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Representation and Recommendations: Participation of People Who Use Drugs in UN-Level Policy-making

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Representation and Recommendations: Participation of People Who Use Drugs in UN-Level

Policy-making

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Fall 2021

SIT: Global Health and Development Policy

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Abstract:

Although participation in health policy-making is a popular topic in the literature and a stated priority of the United Nations, very little research has been published examining the full spectrum of participation by people who use drugs (PWUD) at the UN level. This study aims to describe and evaluate this participation through a combination of a literature review that looks at academic sources, UN publications, and publications by organizations of PWUD, and a series of interviews with representatives of organizations of PWUD who have participated in UN level policy-making.

Data collected demonstrates that there is no comprehensive system for the participation of PWUD in policy-making at the UN, although they are more integrated into spaces concerned with HIV/AIDS than any other, and that people who use drugs face a variety of logistical, discursive, and structural barriers to meaningful participation. However, organizations led by PWUD have created inroads and developed strategies to participate both as activists and technical advisors at the UN, including public appeals, event attendance, and leveraging of UN contacts. Significant structural changes are needed at the UN to fully remove barriers to participation by PWUD.

Acknowledgements

This research would not have been possible without the dedicated SIT staff who gave me the opportunity to do this project and supported me along the way.

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Introduction

United Nations bodies including the UN Office on Drugs and Crime (UNODC), the World Health Organization (WHO), and the Joint United Nations Programme on HIV/AIDS (UNAIDS) regularly make policies and recommendations which affect the lives of people who use drugs across the globe. However, very little research has examined critically how people who use drugs participate, or are blocked from participating, in the creation of these policies and recommendations. Participation in policy-making, and participation especially of minority groups, has been widely researched, but people who use drugs have been largely left out of the conversation.

This study aims not only to examine the “involvement” of people who use drugs in policy-making — in other words, whether or not people who use drugs are present in policy-making spaces — but also the meaningful participation of people who use drugs. “Meaningful participation” is a term designed to capture the idea of participation that goes beyond symbolic presence, in which the full spectrum of people who use drugs are represented, people who use drugs are involved in every space where drug-related policy is made, people who use drugs are heard and the expertise brought is taken seriously and has the potential to affect change, and people who use drugs are credited for their contributions. This study is exclusively concerned with direct participation, not secondary participation as it might occur through the filter of people or bodies which do not directly represent organizations of people who use drugs.

The goal of this study is to describe as fully as possible the current state of participation by organizations of people who use drugs in UN-level policy-making. Emphasis is placed on identifying both the current barriers to meaningful participation and the strategies used by organizations of people who use drugs to respond to these barriers. The aim is to find both the

pathways for participation currently available and recognize the roadblocks which limit participation on the way. This analysis relies heavily on contributions from representatives of organizations of people who use drugs.

The process of policy-making and meaningful participation of people who use drugs therein is important to the field of public health. The process of policy-making impacts both the policy that gets made and the perceived legitimacy of said policy. It is impossible to create legitimate and effective health policy without consulting thoroughly the population which that policy affects. And, as stated in the oft repeated phrase, “all policy is health policy,” one cannot separate policies made about the legal status of certain drugs from policies surrounding harm reduction, treatment, and the overall health and wellbeing of people who use drugs.

After a brief note on language and an overview of methodology, this paper consists of a literature review, which covers broad areas such as current theories of public participation in health policy, mobilization by people who use drugs and the role people who use drugs play in their own health, and the current state of participation by people who use drugs at the United Nations. Then interviews are analyzed for key themes, barriers to participation, and case studies of participation of people who use drugs at the United Nations. Each section is designed to build on the last and create a map of the current state of participation by organizations of people who use drugs at the United Nations.

A note on language

Throughout the paper, the term “people who use drugs,” hereafter abbreviated as PWUD, will be used. Substance use has a long history of stigmatizing language, in and out of the medical community. Many terms surrounding drugs and drug use have the potential to cause harm and

perpetuate stigma: a report from the global commission on drug policy acknowledges the adverse effect of terms including “addict,” “substance/drug abuser,” and “clean,” as used in reference to persons in recovery.¹ Even more seemingly neutral language, such as “drug user” can have a stigmatizing impact by centering a behavior in the conversation instead of human dignity. For this reason, modern scholars and organizations of PWUD are promoting the use of “people-first” language, an idea arising from disability scholarship, which respects the individuals concerned by centering personhood and addressing traits, behaviors, or medical conditions second.² While some scholarship will use people-first language which is more specific than PWUD, such as people who inject drugs, people who use opioids, or people with a substance use disorder, this piece is not interested in one specific mode of delivery, type of drug, or biomedical condition. Rather, the object of study is organizations which explicitly identify as being led by and representing PWUD.

Methodology and Research Ethics

This research was developed through the combination of a literature review and qualitative interviews with representatives of organizations of PWUD who have participated in the creation of international policy. Ultimately the research is qualitative, descriptive and critical, and aims to both identify and critique the current state of affairs in the field.

Literature review consisted of a broad search of available English literature in a set of thematic areas including participation in health policy, mobilization and organization by PWUD,

¹ Global Commission on Drug Policy. The world drug perception problem-counteracting prejudices about people who use drugs: 2017 report. Jan 2018.

www.globalcommissionondrugs.org/wp-content/uploads/2018/01/GCDP-Report-2017_Perceptions-ENGLISH.pdf.

² Broyles, Lauren M., Ingrid A. Binswanger, Jennifer A. Jenkins, Deborah S. Finnell, Babalola Faseru, Alan Cavaola, Marianne Pugatch, and Adam J. Gordon. "Confronting Inadvertent Stigma and Pejorative Language in Addiction Scholarship: A Recognition and Response." *Substance Abuse* 35, no. 3 (07, 2014): 217-221. doi:<http://dx.doi.org/10.1080/08897077.2014.930372>.

and policy participation by PWUD at the UN. In addition, key UN documents that cover or prioritize the participation of people who use drugs in policy making were highlighted. Key publications by a research team at UNSW formed the backbone of the literature review and contributed to the development of other thematic areas and the research overall. These publications represent some of the only available academic literature on the participation of PWUD at the UN. Therefore, aspects of the literature search relied upon publications by organizations of PWUD, specifically INPUD, an organization which publishes opinions, scientific literature, and reviews of its own activities.

Due in part to the limited state of the literature at present, this research relies heavily on data generated through the qualitative interview process. Three people were interviewed: Executive Director of the International Network of People Who Use Drugs Judy Chang, President of the Board of the Canadian Association of People Who Use Drugs and Chair of the Toronto Drug Users Union Frank Crichlow, and a third participant who attended represented a youth organization and chose to remain anonymous. Each of these participants participated in some capacity at the UN as a representative of an organization led by PWUD, and two have leadership roles in their organizations. It was particularly important to contact representatives of INPUD and associated regional networks because of the leadership role this organization has taken in the international sphere. Interview participants were contacted through either emails available on university or organizational websites or through referrals after making inquiries via social media messaging. All interviews were semi-structured, including both pre-written questions shared with the interviewees before the interview and elements of spontaneous conversational interviewing. The goal of the interviews was to capture information about processes of being involved as representatives of organizations of PWUD at the UN and to

provide a forum for interview participants to share opinions and expertise. All interview participants were given the option to remain anonymous, one of whom accepted. In addition, interview participants had the opportunity to review and approve the comments included in the final version of this paper.

A few ethical considerations were necessary to consider in the collection and analysis of interview data. First, this research concerned “drugs” as a broad topic, an issue which is potentially sensitive. However, I engaged primarily with advocates for PWUD about their advocacy, around which they have built their professional careers and which they speak about professionally on a regular basis. In addition, participants were not required to answer any question for any reason, although none of the questions were ultimately refused. Second, this research acknowledges the regular cultural delegitimization of the expertise of PWUD and the failure of many bodies to acknowledge that expertise, even when it is used. Thus I must acknowledge here that this work was driven and informed by representatives of organizations of people who use drugs, including Judy Chang of INPUD and Frank Crichlow of CAPUD, and that I hope that this research might play a role in furthering the participation of PWUD in policy-making and highlighting their voices. Third, Frank Crichlow pointed out to me that the typical language of academia around drug use, in addition to being potentially harmful, is not the language used by PWUD, making it inaccessible to the population about whom it is written. I’d like to thank him here for his insight and acknowledge that throughout this research I will attempt to use accessible language which is not overly “distant” or “academic” in nature, acknowledging my positionality as a university student and researcher which strongly affects my perspective in the context of this conversation.

Finally, there were certain limitations to the development of this research methodology. Initially, I scheduled or attempted to schedule interviews with researchers from academic institutions and doctors who participated in some of these policy-making processes, but who were not from organizations of people who use drugs. A combination of time constraints and unanticipated personal events in the lives of the participants led to these perspectives not being included in research. Two interviews with experienced researchers in the field were also cancelled due to unanticipated personal events. In addition, I initially aimed to incorporate a quantitative element which examined whether there was participation by organizations of PWUD in policy-making processes at UNAIDS and the WHO. However, due primarily to the way that events like meetings of the UNAIDS Program Coordinating Board are documented, the placement of organizations of PWUD only in the recesses of documentation, and limited personal resources, this particular mode of analysis could not be included at this time. Instead, research was oriented entirely around the perspectives and experiences of the representatives interviewed.

Literature Review:

Theory of Public Participation in Health Policy

In theory, public participation in health-system decision making is designed to respect the doctrine of informed consent in the public, create greater responsiveness, increase financial accountability, and produce more effective programs, born of population consensus and priorities.³ Public participation in the formulation of health regulation and policy is associated with greater responsiveness, better services, and healthier populations. However, participation

³ Frankish, James C, Brenda Kwan, Pamela A Ratner, Joan Wharf Higgins, Craig Larsen, Challenges of citizen participation in regional health authorities, *Social Science & Medicine*, Volume 54, Issue 10, 2002, Pages 1471-1480, ISSN 0277-9536, [https://doi.org/10.1016/S0277-9536\(01\)00135-6](https://doi.org/10.1016/S0277-9536(01)00135-6).

also has the potential to exacerbate health inequities if minority populations are not included meaningfully, as vocal majorities may steer health policy to meet primarily the majority's demands.⁴

Much of the literature on participation advocates for theoretical reasons for participation, such as the belief that people have the right to participate in the planning, implementation, and evaluation of their health systems, the claim that health needs and services should be better matched, and that participation fosters community empowerment through the creation of a sense of contribution. Reasons for building more participation into policy-making can also be practical, focusing on untapped community resources mobilized through participation, more inputs and comprehensive solutions through community engagement, and the belief that participation may lead to greater cost-efficacy and efficiency. Citizen participation in the planning of health services may also result in greater awareness of health problems and use of said services. Of course, scholars also argue against public participation on account of the potential for greater expertise by health authorities, potential negative impacts on quality of care, the lower accountability members of the public may have in comparison to professionals, and the potential high costs and inefficiencies of participation.⁵ However, citizen participation has absolutely become a “buzzword” throughout the global health field.

Public participation in health systems governance is a widely accepted idea within the UN system. For example in 2005 the Ninth Futures Forum produced a comprehensive overview of the role of public participation in health systems decision-making, producing a conceptual framework, reviewing European examples, and trying to guide countries in the process of

⁴ de Freitas, Cláudia and Graham Martin. "Inclusive Public Participation in Health: Policy, Practice and Theoretical Contributions to Promote the Involvement of Marginalised Groups in Healthcare." *Social Science & Medicine* 135, (06, 2015): 31-39. doi:<http://dx.doi.org/10.1016/j.socscimed.2015.04.019>.

⁵ Frankish et al, “Challenges of citizen participation in regional health authorities” 1471-1480.

building a participation-based policy-making healthcare system. The World Health Organization advocates for participation as “a goal in its own right” and “a main requirement of policy-making.”⁶ Despite the wide acceptance of public participation as fundamental to policy-making, PWUD are often under-represented in deliberations surrounding their health and health services.

The key role of PWUD in harm reduction

Across much of the world, PWUD are systemically stigmatized and treated, in one way or another, as a form of social ill. However, within the field of harm reduction, scholars and stakeholders have long accepted that PWUD are the most important potential health-promoters within communities of PWUD. PWUD were involved in the initial development and delivery of harm reduction strategies now considered essential to any effective health promotion for PWUD. In high income countries, peer-organizing has had a positive impact on service reach, accessibility, and quality. In low and middle income countries, peer involvement in harm reduction services has resulted in reduced HIV incidence and prevalence, greater service access, acceptability and quality, altered risk behaviors and reduced stigma and discrimination.⁷ Highly effective life-saving harm reduction strategies, such as peer-administered naloxone, “treat the social contexts of drug use as crucial resources for intervention.”⁸ Thus it is important to acknowledge that the participation of PWUD in their own health and the health of their communities is an essential tool for effective health promotion. Finally, if PWUD are essential to

⁶ Jakubowski, Elke, Graham Lister, Regina Skavron, and World Health Organization. "Ninth Futures Forum on health systems governance and public participation: Amsterdam, The Netherlands, 10-11 October 2005." (2006).

⁷ Chang, Judy, Shaun Shelly, Machteld Busz, Claudia Stoicescu, Rachman Iryawan Arif, Dinara Madybaeva, Yuri de Boer, and Andy Guise. "Peer Driven Or Driven Peers? A Rapid Review of Peer Involvement of People Who use Drugs in HIV and Harm Reduction Services in Low- and Middle-Income Countries." *Harm Reduction Journal* 18, (2021): 1-13. doi:<http://dx.doi.org/10.1186/s12954-021-00461-z>.

⁸ Faulkner-Gurstein, Rachel. (2017). The social logic of naloxone: Peer administration, harm reduction, and the transformation of social policy. *Social Science & Medicine*. 180. 10.1016/j.socscimed.2017.03.013.

the organization of their own health and health promotion, it becomes logically inconsistent that PWUD are not systematically included in the development of those health systems at every level.

Community Organizing by PWUD

Organizations of PWUD have existed for decades. In the 1970's the "Junkie Bond" was developed in the Netherlands to lobby about treatment and misrepresentation of PWUD. In 1973 the Committee of Concerned Methadone Patients and Friends Inc. was formed in the United States to advocate for people in drug treatment programs. Since the HIV/AIDS epidemic, PWUD formed organizations in many countries, and such organizations have existed on every continent since 2008.⁹ In 2012, most organizations of PWUD, in this case limited to organizations led by and advocating for users of "hard" drugs, and not including organizations of cannabis-users or people who used to use drugs, were located in Europe, although such organizations were present in at least forty countries throughout the world. These organizations advocate not only for health care and information but also for the rights of PWUD, seeking objectives such as decriminalization. They include local, national, and international organizations. Organizations of PWUD offer many opportunities, but also face challenges. One major challenge to the ability of these organizations to participate in drug policy is that they are often not considered "legitimate actors" in the policy space, due to the frequently illicit nature of drug production, sale, and use, as well as the reality of social stigma. PWUD are often not looked at as experts in the policy field. Organizations led by PWUD can also be vulnerable and unstable on account of the limited number of potential members, the limited personal resources available to many PWUD which reduce their capacity to perform institutional work, and the fact that PWUD often undergo

⁹ Jürgens, Ralf Erich. "Nothing about Us without Us": Greater, Meaningful Involvement of People Who Use Illegal Drugs: A Public Health, Ethical, and Human Rights Imperative. Toronto, Ontario, Canada: Canadian HIV/AIDS Legal Network, 2008.

periods of incarceration. That being said, some organizations, such as the Danish Drug Users' Union, have survived the worst of these challenges, continuing to operate through their president's two year imprisonment. Organizations of PWUD need resources to be stable, and may achieve this through ties to other social services or NGO's, or even the receipt of public funding.¹⁰ One organization of PWUD important to this research due to their UN-level advocacy is the International Network of People Who Use Drugs and associated regional networks including the Eurasian Network of People who Use Drugs, the European Network of People who Use Drugs, the Latin American Network of People who Use Drugs, the Middle East and North African Network of People who Use Drugs, the Network of Asian People who Use Drugs, and the International Network of Women who Use Drugs.

INPUD and associated networks

The International Network of People Who Use Drugs (INPUD) was established through the Vancouver Declaration in 2006. The Vancouver Declaration, established at the International Harm Reduction Conference in April of 2006, sets out demands and promotes the establishment of an international network of activists who use drugs. The declaration highlights the history of marginalization and discrimination against people who use drugs and promotes the right to self-representation and empowerment. The organization now known as INPUD was tasked with promoting a better understanding of the experience of people who use drugs, advocating for universal access to harm reduction tools, promoting PWUD's rights to educate peers and fellow citizens, establishing a right to evidence-based information about drugs, supporting other established networks of people living with HIV/AIDS, Hepatitis, and harm reduction groups, and

¹⁰Frank, Anker, J., & Tammi, T. (2012). Drug User Organizations in the Nordic Countries-Local, National, and International Dimensions." *Substance Use & Misuse*, 47(5), 462–473.
<https://doi.org/10.3109/10826084.2012.644095>

challenging “the national legislation and international conventions that currently disable most of us (PWUD) from living safe, secure and healthy lives.”¹¹ INPUD was seen as a path to liberation through the active involvement of PWUD. INPUD considers itself “a global peer-based organization that seeks to promote the health and defend the rights of people who use drugs.”¹² Regional networks, and the International Network of Women Who Use Drugs are members of the INPUD which focus on regional issues and contribute to INPUD’s international advocacy. In INPUD’s Strategic Plan from 2021-2024, one of their four strategic directions is advocacy and campaigning at a global, regional, and national level.¹³ INPUD represents people who use drugs at the UN and with international development agencies, such as the Global Fund.¹⁴

Participation of PWUD at the UN

UN agencies have acknowledged the importance of participation by people who use drugs in the creation of policy. In the Outcome Document from the 2016 United Nations General Assembly Special Session, they “note that affected populations and representatives of civil society entities, where appropriate, should be enabled to play a participatory role in the formulation, implementation, and the providing of relevant scientific evidence in support of, as appropriate, the evaluation of drug control policies and programs.”¹⁵ The UN Chief Executives Board in 2019 committed to “promote the active involvement and participation of civil society and local communities, including people who use drugs” in their activities as well.¹⁶ However,

¹¹ The International Activists Who Use Drugs. "The Vancouver Declaration." April 30, 2006. <https://www.inpud.net/en/vancouver-declaration>.

¹² INPUD. "Our Aims." INPUD. Accessed December 10, 2021. <https://www.inpud.net/en/our-aims>.

¹³ Baer, James. "Strategic Plan 2021-2024," INPUD Secretariat. April 2021. <https://www.inpud.net/sites/default/files/INPUD%20Strategic%20Plan%202021-2024.pdf>

¹⁴ INPUD. “What We Do.” INPUD. Accessed December 10, 2021. <https://www.inpud.net/en/what-we-do>.

¹⁵ UN 2016. UN, Outcome Document of the 2016 United Nations General Assembly Special Session on the World Drug Problem New York, 19-21 April 2016: Our joint commitment to effectively addressing and countering the world drug problem (2016) <http://www.unodc.org/documents/postungass2016//outcome/V1603301-E.pdf>

¹⁶ UN 2019. UN, Chief Executives Board for Coordination - Summary of Deliberations [Press release]

the literature that actually exists on the participation of people who use drugs in UN policy-making has been largely mixed.

“Making legitimacy: Drug user representation in United Nations drug policy settings” critically examines how “drug user representation” has operated in the UN Commission on Narcotic Drugs (CND) over the last thirty years by critically examining nine policy processes between 1987 and 2019 in which there was evidence of drug user representation. Reviews of formal and informal documentation, interviews, and records of what was said led researchers to conclude that UN processes delimit the role of people who use drugs through the mechanisms for representation and types of spaces made available. In terms of mechanisms, representatives can only participate in UN/CND meetings as members of state delegations or via NGOs with UN Economic and Social Council (ECOSOC) Consultative Status. ECOSOC consultative status can constrain drug user representation because NGO’s need “official government recognition” to gain this status, and peer-based drug user organizations often cannot obtain this status due to the criminalization of drug use. Often, representatives of peer-led drug user networks enter under the banner of other NGO’s, but this obscures the knowledge and expertise of PWUD and the role they play, while also subjecting them to some degree of control by other NGO’s. Throughout the nine processes analyzed, four individuals identified as representing PWUD were part of UN member delegations. In addition, this paper highlights that representatives of PWUD are often only invited to speak at “side events,” which also places limitations on the role of PWUD’s expertise. Finally, this paper highlights that narratives that accept criminalization, stigmatization, and medicalization dominate much of UN discourse. PWUD are often asked only to offer “personal narratives” and are not considered policy experts. Researchers highlight “human rights

discourses” as a way PWUD resist the dominant narratives and delegitimatization of the expertise of PWUD.¹⁷ This paper accomplishes a comprehensive analysis of the participation of PWUD in this UN context and establishes a base for further research in this field. However it does not cover many aspects of the UN advocacy of PWUD, including how organizations of PWUD engage with various UN agencies “behind the scenes.”

Due to the limitations of formal academic research, one must turn to the publications organizations of PWUD produce about their own work. While INPUD’s descriptions of its own role in international policy may be prone to bias and self-promotion, they provide valuable information about INPUD’s ongoing work. In January 2018, INPUD was asked to provide input into a draft of the ‘International Standards on Drug Use Disorders’ in its final stages. A case study published by INPUD highlights how INPUD found problems with statements in this draft and published an open letter which was signed by 188 civil society organizations, which resulted in the postponement of the release of the standards and an opportunity for an INPUD working group to contribute to a revision of the draft.¹⁸ INPUD also engages with the Global Fund, providing technical assistance, receiving grants and advocating for rights-based approaches,¹⁹ consults with UNAIDS, and publishes responses letters and responses designed to put pressure on UN bodies at various points in policy-making processes.²⁰

¹⁷ Madden, Annie, Kari Lancaster, Alison Ritter, and Carla Treloar. “Making Legitimacy: Drug User Representation in United Nations Drug Policy Settings.” *The International journal of drug policy* 87 (2021): 103014–103014.

¹⁸ Agliata, Jake. "Case Study: Drug User Advocates Mobilise around WHO/UNODC International Treatment Standards on Drug Use Disorders." INPUD Secretariat Unit, 26 April, 2021.
<https://www.inpud.net/sites/default/files/INTL%20Treatment%20Standards%20Case%20Study.pdf>

¹⁹ France, Ferris and Mick Matthews. "From Invisibility to Influence: The evolution of participation of people who use drugs in the Global Fund." INPUD Secretariat Unit. 2021.

https://www.inpud.net/sites/default/files/From%20Invisibility%20to%20Influence_v3%20%281%29.pdf

²⁰ INPUD “Joint Response to the UNAIDS Strategy Team on the Global AIDS Strategy 2021-2026.”

<https://www.inpud.net/en/joint-response-un-aids-strategy-tream-global-aids-strategy-2021-2026>

Results and Analysis

Getting “a foot in the door” - Challenges to accessing UN spaces

One common theme throughout research interviews is that access to opportunities for participation is a complicated process for any civil society organization, but especially for groups composed of PWUD.

First, there are a set of challenges described in the interviews which make it difficult for organizations led by PWUD to flourish and reach the point at which they may be invited to the UN. Judy Chang, executive director of INPUD, highlighted that, while INPUD started in 2006 it took an additional ten years for the organization to reach a point at which it managed its own finances, largely due to the legal complications of being an international drug user-led network in a world where many nations continue to criminalize many aspects of drug production and use. In fact, because “drugs” is featured prominently in the name of the organization, INPUD has yet to open an official bank account.

Finances are also a serious challenge for organizations of PWUD, as proposed in previous research on organizations of PWUD in Nordic countries.²¹ Both Judy Chang of INPUD and Frank Crichlow, President of the board of the Canadian Association of People Who Use Drugs (CAPUD) and Chair of the Toronto Drug Users Union, lamented the fact that the amount of work they want to do outstrips significantly the funding that they have. Crichlow highlighted how CAPUD is the biggest organization of PWUD in Canada, and they are involved in almost every other organization and are looked at as the “main” drug users group, but they don’t always have the funding to allow them to serve the role which has been laid out for CAPUD. In addition, Judy Chang highlighted that receiving government funding altered and focused the way that

²¹ Frank, Anker, J., & Tammi, T. (2012). “Drug User Organizations in the Nordic Countries-Local, National, and International Dimensions.” 462–473.

INPUD operates, while Frank Crichlow pointed to the funding that CAPUD receives from the Canadian Ministry of Health as key to the organization's operation: in fact, CAPUD consults regularly with Health Canada.

In addition to the large-scale challenges associated with being an organization led by people who use drugs in the international arena, there are many barriers to participation created by the UN itself and accepted, generally, as “the way things are.” Judy Chang described the processes of accessing UN spaces as “lengthy” and “bureaucratic.” Some of INPUD’s active work is in trying to understand these miscellaneous processes and determine which of them are the most valuable. In other words, INPUD actively works to understand which bureaucratic barriers to participation are worth understanding and overcoming, especially because INPUD is comparatively underresourced as a global NGO.

One bureaucratic process which blocks the meaningful participation of PWUD in events by the Commission on Narcotic Drugs, a process already examined in the literature,²² is ECOSOC status. ECOSOC Consultative status is required to be one of the civil society groups consulting in this key UN space, but according to Judy Chang “There isn’t one drug-user led network that has been accepted and accredited.” Applications for ECOSOC Consultative status are only open every two years, and the review time is typically one year. Chang speculates that INPUD’s ECOSOC application is being blocked by the Russian government. Their application has been held as they receive questions Chang considers “arbitrary” from ECOSOC and suffer long response times. “We are seeing a lot of pushback against organizations working on human rights and any organizations with drugs in the name,” Chang claimed, “especially those led by

²² Madden, Annie et al. “Making Legitimacy: Drug User Representation in United Nations Drug Policy Settings.”

people who use drugs.” In the case of ECOSOC, a seemingly neutral regulatory body ultimately forms a major stumbling block on the path to full participation of PWUD.

The Vienna NGO Committee on drugs represents an opportunity and a challenge for organizations of PWUD as well. INPUD is a member of the Vienna NGO Committee on drugs, a committee designed to facilitate civil society’s involvement with Vienna-based UN offices including the Commission on Narcotic Drugs, the United Nations Office on Drugs and Crime, and the International Narcotics Control Board. While their website highlights the Vienna Committee’s role as it aims to “promote collaboration,” “enhance communication,” and “ensure balanced representation,”²³ Chang highlighted that they also play a role as gatekeepers. The Vienna Committee has control over which organizations are included at CND events and how, and the Vienna Committee is responsible for connecting civil society organizations with UN agencies generally. In a global culture that stigmatizes, discriminates against, and generally devalues PWUD, at an organization immersed in dominant discourses of medicalization and criminalization, it is not hard to imagine that organizations led by PWUD may have difficulty passing through the gate the Vienna Committee keeps.

Often, as a work-around to the challenges of ECOSOC status, organizations of PWUD may participate in side events under the banner of other organizations. As an anonymous representative of a youth organization stated, getting access to CND is “not that hard.” ECOSOC members can organize and submit side events, and they are permitted “10 passes each, so even non-ecosoc members can attend the CND on an ECOSOC members pass.” This, however, can come with a set of challenges to full participation. First, organizations led by PWUD are somewhat “at the mercy” of other civil society organizations. Second, even if organizations led

²³ "VNGOC Board." Vienna NGO Committee on Narcotic Drugs. Accessed December 15, 2021. <https://vngoc.org/about-the-vngoc/officers-of-the-vngoc/>.

by PWUD get the chance to contribute their knowledge, this knowledge is obscured, and PWUD do not get credited for their expertise. Third, Judy Chang highlighted that PWUD are often considered sources of “personal narrative” and not allowed or encouraged to contribute policy expertise. “Many people won’t value our voices,” Chang stated, “and then people who say they do just want you to give personal testimony. They want to organize and brand their events and then pull in a token PWUD to share their ‘life story.’” INPUD wants PWUD recognized as policy experts. While Crichlow highlighted “lived and living experience,” experience that he says comes at a “high cost,” as the key reason that the knowledges of PWUD are necessary and must be promoted, both Chang and Crichlow emphasized that PWUD need to be involved in all aspects of policy-making, and should not be framed as tokenized story-tellers, used to emphasize another NGO’s mission. At present, organizations of PWUD are often subject to the will of organizations not explicitly led by PWUD at the CND.

How organizations led by PWUD participate

Through national and international organizing, organizations of PWUD have gained access to a number of UN agencies, and engage in participation and advocacy at multiple levels. Because “Making Legitimacy” already covers the nature of the “side events” and does extensive analysis of the participation of PWUD at CND conferences, this research will focus much of its attention elsewhere. Analysis of interviews revealed that organizations of PWUD have a greater ability to participate in certain UN bodies, subcommittees, and aspects of work than in others, a subject worthy of review. In addition, this research will focus on three case studies of participation — CAPUD’s involvement in the Canadian delegation to the CND, the development of the International Standards for the Treatment of Drug Use Disorders, and the

not-yet-published World Health Organization Consolidated Guidelines on HIV, Hepatitis and STIs services.

Comparative Spaces

The executive director of INPUD had a lot to say about which spaces INPUD is welcomed to participate in meaningfully and which spaces they still struggle to access. One of the key factors that Judy Chang highlighted is that, across the board, INPUD is much more likely to be invited to consult with teams focused on HIV/AIDS than they are to be involved in other areas of the UN's drug policy. She credited this fact to the long history of human rights-based HIV/AIDS activism stretching back to the 1970's. Activists who fought to end stigma and discrimination, improve treatment, increase international attention and funding, and generally defend the rights of people living with HIV/AIDS and members of vulnerable populations also opened out spaces for members of vulnerable populations to participate in policy-making. This history may make those who work in and study HIV more likely to engage with people who use drugs, as people who inject drugs have long been one of the key populations, and the spaces where work is done often have long-established collaborations with community organizing by PWUD. In fact HIV/AIDS scholarship and harm reduction scholarship are and always have been closely linked. Thus INPUD engages in close collaboration and consultation with UN staff working in HIV. INPUD is a member of the strategic advisory group to the UN on HIV and drug use. INPUD operates as a key advisor to the Global Fund and receives grants from the Fund. INPUD also engages in ongoing collaboration with UNAIDS. Other than, essentially, showing up and doing side events at annual CND meetings, INPUD gains access to UN spaces not strictly focused on HIV and meets with other colleagues primarily because the organization is "brought

in” by HIV/AIDS-connected staff. The fundamental problem with accessing some spaces, like the UN Office of Drugs and Crime, is that compared to health spaces, these UN bodies take an inherently punitive approach to drugs and drug use, as the name of this office clearly demonstrates. In these spaces, people are less likely to collaborate with PWUD or consider them to be experts.

In fact, a representative of a youth organization which participates in CND conferences described the CND, which functions as the governing body of the UNODC, as “the place where dreams go to die,” with a “banality of evil” aspect to it. According to this representative, “any positive reform is fought over the terrain of minor language changes, and resolutions largely do not have huge impacts.” They presented the 2020 attempt to reschedule cannabis which was blocked by Russia on the grounds that the CND was “too incompetent” to reschedule cannabis, despite the fact that CND scheduled many other drugs that year, as an example of this failure. While they acknowledge that there have been productive international discussions, that human rights are in the process of coming into focus, and that the “punitive consensus” of the CND has at last been broken, this representative remained pessimistic about the UN, and the CND specifically, ever operating as a space for true reform where the voices of PWUD are heard.

The Canadian Delegation

There is one notable exception to the general voicelessness of PWUD in these broad drug policy making spaces: as mentioned in “Making Legitimacy” PWUD can participate in CND conferences either through the organization of side events or as members of a national delegation. However, according to Frank Crichlow, only one country has chosen to include representatives of organizations of PWUD as members of their delegation — his home country

of Canada. For multiple years, Canada brought the president and the executive director of CAPUD as members of the country's CND delegation. Crichlow's experience as a representative in the main hall of the CND delegation shows a unique way that PWUD have participated in UN policy and provides insights into the ongoing obstacles for ongoing meaningful participation.

The first year that Crichlow and the executive director of CAPUD had the opportunity to speak at the CND they advocated primarily for changes in the rules of the CND's operations and for the greater participation of PWUD in the CND space, aiming to create a voice. While there, Crichlow was invited to do a side table with the Minister of Health from Sweden. The Canadian and Swedish delegations sat together in private and Crichlow lent his knowledge about the experience of opening a supervised consumption site, primarily answering questions about his experience opening and operating such sites in Canada. The same year Crichlow met with the minister from Portugal to discuss Crichlow's views on the legalization of cannabis in Canada. Crichlow highlighted his opinions that all drugs should be legalized, not just this one, and pointed out the injustice of cannabis in Canada becoming a "money making business" for "the same people who were incarcerating" others for cannabis-related legal infractions, especially black people, indigenous people, and people of color, many of whom were still incarcerated or still had a legal record.

The following year Crichlow returned to the CND as a member of the Canadian delegation and presented on race, stigma and discrimination and the impacts thereof on the black community. He claimed the safe supply program in Canada was racist and designed to benefit white people and not BIPOC. This claim was based on the fact that the safe supply program was designed to protect people who inject drugs, a form of drug use more widely represented in white

populations, even as the program did nothing to protect people who smoke crack, a form of drug use more widely represented among BIPOC.

CAPUD's opportunity to present in the main hall at the CND and participate as a member of a country delegation is unique. Crichlow pointed out that in addition to Canada being on a path to drug decriminalization, providing needle exchanges without limitations, having 24/7 harm reduction services and delivery services, Canada is also the only nation to send PWUD, people with "living and lived experience" to the United Nations. An analysis of Crichlow's statements and forms of participation shows that PWUD can bring a unique and important combination of knowledges to UN policy fora. CAPUD participated both in private and public sessions and brought three broad categories of knowledge: expertise in service provision for PWUD, evidence-based policy recommendations, and policy perspective designed to emphasize the voices of marginalized populations and promote social justice. Crichlow's participation shows what role PWUD can and already do play when PWUD successfully access opportunity for participation.

Crichlow also made a number of observations when interviewed that highlight how far the CND still has to go to promote meaningful participation by PWUD. He emphasized that at the CND the CAPUD representatives only were two people with lived and living experience among thirty-two, the other thirty of whom were trained as doctors and psychiatrists. "Because they have the acronyms behind their names," Crichlow stated, "they believe they are better than us." He emphasized a need to have everyone "at the table," not just a token person who uses drugs: "I'm talking sex workers, LGBTQ people, black and indigenous and people of color. Everyone should be on the panel." In short, Crichlow highlighted two issues: the first is the minimal representation of people who use drugs in spaces designed to create policy pertaining

largely to people who use drugs. This lack of representation is both undemocratic and impractical, because it denies PWUD ownership over the policy that affects them and cuts out one of the best sources for knowledge and experience available. Crichlow pointed out that one person isn't enough, nor is two, because there are a variety of experiences, all of which need to be captured and understood. The second is the delegitimization of the knowledge of PWUD and cultural understandings of expertise. While representatives of CAPUD were present, Crichlow didn't necessarily feel like he was being regarded as an expert in a room full of academics and doctors. "However much you're paying for your school," Crichlow told me, "my expertise cost me more — drugs are expensive." This differential way of valuing certain forms of knowledge is present in and out of the UN, and its construction delimits the role of PWUD in policy-making.

The International Treatment Standards

Close to what was meant to be its final stage, the WHO/UNODC International Standards for the Treatment of Drug Use Disorders came across the desk of the Executive Director of the International Network of People Who Use Drugs. Typically when INPUD consults on UN documents, they are commissioned and participate in the review process at all stages. This was not the case when it came to the International Treatment Standards, which were approaching field testing stages. Chang described what she found in the document as "very awful." Chang's primary issue with the Treatment Standards at that stage was that it leaned very heavily on the "brain disease model" of addiction, a model deemed by INPUD to be stigmatizing and pathologizing. In addition, INPUD objected to the lack of meaningful inclusion of PWUD in the

development of The Standards and the failure of the Standards to mention harm reduction and other important health measures for PWUD.²⁴

INPUD responded in two ways simultaneously: they submitted ten pages of line-by-line input on the document as written and published an open letter which detailed three main objections to The Standards. The open letter was signed by 188 community and civil society organizations. As part of the strategic advisory group to the UN INPUD also published another letter to the executive director. By Chang's report, high level UN officials were upset about the letter, and the situation reached the office of WHO Director-General Tedros Adhanom, who was "quite embarrassed about what happened." Quickly, INPUD heard back that the Treatment Standards were going to be completely rewritten. INPUD was invited to meet with two department heads, one from WHO and the other from UNODC. INPUD had a small meeting in exchange during which they shared their concerns. Ultimately, an entirely new consultant was hired to rewrite the standards and INPUD was in constant dialogue with the writers throughout the revision process. During the field testing stage, three countries worked with INPUD contacts allowing there to be "more detailed inputs" to the field testing portion. INPUD was invited to speak at a side event when the International Treatment Standards with field testing were launched. A member of the South African Network of People who Use Drugs attended.

Judy Chang described The Standards as they currently exist as an "imperfect but better document" than the original. This case study demonstrates how organizations of PWUD use different tools in order to participate fully in the creation of UN-level drug policy. First, INPUD has gained sufficient expertise to be considered an international expert, so they are consulted on WHO/UNODC publications. In this particular case, the obstacle to participation which INPUD

²⁴ Agliata, Jake. "Case Study: Drug User Advocates Mobilise around WHO/UNODC International Treatment Standards on Drug Use Disorders."

overcame was the fact that they were only included in final-stages review of the initial document, instead of being welcomed throughout the process. In order to resist and advocate for greater participation, the organization made a public appeal in the form of an open letter. This allowed for widespread mobilization of PWUD and called public attention to the issue, prompting UN bodies to respond. Having largely succeeded in their public appeal, INPUD then provided behind-the-scenes expertise, actively participating in the development of what would become the International Treatment Standards. Because INPUD is a global network, they were able to participate in and exercise some control over the field-testing stage. Throughout the process, they also gained more contacts and ways of participating in the WHO/UNODC.

In the interview, Chang emphasized that INPUD does not take the decision to “go public” lightly. Making public appeals such as the open letter risks offending and embarrassing key contacts INPUD has within the UN and hurting their ability to consult in the future. INPUD largely prefers to push back and create change as documents are developed, accepting a certain degree of give and take. “Once you’re at the table you have to use tactics,” Chang stated, “our role is to negotiate and collaborate with UN agencies while holding them accountable.” “You can call people out and draw attention, but other times it’s more collaborative and discussion-based.” She emphasized the necessity of reading the political environment. They hope to improve policies, even though they may not get every change they would like throughout the development process. The development of The Standards demonstrates how organization by PWUD can allow PWUD to both resist UN action and collaborate with the UN to create policies more in line with the will of PWUD.

WHO Key Populations' Values and preferences for HIV, Hepatitis and STIs services

INPUD is involved in an ongoing process of creating consolidated guidelines for key populations with the World Health Organization. The guidelines are for HIV/AIDS, Hepatitis and STI services. Instead of meeting with department heads, as they did after demanding a rewrite of the International Standards for the Treatment of Drug Use Disorders, INPUD has regular meetings directly with internal technical specialists involved in the production of the consolidated guidelines. INPUD produces their own work and receives commission for research which they send in to the team creating the guidelines.

This process is considered to be more in line with the INPUD's usual form of involvement with the creation of UN policy and publications. By positioning themselves as experts with research capacity and access to groups of PWUD throughout the world, INPUD has gained the ability to participate and interact with UN bodies. "We've built relationships and proved ourselves to be a valuable partner," Chang stated. INPUD highly values the relationships that they form with technical specialists within the UN, because they form a path to further participation and greater political power. The internal technical specialists INPUD works with become touchpoints when INPUD has concerns about what is happening globally. "If there's an issue with a stockout in Lebanon, we'll be in contact with those people," Chang stated, "when there are changes to harm reduction programs in Vietnam, we'll reach out." INPUD leverages the contacts they form on a global level to change regulations at the national level, even in small ways.

INPUD leverages their role as experts to contribute to the development of international policy guidelines, but they also gain and develop relationships with contacts in the process. Relationships with individuals are a key way INPUD finds a way to access opportunities for

participation internationally, nationally, and locally. “Networking” becomes a key element of ongoing advocacy and participation.

Opinions of Organizations: what is necessary for improved participation

Both Frank Crichlow and Judy Chang emphasized the necessity of two elements to produce meaningful participation of people who use drugs in UN fora. One is involvement of diverse groups of people who use drugs: INPUD set up its regional structure to reduce the hold that the Global North had over the organization. The board of CAPUD comes from every region of Canada. Organizations of PWUD resist the tokenization of PWUD and emphasize the perceived need for a plurality of representatives whose knowledges are legitimized. Frank Crichlow especially emphasized the stance that PWUD who are also members of marginalized communities, such as LGBT people, sex workers, and BIPOC, need to be at the table participating in decision making.

Conceptualizing this as an obstacle to participation, one can say that currently the existing policy fora at the UN do not offer sufficient opportunity for participation of high numbers of PWUD. While individual executives at INPUD can work behind the scenes with the UN, and occasionally representatives of PWUD appear at the CND main hall or side events, there simply isn't sufficient space for the continuous participation of multiple PWUD. PWUD are continuously tokenized and are numerically underrepresented, making it especially difficult for minority communities to be represented.

Chang also emphasized the need for PWUD to be involved “in the beginning of every long term process,” leaving PWUD “less in the dark” about what is happening in the world of relevant policy development, reducing confusion and making it easier for people who use drugs

throughout the policy-making process. The two INPUD case studies of The Standards and the Key Population guidelines highlight how the experience of participation differs greatly when PWUD are involved early, in contrast to only being involved in a last-minute review. Crichlow echoed this sentiment, stating that “people who use drugs should be involved from the beginning to the end, in every facet of life.” A failure to continuously and systematically include the perspectives of PWUD poses a serious obstacle to the true and meaningful participation of people who use drugs in policy making.

Overall, PWUD remain broadly underrepresented in spaces where the UN makes policy pertaining to PWUD. This is true despite the fact that PWUD are and always have been central to harm reduction and other effective health efforts in their communities. In addition, a combination of factors, including the tendency for representatives of organizations of PWUD to need to contribute under the umbrella of other organizations, has resulted in PWUD going uncredited. Organizations led by PWUD are currently permitted only limited roles in policy-making: They are often consulted too late for meaningful participation, as highlighted through the events surrounding the International Standards for the Treatment of Drug Use Disorders. In addition, PWUD are only granted to certain roles and spaces. They may be involved through UN contacts, through the application of public pressure, or because the gatekeepers to conferences and policy-making spaces let them through, but the participation of PWUD in policy making is by no means comprehensively integrated into policy-making procedure. In addition, PWUD are somewhat confined in the narratives they can convey in the policy-making spaces due to dominant discourses and the way that power is allocated within the UN. Stigma, discrimination and criminalization limit the participation of PWUD in policy-making at every level. Bureaucratic hurdles such as acquiring ECOSOC consultative status play a role in limiting the

participation of PWUD in policy-making, as do limitations in financing. Organizations of PWUD consider community mobilization to be an important path to accessing a greater role in policy-making. PWUD are able to contribute a unique combination of knowledge and experience to policy-making spaces. Organizations of PWUD use a variety of strategies to make their voices heard despite obstacles. Some examples of the strategies described include the leveraging of contacts within the UN, the application of pressure through public appeals, developing research capacity which makes organizations of PWUD a valuable UN partner, engaging in private consultations with various health authorities, and showing up to conferences and events and speaking out about issues.

Conclusion

The aim of this research was to fill a gap in the academic literature and elucidate the current modes of participation of PWUD in drug-related policy-making at the United Nation. In place of merely identifying the current barriers to involvement, this research was organized around the idea of “meaningful participation” and aimed to both acknowledge obstacles and highlight the work that organizations of PWUD are already doing at the UN.

While organizations of PWUD have developed significant inroads which grant said organizations access to many aspects of policy-making and recommendation-development, there is no comprehensive system for the participation of PWUD on policy-making at the UN. This is true despite the UN’s purported belief that participation, including participation of PWUD, is a “main requirement of policy-making.” Instead, organizations of PWUD jump through hoops to gain access and prove themselves valuable to the UN. Organizations of PWUD do use the strategies available to them to make changes within the UN system. They are engaged constantly

in attempts to contribute as much as possible to the policy which impacts the lives of PWUD. This sometimes involves negotiation and tactical compromise. Organizations of PWUD decide whether to represent themselves under the banner of other organizations, and whether to publicize criticisms or preserve certain valuable partnerships. Continued participation is anything but guaranteed and freedom of expression is limited in multiple ways. However, overall patterns show that PWUD are gaining more access to meaningful participation over time.

Several limitations ultimately impacted this research. First, while the research aimed to fill a literature gap, this gap also created challenges in gathering all the necessary information. In addition, the research was time-constrained which limited the number of participants. Many conclusions rely heavily on the perspectives of two people from connected organizations. In addition, because some private correspondences and meetings were discussed, certain elements of the research used as evidence cannot be confirmed. Thus this paper is in part a work of trust. With additional time, this research may have covered more comprehensively the participation of PWUD throughout the United Nations as well. Continuing research is necessary to model the full participation of PWUD in UN-level policy-making and shape a comprehensive theory of this process. In addition, there is potential for research on UN-level drugs policy-making to place this process within comprehensive frames of power, racial capitalism, neoliberalism and neocolonialism.

There are practical responses to the limitations still placed on the meaningful participation of PWUD in UN-level policy-making. UN bodies might begin to build up systems for inclusion and reform gatekeeping mechanisms such as ECOSOC. As nations like Canada move towards decriminalization national delegations may begin to play a role in promoting inclusion as well. However, the current lack of meaningful participation of PWUD in many areas

is directly tied into globally dominant forces and discourses. Medicalization denies PWUD agency and choice, framing PWUD only as "diseased" and therefore weakening their voices as experts while elevating medical expertise which is also biased by biomedical structures. Criminalization, perpetuated by the UNODC, produces significant challenges for the organization and mobilization of groups of PWUD which is a precursor for participation and liberation. It creates legal hurdles and justifications for non-inclusion. Broad cultures of stigmatization delegitimize the voices of PWUD as well. The UN is not only subject to these forces — it is fully entrenched in them — and only a deliberate, critical engagement with this reality can move the UN towards fuller participation by PWUD. PWUD are already pushing the United Nations in this direction and opening up more spaces for their voices to be heard.

Abbreviations List

AIDS - Acquired Immunodeficiency Syndrome

BIPOC - Black, Indigenous, and People of Color

CAPUD - Canadian Association of People who Use Drugs

CND - Commission on Narcotic Drugs

ECOSOC - United Nations Economic and Social Council

HIV - Human Immunodeficiency Virus

INPUD - International Network of People who Use Drugs

LGBTQ - Lesbian, Gay, Bisexual, Transgender, Queer or Questioning

NGO - Non-governmental Organization

PWUD - People Who Use Drugs

UN - United Nations

UNAIDS - Joint United Nations Programme on HIV/AIDS

UNODC - United Nations Office on Drugs and Crime

WHO - World Health Organization

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