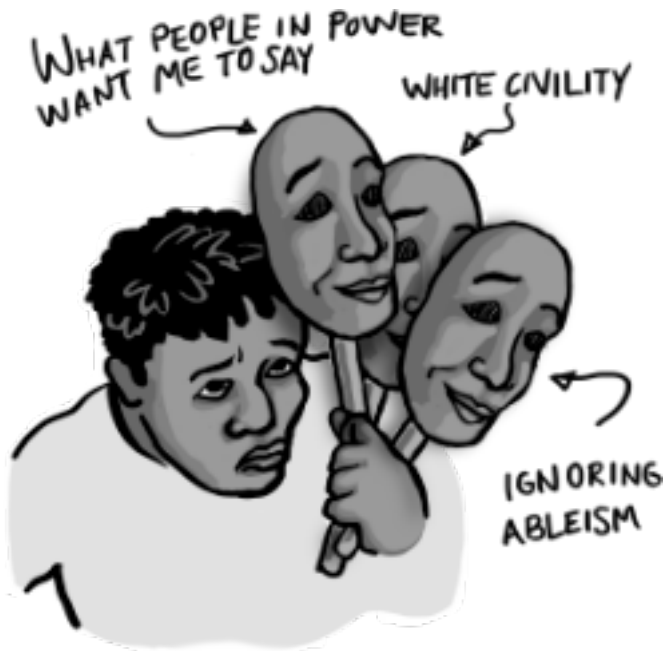
Labour fragmentation

Overall, service user labour is organized in pockets and compartments that make little sense when considering the system as a whole. Our work is scattered across organizations, departments, and initiatives. We are recruited selectively, conditionally, and transiently. This fragments our work and hampers our ability to organize and advocate. It creates what our friend Ali Aird called a "padded ceiling," which, as a labour dynamic, limits our impact and hinders our advancement, individually and collectively.



Emotional labour

Emotional labour, in service user labour, refers to having to manage one's emotional expression as a condition of work. A way of expressing emotion that is considered appropriate for non-service users may be considered inappropriate for service users. Many service users experience prejudice, micro-aggressions, and exploitation in jobs or mental health initiatives. They often try to hide their emotions in order to be accepted, or be seen as "professional" or "appropriate."

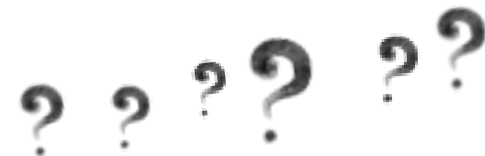


Service users talk about the pressure they feel when they attend meetings where their very presence is met with resistance and hostility. Sometimes when service users express conviction with emotion in meetings with people who are very powerful, like wealthy donors and hospital executives, the responses they get can leave them feeling very intimidated.

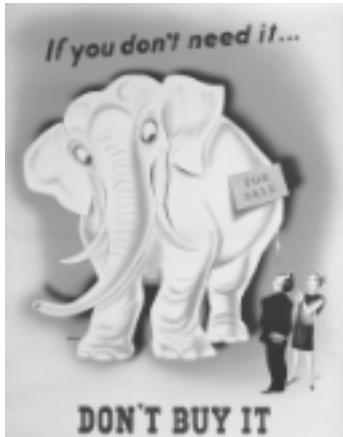
Some more things to think about...



- How do the working conditions and compensation of colleagues who don't have lived experience compare to your own? (If you work in a unionized job, you may find this information in your collective agreement.)
- Does the funding for your work come from a different budget than that of non-service user workers? Is it contingent on a grant or pilot project funding?
- Have you worked in the same position on back-to-back contracts? Has your employer discussed whether your contract position can be converted to a permanent one?
- Do you know who else is doing service user labour in the organization you're working for? Have you ever met as a group for any reason?
- Have you ever talked to a union representative or another colleague about concerns you may have as a service user worker?
- Do you feel hyper-scrutinized as an employee with lived experience? Do you feel like your mental health is being evaluated in addition to how you perform your duties?
- Are policies such as codes of conduct enforced differently for service user workers than other people in the organization?



HOW DOES THIS RELATE TO THE ECONOMIC CONTEXT?



In the earlier section on psychiatric institutional economies, we looked at the bigger picture. We talked about how systemic factors like value for dollar, competing priorities, and perceived therapeutic benefits of service user labour affect budget decisions. In the last few pages, we examined how identity-based labour issues affect individual service user workers, and also our communities.

When each of us only sees the problems in our own situations, the causes appear to be unique. But when we see these same problems replicated across entire systems of health care, we can see a pattern. These working conditions isolate us as individuals, wear us down, and prevent us from sharing and analyzing information. This makes it difficult to advocate for change. Most people would say that for mental healthcare systems to engage with service users is a good thing, but the way that they're going about it is actually contributing to our marginalization.

This isn't happening due to accident or oversight. The problems we're naming here aren't new. That the sector and its funders have failed to address these problems for so long is a decision.



Disability benefits:

Depending on the jurisdiction, service users on disability benefits who receive honorariums for service user labour have to claim them as extra income. This of course penalizes people who are already struggling with poverty, who want to participate in spite of disability challenges, which are complex and sometimes episodic.

a few

Observations



Free income tax clinics are a valuable resource for low-income taxpayers. Tax clinics file returns on behalf of people who meet income and employment criteria. Different clinics have different income policies, so call to confirm that you're eligible for support.



Unions have always been really important for fighting for and protecting workers rights, but there has been some resistance from unions to supporting the concerns and needs of people with psychiatric disabilities. There have been examples of unions perpetuating the myth that psychiatric patients are violent, and that nurses and other clinical staff need to be protected. This is a problem on a number of levels.

It assumes clinical staff are not people with psychiatric disabilities themselves, and it also doesn't try to understand the realities of violence, incarceration, and coercion that are built into the system.



messy stuff: complicity and accountability



FROM ACTIVISM...



...TO PATIENT ENGAGEMENT

It has been a long road to fight for human rights in health-care, housing, and employment for service users. When we take on employment specifically related to service user experiences (e.g., peer work) or take on the responsibility of speaking as the voice for others in the system, it matters. Our labour, big or small, is connected to the larger goal and vision of advancing rights for service users.

Unfortunately, the difficulties many of us face because of our need to work, bring in some extra money, or just survive means that there are times when we can become complicit in our own oppression. Complicity is “when there is an alliance or participation in a wrongful or unjust act.” We become complicit when we uphold the dominant assumptions built into institutions, or ignore historical harms rather than working to name and reconcile them.

Some of the ways complicity plays out in the politics of service user labour, especially within institutions, are when we:

- Ignore truths about the psychiatric system, such as its history of exploitation and abuse;
- Defend this history or apologize for it;
- Pretend to speak to the limitations of the psychiatric system, but avoid addressing real problems or naming its violence;
- Deliberately work to shut down other service users’ arguments about psychiatry’s complex past;

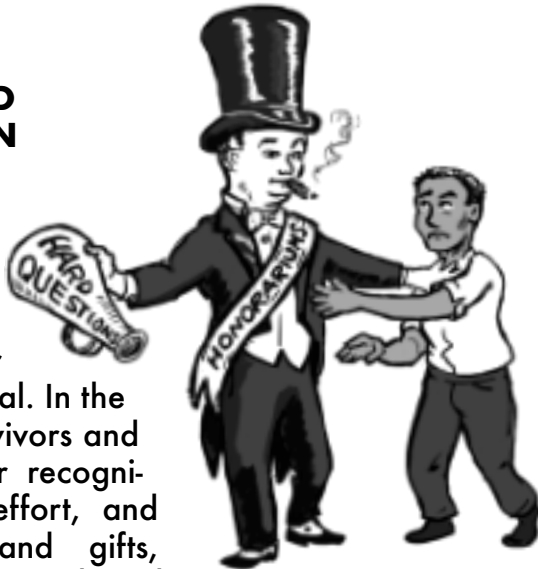
- Stay silent about prejudice because we prioritize being liked and accepted by people in power;
- Refuse to learn from what service users have written about, including contributions on human rights, equality, antiracism work, LGBTQ2S+ anti-oppression, anti-Indigenous racism, ableism, and ageism.

We need to be mindful of the dangers of being complicit, and how it affects people whose circumstances are worse than our own.

HONORARIUMS, ENTITLEMENT, AND ACCOMMODATION

Honorariums

The practice of offering honorariums in exchange for service user participation is political. In the '70's, psychiatric survivors and advocates fought for recognition of their time, effort, and labour. Payments and gifts, however small, were an acknowledgment that service users made valuable contributions to system change efforts.



But now, honorariums – while still extremely important – have become a tool in the psychiatric institutional economy. They can be a way for individuals, organizations, and institutions to pay for who they want to participate and what they want them to say. In other words, honorariums influence and shape service user feedback, like an intellectual straightjacket.

We encourage service users to reflect on the following questions...

When offered unpaid work:



- *What am I specifically expected to do in exchange for an honorarium?*
- *How does an honorarium influence or change my participation or feedback?*
- *Will I be in a conflict of interest if I accept an honorarium? For example, would getting paid an honorarium prevent me from speaking up or challenging an organization's practices?*
- *How do I make sure honorariums do not get in the way of asking questions about accountability?*
- *Do I expect an honorarium every time I participate, even if my effort is minimal?*

More generally:

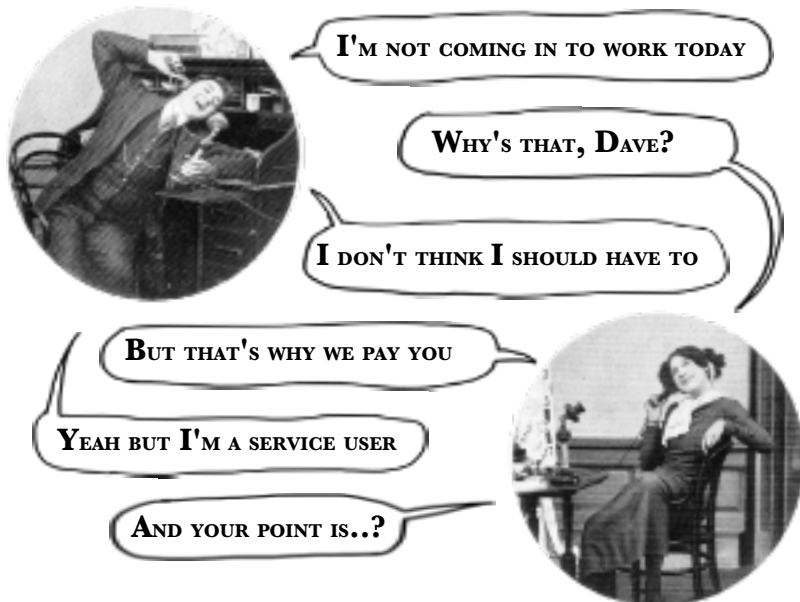
- *Which service users are typically invited to participate, in exchange for gifts or money, and which service users are excluded?*
- *How are service users accountable to the community? Who do they speak for and how do they decide which issues to raise? To whom do they report if they get an honorarium?*



ENTITLEMENT VERSUS ACCOMMODATION

Most people don't expect to get paid because of their identity, yet we hear more and more stories of service user workers having precisely that expectation. They may think this even if they've compromised the work by not having completed it. This is especially troubling when they're in service user-specific jobs or user-controlled research projects.

Service users in leadership positions speak of the challenges of addressing fellow service user workers who don't follow through with what's expected of them. They find these conversations especially delicate given the struggle for survival many service users are facing. Sometimes issues can be easily addressed in job performance evaluations, but that's not always possible because so much labour is precarious. And sometimes the funder of a particular project isn't all that supportive of service user labour in the first place. As people who are fighting for and supporting opportunities for service users, they're in a sticky situation.



We need to work together to create spaces where we can discuss these issues and move towards useful solutions.

Disability supports, including leaves of absence, are a right and must be accommodated by employers. However, a worker who does not fulfil their responsibilities isn't entitled to be paid simply because they identify as a person with lived experience.

Workers requiring accommodations for disabilities can find resources through community legal clinics, provincial human rights councils or tribunals, and their union (if applicable). It is helpful to know your rights before you meet with a supervisor, which is usually the first step in arranging for an accommodation.

ACCOUNTABILITY

Community accountability

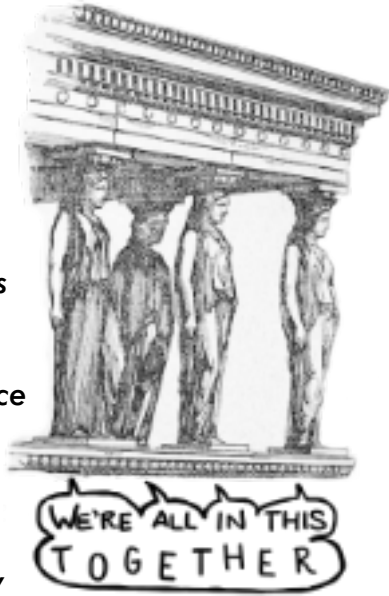
It's important to remember that being included or employed in a some kind of lived experience employment does not automatically translate to meaningful inclusion. When we're invited to sit at the table it can feel validating and empowering, but are we allowed to speak? When we speak, what are we allowed to say? Are we heard? What happens next? Who is absent? What are the compromises made by our "engagement"?

We encourage service users interested in labour and engagement issues to reflect upon the following questions:



- *Who am I accountable to in my labour or "engagement?" – agencies and organizations, myself, other service users, someone or something else?*

- How does privilege – racial, colonial, gender, and other – affect my participation?
- How does my inclusion reflect my privilege?
- Who else is included? Who is excluded?
- How am I connected to service users who are not invited to “engage?”
- How can I create those connections if I don’t already have them, particularly with those who have less privilege than I do?
- Who am I being asked to represent?
- What kind of work am I providing?
- Am I allowing myself to be tokenized by accepting payment in exchange for being a silent service user?



Service user/survivor organizational accountability

When joining a research project, board of directors, or organization run by service users, it’s important to understand the history of its development. What drove its development, and by whom, will have impacted its social justice work or employment goals.

You might want to ask these questions:

- What principles and values define this organization?

- What’s the evidence that the organization or project is guided by the experiential knowledge of service users, patients, consumer/survivors and people with substance use histories?
- Does the organization have a strong board of directors or other accountability body that is driven by service user experiential knowledge?
- Does the board of directors have a secure understanding of their roles and responsibilities?
- What are the processes of evaluation for all members of the organization?
- Is there transparency and accountability with funding and expenditures?

good governance...



what does it look like?

where to go from here?

As we mentioned in our introduction, this zine is a work in progress, a dialogue. We know the topics we're raising are familiar to people across different jurisdictions in different ways. We believe that the labour that powers social movements can push for and enact change. After all, it is through the labour of activists and service user/survivors that justice has always been won. Let's keep at it!

WE CAN...

- Work with governments and employers to follow through on employment equity legislation, and on accessibility and accommodation requirements (e.g., the Accessibility for Ontarians with Disabilities Act, the UN Convention on the Rights of Persons with Disabilities, etc.)

- Join the fight to increase minimum wage;
- Build more access and opportunities to meaningful education for service users;
- Research and revolutionize how services users fit into visible and invisible market economies;
- Create forums for and by service users to discuss accountability for service user labour and representation in projects such as advisories, committees, etc.;
- Foster community meetings for and by service users to discuss accountability, and the challenges and ethical dilemmas in service user participation;
- Connect with unions and find places of solidarity and alliance;
- Celebrate when we win – even the small stuff.



