

Ageing disgracefully with Jude Byrne: A special section recognising her life and work

While most special sections in *Drug and Alcohol Review* are focused on a particular research topic, this collection is devoted posthumously to a person and her interests; Jude Byrne. Unique in her ability to lead work across advocacy, policy and research, Jude used her intelligence and living experience as a person who used drugs to influence policy and practice across the alcohol and other drug, blood-borne virus and community sectors. As we noted in an earlier editorial [1], Jude's impact was significant and wide-reaching. Beginning locally, Jude was responsible for many grassroots initiatives based on local emerging community needs, including respite services for mothers and their children, and forming drug user organisations. Jude also contributed to policy and service delivery for people who use drugs (PWUD) on a global level. She pursued the ethical and methodological development of our field by representing the voices of PWUD in numerous international forums, including on World Health Organization Guidelines Development Working Groups and through her longstanding leadership on the International Network of People Who Use Drugs Board. This collection reflects the key areas influenced by her life and work.

Celebrating Jude's life and work, we have also included her recorded voice. In February 2020, Peter Higgs recorded this (<https://bcove.video/3KqLnCH>) video interview with Jude for a conference in Manchester that was cancelled because of COVID. Cheekily titled, *Ageing Disgracefully*, Jude's recording reminds us that older PWUD are absent from much of the narrative about harm reduction and care. Jude describes her involvement in one of the last projects she worked on—*A Hidden Population*—aiming to build capacity within aged care providers to respond to the unique needs of older PWUD. We hear her powerful narrative about the fear that many people with a history of drug use have about relying on aged care services for support. Indeed, the need to include lived and living experience in academic, clinical and policy work is a thread that runs through this special section.

Three of the papers included in this issue outline approaches to community–researcher partnerships.

Building on early work by the Australian Injecting and Illicit Drug Users League, International Network of People Who Use Drugs and other organisations, these papers examine not only why community–researcher partnerships are good practice but also address the pragmatics of building, performing and assessing these partnerships.

Berg et al. [2] advocate for meaningful roles for people with lived-experience in research. For example, the dual-interview approach, where peer and academic researchers conduct research interviews together, breaks down power dynamics and assumptions about identity and capability in research. While peers and academics are often considered to bring different skill sets to research, Berg et al. argue that, in practice, these partnerships co-constitute transformative knowledge generation in alcohol and other drug research.

Community and peers engaged in research are most often people with past or present drug use experience; however, Haines-Saah et al. [3] explore parent and family advocacy as an emergent area of drug policy advocacy and research. The authors describe a partnership between academics and three parent groups representing families in Canada bereaved by drug-related deaths. Using this new partnership as a case study for good practice in research, four guiding principles were developed to capture ethical practice and equity around issues such as data sharing, joint ownership and dissemination. In particular, Haines-Saah et al. emphasise the delicacy of emphasising parents' knowledge and opinions without eclipsing the perspectives of PWUD. Ultimately, a greater understanding of how families and communities can be allies in drug policy reforms is urgently needed to progress harm reduction and prevent overdose deaths.

Similarly, Meyerson et al. [4] focus on how to design and execute equitable and ethical research with affected communities. They argue that the philosophical underpinnings of community research as community-led and transformative in its objectives are often not valued or realised within the hegemonic structures of universities and funding bodies. They look to quality appraisal and

indicator tools as a way of monitoring and influencing practice in community-research partnerships. Meyerson et al. outline the development of a tool that assesses the equity of community-research collaborations, with a focus on structural elements of partnerships such as power and financing. The aim of the tool is to enable coalitions to plan for equity and to design research that is transformative for communities of PWUD.

Jude was always focused on transformation. As a woman and a mother, she advocated for the rights of women who use drugs throughout her career. Jude worked with the United Nations Office on Drugs and Crime and other organisations to identify and raise awareness of the ways in which societal responses to drug use are gendered. She would share her own experiences of felt stigma and eloquently called-out discriminatory practices in healthcare and policy.

Dertadian et al. [5] present a qualitative case study of women who inject drugs in an affluent suburb of Sydney, Australia. Their data elucidate that the harmful forms of gendered stigma related to injecting drug use occur even when a woman occupies a relatively prosperous social status. Conceptualising stigma and discrimination as structural violence, the authors argue that being able to hide drug use enables some safety for women. When drug use is exposed, cascading life events can result in harassment and violence as well as impact on housing and family stability.

Using survey data, Brener et al. [6] demonstrate the impact of stigma on women who inject drugs. They begin their paper arguing that research into drug use-related stigma tends to be male-dominant and does not consider gender. With a focus on stigma in the healthcare system, Brener et al.'s analyses reveal that women attempted to reduce their exposure to stigma by avoiding and delaying healthcare access. Avoiding healthcare was associated with lower personal well-being scores, especially if women had recently been treated negatively by a health worker, were injected more frequently, identified as LGBTQ or were unemployed.

In another study exposing the issues of healthcare access for Australian women who use drugs, Valerio et al. [7] found that hepatitis C treatment uptake was lower among women with children, those with recent drug dependence and for Aboriginal and Torres Strait Islander women. The authors provide evidence for intersecting, sex-specific barriers to treatment access and call for a focus on hepatitis C care and treatment for women of child-bearing age.

Jude lived through the heights of the HIV/AIDS and hepatitis C epidemics in Australia and was at the forefront of public health responses. She delivered education



on hepatitis C testing and treatment as well as stigma and discrimination training for healthcare providers, as well as for her community as a peer education champion and fierce advocate for drug user organisations and self-autonomy, determination and agency. Arguably one of the biggest changes in alcohol and other drug research, healthcare and policy during Jude's career was the increased prominence of peers as advocates and organisational staff.

Low-threshold services, for example, can provide an alternative setting for healthcare provision with peer integration. Trialling a peer-nurse partnership model within a women's residential drug treatment program, Crespi et al. [8] found that providing training, testing and follow-up increased women's self-reported knowledge of hepatitis C and motivation to attempt treatment. Most women in the program also initiated hepatitis C treatment, suggesting that co-location of services and peer-led models can be highly effective in engaging women who are typically discriminated against in mainstream healthcare services.

Jude persistently advocated for the privileging of peer knowledge and expertise in research and policy. Posthumously named as senior author on the paper by Sutherland et al. [9], Jude encouraged researchers to work with peers and ask questions pertinent to their lives. These Australian survey data show that peers were the preferred source of information across a range of topics for PWUD. This provides evidence for the expansion of the peer workforce, embracing the capacities and expertise of PWUD in all areas of our sector.

The final paper in this special edition is written by a colleague and friend of Jude's, Maureen Steele [10]. As a strong peer advocate and healthcare worker, Maureen reflects on how far we have come in terms of providing quality services for PWUD; and how far we have to go. Steele problematises the restricted and narrow approach to drug treatment and calls for the expansion of treatment modalities and psycho-social services. Like Jude, she reminds us of the hidden population of ageing PWUD and how inadequate current services are for their needs.

Through this broad array of papers, spanning multiple methodologies and topic areas, we remember Jude's impact as ongoing and far-reaching. Jude's life was spent challenging and addressing inequalities, centring the experience of PWUD and championing the human rights of her community. Her commitment to justice, human rights and self-agency is a powerful legacy that lives on in the work of the Australian and global peer-based drug user, research and civil society human rights communities.

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