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Introduction: 'Nothing about us without us', a history and application for criminology

Yasmine Ahmed, James Windle and Orla Lynch

'Nothing about us without us' surmises a burgeoning movement in criminology that is about giving voice to diverse perspectives and a way of doing research. Primarily it refers to the importance of an approach to criminology that is inclusive of those voices that have historically been hushed, marginalised, silenced or ignored. It also refers to the need for researchers to work with state and grassroots practitioners, especially those who provide a conduit to peoples most impacted by social injustice and crime. This edited volume will explore the importance of diversity and inclusivity in criminological discourses and, consider how researchers might bridge the gap between theory and lived experience, and how the authenticity of the voices of those who have been silenced can be incorporated into a meaningful criminology. This introductory chapter will explore the conceptual history of 'nothing about us without us' before summarising some of the key themes explored in this volume.

Criminal justice policies are formed through consultation and deliberation between moral entrepreneurs, politicians and, bureaucratic and economic actors (Monaghan, 2011; Windle, 2014, 2018). This, however, often occurs from positions of authority (Becker, 1963) and those most impacted by such policies are seldom included in decision making processes (see Askew and Bone 2019; Joyce and Lynch, 2017; Leonard and Windle, 2020; Lynch and Argomaniz, 2017).

The marginalisation of these voices occurs both explicitly and implicitly. Marginalisation may centre upon racism, classism, sexism, or other forms of discrimination, or because the group is criminalised or stigmatised (see Lancaster et al., 2018; McCullagh, McGarry et al., O'Rouke

et al., this volume), including geographical stigmatisation (see Leonard, Windle, this volume). Policy makers and practitioners may also fail to include marginalised voices because they lack the time or resources to fully engage them in the process, or because policy/practice from above is how 'it's always been done'. Furthermore, as chapters by McCullagh and O'Rouke and colleagues (this volume) show, those in positions of power can use their authority, and the law, to silence those lobbying for change.

The essence of 'nothing about us without us' is a demand that the voices of those most affected by a policy or practice must be fully and directly involved in all stages of planning, implementation and evaluation (Jürgens, 2016). As a slogan it 'forces people to think about the broader implications of "nothing" in various political-economic and cultural contexts' and implies that policies or practices which do not include full participation are hollow (Charlton, 1998:17).

The slogan also requires affected peoples themselves to 'recognize their need to control and take responsibility for their own lives'; to lobby for what they need rather than unwittingly accepting policies and practices from above. Overall, it is a demand for, and affirmation of, 'independence and integration, empowerment and human rights, and self-help and self-determination' (Charlton, 1998:17). As a slogan it unites 'all the marginalized and invisible individuals and groups who are demanding a seat at the table' (Wolff and Hums, 2017:np), locally, nationally and globally. 'Nothing about us without us' is a relatively new social movement and like all processes of social and institutional change it happens slowly and incrementally.

The aim of 'nothing about us without us' is thus to promote democratisation in policy development and delivery, a refocus on social justice, a pragmatism regarding the voices that matter in criminal justice and, to improve policy and practice based on an understanding that

affected groups are 'often best able to identify what works in a community that others know little about' (Jürgens, 2016:12). Conversely, ignoring and excluding affected communities can result in changes to policy or practice becoming 'sterile and moribund' (Ryder et al., 2014:524).

Including marginalised stakeholder groups is not only about improving policy, but can be beneficial to individuals. 'Nothing about us without us' implies that members of affected groups should support their peers (Jürgens, 2016), advocate for themselves (Charlton, 1998) and lobby for what they need rather than having to accept policies and practices from above. Research has shown that involvement in advocacy can be 'self-enhancing' and can 'help to restore self-esteem damaged by stigma' (Wahl, 1999:476) while providing individuals with 'meaning, purpose and significance' (Maruna, 2017:15) and the sense of empowerment gained from exerting control over oneself (see Mulcahy, this volume). Of course we should not expect individuals to *have* to advocate and lobby for themselves, and a part of 'nothing about us without us' is that we should bring the discussion to people rather than having them have to fight for a voice.

The conceptual history of 'nothing about us without us'

The slogan is believed to have first been used during the 16th Century in the United Kingdom of Poland-Lithuania to dictate that the king could not govern without the participation of the nobility (Wagner, 2003). The modern use is commonly associated with disability rights activists and was popularised in the late-1990s by two books, by James Charlton and David Werner. Charlton (1998) reports first hearing the slogan in 1993 from two South African disability rights advocates, who had themselves heard it used by an Eastern European advocate and then again, in 1995, by Mexican farmers chanting 'never again without us' (in Spanish: *Nunca Mas Sin Nosotros*). Werner (2009) reports borrowing the slogan from the Independent Living Movement, to mean that disabled peoples' work as equals in their own rehabilitation.

Werner's (1998) was the more criminological of the two texts. The book documents the experiences of a rehabilitation programme for young people with disabilities in Mexico. The programme was created in response to the rising numbers of youths presenting with spinal-cord injuries from bullet wounds and psychological trauma of gang violence, which Werner (198:np) attributed to 'the widening gap between rich and poor' coupled with progressively repressive state responses. Werner reported that the project helped young people not only with their mental and physical rehabilitation, but to transition away from violence, crime, gangs and addiction: 'Time and again, disabled youth who arrive socially scarred and violent have become among the most considerate care providers for those in greatest need'. The young people became what Shadd Maruna (2017:9) referred to as 'wounded healers': prisoners and former prisoners who draw 'on their experiences to help others avoid their mistakes and benefit from the inspiration of their achievements' (for examples see Leonard, Mulcahy, Pompa, this volume).

The slogan diffused out to a wider range of marginalised groups during the mid-2000s. In 2005, advocates for Roma communities used the slogan as part of their Decade of Roma (2005-15) inclusion campaign (Ryder et al., 2014) and the Canadian HIV/AIDS Legal Network published the booklet, *"Nothing About Us Without Us" – Greater, Meaningful Involvement of People Who Use Illegal Drugs*: it was written by people who use drugs to demand a seat at the table and provided guidelines on how, and how not, to include people who use drugs in policy and practice. The booklet influenced the 2011 World Health Organisation report *Ethical Engagement of People who Inject Drugs in HIV Prevention Trials* (Boyd and NAOMI Patients Association, 2013).

Other examples of organisations working under the slogan include RISE: an Australian organisation, launched in 2010, to support the welfare of refugees, and advocate for their rights,

which is 'entirely governed by refugees, asylum seekers, and ex-detainees'.[1] The 2013 World Conference of Indigenous Women 'endorsed' the slogan in the Lima Declaration (Cultural Survival, 2013:np) and identified themes common to Green Criminology (see Beirne and South, 2013): that deforestation, climate change and loss of biodiversity are strongly connected to increased rates of violence against Indigenous women. One delegate, Victoria Tauli Corpuz of the Philippines, argued that not only would having a say help Indigenous women, but their expertise and insights could be of services outside of their communities: 'we have answers to the environmental, social, economic, and cultural crises that the world faces today' (cited in Cultural Survival, 2014:14).

More recently, Maruna (2017:11) has used the slogan to argue that desistance from crime be reframed as a social movement; that the concept of desistance move 'from the Ivory Tower to the professional world of probation and prisons, back to the communities where desistance takes place'. A sentiment shared by several chapters in this volume (i.e. Cresswell, Leonard, Mulcahy, Pompa). In the UK, for example, User Voice lobbies for prisoners to be given a say in how prison and rehabilitation works. Their 'work is led and delivered by ex-offenders [who] work to provide ways that enable unheard voices; to make a difference, to urge policy-makers and people with power who make decisions to listen'.[2] Involving offenders in activism is not

[1] http://riserefugee.org/

[2] http://www.uservoice.org/our-story/

new,[3] but has been repackaged under a slogan which adds a sense of urgency and allows former prisoners to feel connected to other marginalised groups under a common banner.

The core values of 'nothing about us without us' - self-determination, liberation, integration, empowerment, self-help - pre-date the slogan and are long established elements of critical criminology. The slogan may best fit Left Realism due to its critique of theorising from above and, assertions that: all theory and practice reflect the reality of crime, which can only be understood by speaking to those with lived experiences, and that policy and practice must reflect the needs of those most impacted by crime and social injustice (Young and Matthews, 1992).

The difficulties of 'nothing about us without us' in practice

'Nothing about us without us' is not without limitations. First, while many organisations are beginning to commit to involving affected communities in the policy process, or in service delivery and evaluation, there is a danger that involvement can be tokenistic and become part of box ticking bureaucratic managerialism rather than truly interactive experiences. Participation that should be enriching can be harmful if individuals feel that they are 'trotted out' and exploited. Furthermore, even when individuals are listened to, and the process is genuine, there is a cost for those who have to repeatedly tell their story.

Second, marginalised groups are not homogeneous. A number of studies have shown, for example, that people who use drugs exhibit diverse opinions on drug policy and, their opinions

[3] For example, in the 1980s, John Hagedorn (1998) lobbied for gang members to be bought into the political process. He argued that this would help them exit from gang culture whilst enlivening local politics and youth policy.

are embedded in individual experiences and self-image (see Askew and Bone, 2019; Lancaster et al., 2018; Leonard and Windle, 2020). As such, just bringing representatives from a marginalised group to the table does not mean that all voices will be heard.

Third, multiple marginalisation can further silence some voice (see Cusack, McGarry et al., this volume). For example, Jürgens (2016) notes that government consultation on HIV/AIDS policy seldom includes young people, women or people who use drugs and participants are rarely compensated for their time, which excludes those who cannot afford to travel or take time off work. Indeed, Werner (1998) was critical of middle class disability rights activists speaking for, not with, the working class and those living in the Global South. He argued that as middle class activists could access essential personal aids, they focused on the civil right of inclusion. This projection of their own priorities ignored that many people needed basic necessities before civil rights could be realised.

Fourth, and connected to the last two point, those most affected may be reluctant, or unable, to take on the responsibility of lobbying (Charlton, 1998; Werner, 1998). Most social movements are composed of an inner core of a small number of politically active people who direct and organise (Charlton, 1998). Those representing affected groups, who get to have their voice heard, may be the more charismatic, aggressive, articulate, better educated, have the greatest cultural capital, or just those with the time and inclination to engage in political action. Those who talk may be the most appropriate to articulate broader concerns or may represent a small segment of the group in question. The challenge for policy makers and practitioners is, therefore, to identify the voiceless within the voiceless. This may be the core role of researchers, especially insider researchers, as we can open options for those who are voiceless and use our platform of inclusion to lobby for change. This is precisely what many of the chapters within this volume have tried to achieve.

Fifth, lived experience is not necessarily the only valuable narrative for voiceless groups, and expecting individuals to be *experts* about their own conditions may be unrealistic. However, the insight brought to the table by people who experience marginalisation and silencing is a valued and essential part of the overall story. Researchers, practitioners and members of affected groups have different perspectives, born of different experiences and access to different data, and different skills; but none of these perspectives should be ignored or belittled.

Sixth, it is important to realise that different groups have varied and at times competing objectives. For example, people who inject drugs have long lobbied for safe injecting facilities. While the health benefits of such facilities are well known, where facilities are located and, how they are funded and administered will inherently involve interaction between different groups (see O'Sullivan and Gatto, this volume). Ideological differences will occur, some voices will dominate but a democratic discussion between different affected groups is inherent in the 'nothing about us without us' approach.

Finally, McCullagh (this volume) argues that our conceptualisation of marginalisation is often inadequate, and should be 'understood as a double-edged process'. That is, while one group is 'excluded from full participation in society' others, those with money and power, are 'excluded from the responsibilities of citizenship'. As this marginalisation of responsibility facilitates crimes of the powerful, it is not enough to focus our enquiry on those lacking a voice if we do not hold those with a voice to account (also O'Rourke et al., this volume).

Research and 'nothing about us'

The assumption underpinning 'nothing about us without us' highlight the imperative that researchers engage broadly and inclusively on the research topic. Methodologically it demands, at a minimum, that all stakeholders are included in research thus providing a platform for the

voiceless. Qualitative research is considered to have more potential for inclusivity, notably: interviews (Charlton, 1998; Werner, 1998; Cresswell, Mulcahy, this volume), participatory action research (Chou et al., 2015; Yarbrough, 2020; McGarry et al., Mouriki, O'Neill and Campbell, this volume), focus groups (Boyd and NAOMI Patients Association, 2013) and, auto-ethnography, personal reflections or insider research in general (Charlton, 1998; Leonard, McCullagh, Pompa, Windle, this volume). Linked to this are, of course, the ethical assumptions of 'nothing about us without us' whereby research must avoid objectifying and further excluding marginalised groups (Yarbrough, 2020).

Yarbrough (2020) has argued that some 'outsider academic and elite voices and perspectives are legitimized over those of the people who are directly affected by the policies'. That is, research itself can silence marginalised groups (see Windle, this volume). The slogan demands that our job as researchers is to not only take from participants, but to 'amplify marginalized participants' voices and encourage an audience that has historically ignored them to actually listen' (Yarbrough, 2020). This can require, for example, including affected communities in research design, implementation and dissemination (see McGarry et al., O'Neill and Campbell, this volume) where possible.

Chapter summaries

A limitation of this book, and criminology in general, is that the majority of our research comes from the Global North and thus excludes the perspective of those living in the Global South (Aas, 2012) – this in itself is a contra-indication of the assumptions underpinning 'nothing about us without us'. In our paltry defence this book emerged from a conference hosted in University College Cork, Ireland in September 2019: the North South Criminology Conference. The theme of the conference was 'nothing about us without us', and it drew participants predominantly from the island of Ireland and the UK. Focused on building

relationships across the island of Ireland, irrespective of the political boundaries and borders that define the island, the conference is arranged each year in the spirit of inclusion and openness. A key part of this annual event is ensuring representatives from minority groups and silenced populations from both jurisdictions are included.

The slogan provides a rallying call to attract disparate groups of advocates and those who had stayed or were kept silent. It articulates in one sentence what is expected or demanded by those most impacted by political and legal decisions - involvement in all aspects of policy and practice. Not all chapters in this book engage with groups traditionally working under the 'nothing about us without us' banner, but all do engage with the core principles or champion the values inherent in the slogan.

The book is divided into three sections in an effort to capture the three components of 'nothing about us without us'. The chapters in Part I, including this introduction, conceptualise the issue. The chapter by Maggie O'Neill and Rosie Campbell focuses on the research context of 'nothing about us without us' by exploring how participatory action research (PAR), as a collaborative research method, can bridge the gap between theory, lived experience and praxis in order to do social justice and work together to create change. Drawing on PAR with sex workers within a British community, the chapter focuses on the issue of *meaningful* engagement of individuals in research and the opportunities that PAR holds as a framework for inclusivity.

In Chapter three, Ciaran McCullagh explores the issue of white collar and corporate crime in relation to the notion of marginalisation and silencing alongside how we conceive of crime and the *criminal* in Irish society. McCullagh focuses on the assumption that crime is carried out predominantly by working class individuals who are marked by the notion of marginalisation due to their experiences in the labour market and, with addiction and education. He points out that while one group or set of groups are marginalised or excluded from full participation in

society, those engaging in white collar and corporate crimes are often freed from the constraints and obligations of citizenship.

Following on from the discussion on research and, the construction of meaning and labelling in the first section, Part II addresses the experience, testimony and reaction of silenced and marginalised groups. In their chapter examining institutional abuse in Ireland, Maeve O'Rourke, Jennifer O'Mahoney and Katherine O'Donnell present interviews with Magdalene survivors and legal professionals (practising both in Ireland and the UK) who have worked with Magdalene survivors. The chapter offers critical insight into the barriers survivors of institutional abuse face when trying to access civil and criminal justice systems.

Chapter five focuses also on the meaning making derived from hearing the accounts of individuals invested in issues of policy development and criminal justice practice. Here Jane Mulcahy focuses on the issue of trauma, taking a developmental approach to understanding the impact of adverse childhood experiences on the risk-taking behaviour of individuals later in life. By exploring the life histories of individuals who served time in prison the author explores how stress and adverse experiences might be understood and addressed.

Continuing with the theme of incarceration and trauma, Dimitra Mouriki presents her work on the experience of women in refugee camps in Greece. Given the omnipresence of violence in these women's lives, the author focuses on the necessity of taking a lifespan approach to understanding and conceptualising the experience of sexual and gender-based violence for these women. Based on fieldwork conducted in refugee camps in Greece, the chapter explores refugee women's experiences of violence and the views of professionals working directly with these women.

Chapter seven is somewhat of a divergence from the previous chapters but picks up on some of the labelling and marginalizations issues raised earlier by McCullagh. The chapter focuses on the dominant and widely accepted media driven narrative around the cause of a riot which took place in Oxford (UK) in 1991. In this insider account, James Windle challenges the dominant narrative that the rioters belonged to an underclass. In reviewing how powerful voices, notably the media, misrepresented marginalised working class youths, the chapter reinforces the need for the 'nothing about us without us' movement.

In the final chapter in this section James Leonard shares his own experience of incarceration and offers an insightful analysis of his story using criminological theory. Leonard recounts with generosity his experience of education, his treatment pre- and post-prison and the barriers he now faces in his professional life. He considers how a range of criminological frameworks can explain his experiences and, have utility in how we understand and conceptualise incarceration. The issue of masculinity is sensitively discussed and complements the discussion by Windle in the previous chapter. Leonard closes the chapter with four succinct and important recommendations based on his lived experience and academic research.

Part III focuses on policy responses and reforms. Chapter nine, by Katherine McGarry, Paul Ryan, Adeline Berry and Belle Guarani, examine sex worker wellbeing in the context of the criminalisation of sex work. Using a peer-to-peer approach to research, the chapter positions sex workers as experts in their own lives. The authors argue that when we inhibit or limit access for sex workers to arenas where knowledge on sex work is produced and communicated, we at once perpetuate the kind of stigma that has long disenfranchised sex working communities, whilst also limiting opportunities for developing the depth of knowledge and experiential understanding that sex working communities hold. This study provides an important contribution to the knowledgebase on sex workers' experiences in Ireland in the aftermath of

the Criminal Law (Sexual Offences) Act 2017. At the heart of this study is a commitment to the foregrounding of sex worker voices, informed by the principle 'nothing about us without us', in order to challenge the undemocratic practices that have long disenfranchised sex workers.

Chapter ten addresses the frameworks used to understand, conceptualise, and criminalise drug use. Marcus Gatto and Sarah Bryan O'Sullivan present their research on the difficulty of establishing Ireland's first safe injecting facility. Based on an historical survey of Irish drug policy, their work reveals a gradual acceptance of a public health approach towards persons who inject drugs as opposed to the strict and exclusive operation of criminal law. The authors examine the disjuncture between public opinion and legal measures while examining the sensitivities around the housing of safe injecting facilities within communities. They point out that while injecting facilities are often largely supported by people who use drugs, they can be opposed by others within the local community.

Returning to the issue of desistance, chapter eleven, by Clare Creswell, addresses the issue of individuals convicted of sexual harm and the potential for their desistance within the community. Creswell addresses the issue of public opinion and the strong emotions prevalent around issues of sexual offending. The chapter examines how powerful political voices, in their efforts to respond to public anger impede the implementation of evidence-based effective interventions. Throughout the chapter the possibility of desistance and the impact of social expectations, labelling and stigmatisation are examined. Both this chapter and, Gatto and O'Sullivan's chapters, highlight how wider community fears can override the needs of marginalised peoples. O'Neil and Campbell's chapter more optimistically shows how arts-based workshops can break down stereotypes and bring people together. They relate how one

resident who wanted those 'dirty prostitutes off our streets' later became a champion of sex workers rights.

In chapter twelve, Alan Cusack focuses on the experience at trial for individuals with an intellectual disability. The author examines the balance of needs between meeting the evidential safeguards for the accused and the resultant intimidating, frequently hostile, courtroom environment for those with an intellectual disability. Cusack examines the measures and accommodations put in place for vulnerable witnesses but reflects that the adversarial trial system is at its core not designed in contemplation of persons with intellectual disabilities as victims of crime. Cusack advocates that, as exceptional consumers of the criminal process, victims of crime with intellectual disabilities require exceptional accommodations.

The volume concludes with a reflective account by Lori Pompa, the founder of the Inside-Out Prison Exchange Program. Pompa provides a personal reflection of the history of Inside-Out, interwoven with quotes gathered over the years from students. Inside-Out is a unique university programme involving an exchange among 'inside' (incarcerated) and 'outside (campus-based university) students, held inside of prisons across the globe. Pompa reflects on the impact of the programme for students and also for herself. One of the editors, James Windle (with our colleague Katharina Swirak), facilitates an Inside-Out programme in Cork Prison and fully concurs with Pompa's analysis that it offers a unique opportunity to 'learn about ourselves, about other people, about how we are both different and alike, about communication and working through conflict, and about the systems that impact our lives and our relationship to those systems'. At its heart, the programme involves breaking down stigmas and dialogue between those within and outside of prison. It is, in short, a programme which exhibits many of the core values of 'nothing about us without us'.

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