

# Pushing for change: using advocacy to make better policy

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Welcome to this issue of *HIV Nursing*. Writing an editorial at the end of a year allows a reflection on the previous 12 months, and internationally, the launch of the Sustainable Development Goals (SDGs) to replace the Millennium Development Goals (MDGs) has been a key development [1]. During 2014 and 2015, heated debate dominated the discussion of what should be included in the SDGs at country level and at the United Nations, not least because HIV and sexual and reproductive health goals were merged with broader health outcomes (and at risk of losing prominence). After many long nights at the United Nations, and extensive efforts from civil society advocacy groups, the final SDGs included key statements around HIV and sexual and reproductive health. Although still missing a reference to sexual and reproductive *rights* (which would have been pivotal for people of diverse sexual orientations and gender identities), these statements are seen as a hard-won success [2]. How government and civil society choose to implement these goals will be vital in seeing them become successful.

Advocacy is immensely important to achieving meaningful change, but also an odd and sometimes misunderstood concept. It isn't lobbying, and it's not just shouting. Advocacy is an ongoing process aimed at changing attitudes, actions, policies and laws through influence on the people with power. Although advocacy does not always give the satisfaction of immediate and measurable results the work of changing institutionalised systems and structures for the better at all levels is vital, particularly to people from marginalised groups [3].

Advocacy work tends to be long term and successes are often not visible for some time, making evaluation and measurement of outcomes difficult. During 2015 I have been involved in a large project in six Asian countries, 'Asia Action on Harm Reduction' [4]. The project aims to improve policies, legislation and health services to support (not punish) people who use drugs. This includes referring people who use drugs to community-based treatment centres, rather than incarcerating them. I have also worked on 'Link Up', a project active in five countries in Asia and Africa that aims to improve the sexual and reproductive health and rights (SRHR) of young people living with and affected by HIV (including young LGBT people, young people who do sex work, and young men who have sex with men) [5].

Core activities for both projects centre upon advocacy and include targeting policymakers and working with people from marginalised groups to generate positive change for improving their lives, health and safety. These people are often denied services and liberty that is the norm for others. What have we learned about effective advocacy so far? I'd like to focus on three things: the importance of meaningfully including people from affected groups from the beginning; in planning, setting markers to monitor progress; and the significance of strategic forward planning for sustainability.

Firstly, including people from affected groups. In Link Up young people were involved in the project from its inception, as participants rather than as targets (reported on by Julie Mellin in this issue of *HIV Nursing*). Through community dialogues held at the start of the project, young people identified what were central issues for them and should be prioritised in the project – for example, in Ethiopia young people reported a lack of privacy when accessing HIV testing in a health centre. For the Asia Action project, networks of people using drugs were engaged from the beginning in planning for a community-based treatment centre, and at the national level working with the government to change policy and 'lock in' community worker training to support people who use drugs. With the buy-in of affected people, advocacy impact can be potent; their voices are central to effective and inclusive advocacy [6].

Secondly, planning and setting markers to monitor progress. Advocacy requires strategic planning and the development of a 'Theory of Change' that tracks short-term objectives on the way to achieving an overall goal. Monitoring and evaluating advocacy can be tricky – how do we know when a change has been achieved? Is it a change in an individual's mind, a law, or the way someone is treated? Theory of Change is currently a popular way of mapping change over time, showing a sequence of events expected to lead to a particular desired outcome [7].

Link Up and Asia Action used Theory of Change extensively in collaboration with partners, and Theory of Change is now being used for final evaluations. Using this step-by-step approach, seeing how and why change has occurred and how it impacts people on the ground becomes easier. For example, we see that governments have changed policy in Vietnam; that young people and civil society are teaching government ministers the importance of sex education

in schools in Ethiopia; and that police in parts of Indonesia have been trained and inspired to refer people who use drugs to treatment centres rather than detaining or arresting them. Inclusive planning from the beginning of these projects was key to measurement and to success.

Thirdly, forward planning and sustainability. Once an outcome has been achieved – it could be a new policy passed, service provided or forum established – what's to stop regression? Advocacy work in a strongly political environment is always subject to flux. For Link Up and Asia Action, building people's capacity is a central component, increasing the knowledge and skills of new advocates to continue pushing for long-term change. In Link Up, young people were treated as full participants and were provided with the resources needed to build their skills as independent advocates – rather than as tokens, which is often a real risk when working with adult partners [8].

For significant change in the HIV sector, advocacy and activism can and have been powerful mechanisms. We work in an environment that, without sufficient advocacy, is always at risk of drifting towards less empathy for the people least likely to hold power, but most likely to be marginalised. For as Francis Bacon noted: 'Things alter for the worse spontaneously, if they be not altered for the better designedly.' Let's make sure we continue pushing for better.

We have a number of interesting articles in this issue of *HIV Nursing*, focusing on a range of issues in Europe and worldwide.

Julie Mellin writes about the challenges facing young people (particularly those living with and affected by HIV) in accessing appropriate sexual and reproductive health services. Too often young people living with and affected by HIV are either denied services or offered moral 'advice' rather than realistic and empowering support to protect and promote their sexual and reproductive health and rights. With more young people (between ages 10–19) than ever before, it is vital to ensure that access to sexual and reproductive health services, and to integrated HIV prevention and treatment, is maximised. The article describes one advocacy project working with this group of people.

Jacqui Stevenson discusses the growing significance of HIV and ageing. With a rapidly increasing life expectancy for people living with HIV, there is now a growing need for a better understanding of the issues facing people growing old with HIV. This demographic of people is poorly researched and understood, and the article reflects on a planned study focusing on women, ageing and HIV. How should HIV

service providers – not designed for ageing people – adapt and refine interventions for people living with HIV entering their sixth decade?

Denise Cummins and colleagues describe a recent visit by Australian HIV nurses to Myanmar. The aim of the initiative, part of the Australian Awards Fellowship, was to provide HIV education to a range of workshop participants in Yangon, who included people living with HIV, young people, field workers and counsellors. The initiative confirms the value of knowledge-sharing and promoting a collaborative approach to HIV prevention and support in Myanmar.

Sanja Kovacevic describes a study on HIV stigma in Croatia. Croatia is a country where HIV prevalence is relatively low and, according to the data, people living with HIV face breaches of confidentiality in health services and strong stigma from health care workers. This risks unwillingness to access services and reflects an experience that is not unusual in many other European (and other) countries. It reminds us of the vigilance needed to ensure health care workers, especially non-HIV specialists, are properly supported and prepared to care for people living with HIV.

We hope you enjoy this issue of *HIV Nursing*, and as always we invite feedback on these articles. If you would like to comment please send a message to: [hivnursing@mediscript.ltd.uk](mailto:hivnursing@mediscript.ltd.uk)

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