

## Part 4: Justification: Children, Drug Use, and Dependence

Part 4 focuses on the policy justification of protecting people, especially children, from the harmful effects of drugs, including drug dependence. This premise is not challenged. Let us take it as read, and agreed by all, that it is not a good idea for children to use drugs, and that the use of drugs at an early age can be especially harmful—physically, socially, and psychologically.<sup>1</sup> This is clear from a number of the chapters in this section. But policies aimed at dealing with this concern must be interrogated. Is the desire to protect children from drug use and dependence justification for the measures that have been adopted? And what does a closer look say about future strategies? In this section, five very different chapters ask searching questions of the policy responses that have been put in place to deal with drug use among children and young people, and of some of the assumptions underlying prevailing views of drugs, drug use, and dependence.

The first chapter in this section is “Youth Drug-Use Research and the Missing Pieces in the Puzzle: How Can Researchers Support the Next Generation of Harm Reduction Approaches?” by Catherine Cook and Adam Fletcher. The chapter cuts to the root of this central justification for the war on drugs, challenging what we really know and do not know about drug use among young people.<sup>2</sup> It explores the extent of our knowledge regarding drug use among young people around the world, concluding that far too little is known about emerging patterns of drug use in low- and middle-income countries, rendering the global picture incomplete. It goes on to challenge data collection methodologies and the predominance of “war on drugs” discourses that inhibit a deeper understanding of routes into problematic use and potential drug-related harms. According to the authors, the result is that the most vulnerable young people are excluded from the existing empirical evidence and their needs are ignored. The chapter concludes with recommendations for a new research agenda to inform more appropriate and effective youth-centered harm reduction interventions.<sup>3</sup>

Michael Shiner’s chapter, “Taking Drugs Together: Early Adult

Transitions and the Limits of Harm Reduction in England and Wales,” focuses on recreational drug use among young people. According to Shiner, the potential of the harm reduction approach has not by any means been explored because of a focus on problematic drug use, including injecting, and the prevalence of abstinence-based messaging. For most young people, the majority of drug use is closely tied to the “nighttime economy,” and it is here, claims Shiner, that interventions should be focused if the harms associated with club drugs such as ecstasy and the consumption of alcohol are to be mitigated. In relation to alcohol, this has included “air conditioning, ventilation, the availability of drinking water, the demeanor of door staff, transport home, the availability of information and outreach services, and access to health services.” But for other drugs this approach may require a level of tolerance that many are not willing to accept. The controversy surrounding “pill testing” to inform clubbers of what they have purchased is testament to this, as authorities see it as conflicting with messages that condemn drug use.<sup>4</sup>

Prevention is often seen as the most important aspect of policies aiming to address drug use among children.<sup>5</sup> Year after year, UN member states report to the UN Commission on Narcotic Drugs about the antidrug and prevention campaigns that have been undertaken.<sup>6</sup> Yet despite this, all raise their ongoing concerns about drug use among children and young people in their societies. What is clear is that prevention campaigns are at best limited in effect. They have not, by very definition, worked for young people who do use drugs, recreationally or otherwise. Adam Fletcher’s second contribution to this section “Drug Testing in Schools: A Case Study in Doing More Harm Than Good,” challenges a more direct and intrusive form of prevention. In many countries random school drug testing is employed both to weed out young people who are using drugs and, more important, to act as a deterrent to others who may be thinking about starting. Fletcher argues that such programs are lacking not only any solid evidence base but also any central theory to explain their aims and methods. As a result, he argues, random school drug testing can result in more harm than it seeks to prevent, such as school absences, distrust of school authorities and teachers, and pushing young people toward more dangerous drug use. Meanwhile, he demonstrates, they do not reduce drug use.<sup>7</sup> For Fletcher the answer is more holistic. Far more effective in reducing overall levels of substance use have been “school-wide interventions that promote school engagement

and positive connections between staff and students, and reduce disaffection.”

Jovana Arsenijevic and Andjelka Nikolic, meanwhile, provide a fascinating insight into the lives of heroin users in a very different part of the world—Serbia. Their chapter, “‘I’ve Been Waiting for This My Whole Life’: Life Transitions and Heroin Use,” challenges many of the stereotypes attached to people who are drug dependent by considering the complex factors contributing to initiation into drug use and to drug dependence. The chapter considers the socioeconomic status of young drug users attending harm reduction programs, and through interviews charts the life trajectories of eight heroin users, all of whom started using when they were very young. What emerges is an engaging and complicated psychosocial picture against which simplistic “just say no” prevention messages and claims that “addiction is a choice” are rendered redundant. As the authors succinctly state, “There is no universal explanation for heroin addiction” but what is an almost universal barrier to addressing it is the social stigma it attracts.<sup>8</sup>

The final chapter in the section, “Why Should Children Suffer? Children’s Palliative Care and Pain Management,” by Joan Marston, changes direction from reducing drug use to ensuring access to drugs. In this case, the drugs in question are essential medicines for child palliative care, including morphine. Access to the medicines under international control is not often a focus of drug policy discussions,<sup>9</sup> but according to the World Health Organization, about 80 percent of the world’s population has no access or insufficient access to opiates for pain relief.<sup>10</sup> This affects millions suffering from terminal cancer, late-stage AIDS, and other conditions. For children, the situation is even worse, as child palliative care lags far behind that for adults. In most countries there is next to no child palliative care. The reasons for this are complex, and Marston sets out many of them as well as the range of measures required simultaneously to deal with this problem. Important barriers to overcome include overly restrictive narcotics laws and regulations, compounded by fears about diversion of medicines into the illicit market, and, of course, addiction. According to Marston “Where governments see control of illegal trafficking and diversion as more important than the relief of suffering, children will continue to suffer. We must set our priorities straight.”

## Endnotes

1. See European Monitoring Centre on Drugs and Drug Addiction, thematic page on young people, [www.emcdda.europa.eu/themes/young-people/](http://www.emcdda.europa.eu/themes/young-people/).
2. See also UN Office on Drugs and Crime, *World Drug Report 2009* (Vienna, 2009), 23–29, 265–86.
3. Harm reduction for young people can be particularly controversial as it is seen by some to tacitly endorse or tolerate drug use among this group. The reaction tends to be to place age restrictions on harm reduction services. See, for example, Eurasian Harm Reduction Network, *Young People and Injecting Drug Use in Selected Countries of Central and Eastern Europe* (Vilnius: EHRN, 2009).
4. On ecstasy testing, see, for example, J. Johnson et al., “A Survey of Regular Ecstasy Users’ Knowledge and Practices Around Determining Pill Content and Purity: Implications for Policy and Practice,” *International Journal of Drug Policy* 17, no. 6 (2006): 464–72.
5. See, for example, International Narcotics Control Board, *Annual Report for 2009*, UN Doc. No. E/INCB/2009/1, 1–13.
6. See [www.cndblog.org](http://www.cndblog.org), run by Harm Reduction International and the International Drug Policy Consortium, which records the statements of Member States of the UN Commission on Narcotic Drugs.
7. Proponents claim that random school drug testing works. See, for example, Office of National Drug Control Policy, *What You Need to Know About Drug Testing in Schools*, [www.ncjrs.gov/ondcppubs/publications/pdf/drug\\_testing.pdf](http://www.ncjrs.gov/ondcppubs/publications/pdf/drug_testing.pdf).
8. See, for example, C. Lloyd, *Sinning and Sinned Against: The Stigmatisation of Problem Drug Users*, UK Drug Policy Commission, August 2010, [www.ukdpc.org.uk/resources/Stigma\\_Expert\\_Commentary\\_final.pdf](http://www.ukdpc.org.uk/resources/Stigma_Expert_Commentary_final.pdf). “Problem drug users are a very strongly stigmatised group and this has a profound effect on their lives, including their ability to escape addiction,” 11.
9. See, however, the recent Human Rights Watch reports: *Needless Pain: Government Failure to Provide Palliative Care for Children in Kenya*, 2010, [www.hrw.org/en/reports/2010/09/09/needless-pain-0](http://www.hrw.org/en/reports/2010/09/09/needless-pain-0); and *Please Do Not Make Us Suffer Any More: Access to Pain Treatment as a Human Right*, 2009, [www.hrw.org/en/reports/2009/03/02/please-do-not-make-us-suffer-any-more-0/](http://www.hrw.org/en/reports/2009/03/02/please-do-not-make-us-suffer-any-more-0/).
10. World Health Organization, *Access to Controlled Medicines Programme*, “Briefing Note,” February 2009, [www.who.int/medicines/areas/quality\\_safety/ACMP\\_BrNoteGenrl\\_EN\\_Feb09.pdf](http://www.who.int/medicines/areas/quality_safety/ACMP_BrNoteGenrl_EN_Feb09.pdf).

# 12. Youth Drug-Use Research and the Missing Pieces in the Puzzle: How Can Researchers Support the Next Generation of Harm Reduction Approaches?

*by Catherine Cook and Adam Fletcher*

## Introduction

Young people's use of substances, both illicit and licit, is a global phenomenon. Young drug users predominantly use substances recreationally with friends, and for many, drug use will not lead to negative health, social, or economic harms. However, a small but significant proportion of young people who use drugs will experience harm and can be particularly vulnerable to health harms for several reasons. They are more likely to take risks in their drug-taking behavior and may have a poor awareness of their own tolerance to substances.<sup>1</sup> Young people are also often the first to experiment with new substances (including new "legal highs" sold via the Internet) and to adopt new drug-taking methods, and they are often strongly connected to dense drug-supply networks.<sup>2</sup> As with adults, drug-related harms among young people are also determined by a complex of individual, social, and structural factors, such as poverty and social exclusion, which can further increase vulnerability and may mean that the harms are more profoundly experienced.

Despite these vulnerabilities, harm reduction interventions are rarely tailored to young people's needs and they are often denied access to evidence-based interventions such as needle and syringe exchange and opioid substitution therapy. In Central and Eastern Europe, for example, there are strict age restrictions on access to sterile injecting equipment and opioid substitution therapy.<sup>3</sup> Even in Australia, where harm reduction has a long tradition, an audit found that specialist services for young people were "thin on the ground" and identified several barriers to their accessing harm reduction and drug treatment services, including homelessness, appointment-based service provision, and a lack of youth-work expertise among practitioners.<sup>4</sup> The lack of youth-focused harm reduction services

represents a missed opportunity to protect and improve the health of the next generation of people who use drugs.<sup>5</sup> It is also a fundamental human right of every young person around the world to have access to the highest attainable standard of health, including harm reduction.<sup>6</sup> While this standard continues to be left unmet for the majority of young people, their human rights are being violated.

In order to respond with appropriate evidence-based and human rights-based approaches, it is necessary to have a clear picture regarding the nature and extent of youth drug use, routes into problematic use at a young age, and the drug-related harms to which young people are vulnerable. Much research is undertaken to study youth drug use, but this is not to say the evidence base needed to inform harm reduction programs for young people is complete: several key pieces in the puzzle are missing. To date, although significant attention has been given to reviewing the theoretical literature and “organizing pieces of the puzzle” in order to understand the determinants of youth drug use,<sup>7</sup> limited attention has been given to the incompleteness of the empirical evidence base and the limitations of the research methods and ideologies that inform data collection.

This chapter explores the extent of our knowledge regarding drug use among young people around the world, and the implications of this for the next generation of harm reduction. First, far too little is known about emerging patterns of drug use in low- and middle-income countries, thus the global picture remains incomplete. Second, school-based surveys are the dominant method used to study prevalence and trends in youth drug use and these have several major limitations, which are outlined. Third, most “war on drugs” discourses continue to focus research as well as policy and practice on prevention, thus inhibiting a deeper understanding of routes into problematic use and potential drug-related harms. With all three of these limitations, the result is that the most vulnerable young people are excluded from the existing empirical evidence and their needs ignored. The chapter concludes with recommendations for a new research agenda to inform more appropriate and effective youth-centered harm reduction interventions.

## An Incomplete Global Picture

At the global level, limited surveillance from many of the world’s

most populous nations makes it impossible to accurately estimate the total number of drug-involved young people. Many of the best available data are restricted to youth drug use in high-income countries of Europe and North America. In these countries, cannabis remains by far the most widely used drug among school-age youth, although levels of use are stabilizing.<sup>8</sup> European surveys report that more than one in four fifteen- to sixteen-year-old school students have smoked cannabis in the United Kingdom, Italy, France, Switzerland, the Netherlands, and the Czech Republic.<sup>9</sup> Rates are even higher in the United States and Canada where nearly one in three young people have smoked cannabis by the age of sixteen.<sup>10</sup>

While overall rates of cannabis use among school-age young people have stabilized in high-income countries, ecstasy and amphetamine use have increased, converging on—and in some cases overtaking—the high rates of “club drug” use first observed among young people in the UK in the mid-1990s. In 2007 a survey of tenth-grade students in the United States (aged fifteen to sixteen) found that 11 percent had used amphetamines and 5 percent had taken ecstasy, and similar levels of ecstasy use (6 percent) have been found among twelve- to seventeen-year-olds in Canada and sixteen-year-olds in Australia.<sup>11</sup> Although reports of cocaine use among school students remain much rarer than cannabis and “club drug” use, this stimulant is increasingly entering the landscape of youth drug cultures, and by the end of the 1990s, 8 percent of U.S. tenth-graders had used cocaine.<sup>12</sup>

However, these young people in Europe, North America, and Australia represent only a fraction of the total global youth population as more than four-fifths of the world’s children and young people live in low- and middle-income countries in Asia, Africa, and South America. In many parts of these regions there is evidence that illicit drug use among young people is rising. As a result, recent United Nations reports have drawn attention to “historic highs” of global youth drug use.<sup>13</sup> For example, in Kenya 19 percent of young people now report having smoked cannabis.<sup>14</sup> As in the world’s wealthiest countries, youth drug use in low- and middle-income countries also goes beyond cannabis use, with new practices emerging in some regions. In East and Southeast Asia, increased use of methamphetamine among young people is of growing concern,<sup>15</sup> and recent data suggest that cocaine use is increasing among school-aged youth in South America.<sup>16</sup>

Despite these insights into the prevalence and patterns of youth

drug use around the world, data on young people's drug use in Africa, Asia, and South America remain scarce. Monitoring trends in global youth drug use is therefore extremely difficult without annual survey data from low- and middle-income countries. At present, strategic information from such countries is "patchy" with no harmonization of methods or measures.<sup>17</sup> The surveys that are undertaken in developing regions are carried out irregularly and have sampled young people differently, often recruiting different age groups, across countries and over time, which limits the scope for cross-national and temporal analyses. This is the case with the existing mechanism for collecting information on young people's health-related behaviors via the World Health Organization's (WHO) Global School-based Health Survey (GSHS), whereby surveys are developed locally and undertaken by ministries of health with the assistance of the WHO, a process that results in different indicators and sampling frames being used between countries.

The WHO GSHS also fails to capture information on problematic drug use and drug-related harms experienced by young people in low- and middle-income countries, instead focusing on how many young people have "ever used" drugs, and at what age drugs were first used. For instance, one question asks participants to state how many times in the past twelve months they have used a particular drug, with options ranging from never to ten or more times.<sup>18</sup> However, this provides no indication of whether or not using the drug has resulted in any harm to the young person and does not distinguish between occasional, relatively "normalized" patterns of youth drug use<sup>19</sup> and more problematic and chaotic polydrug use. The information currently collected is therefore not instructive for informing the design and implementation of appropriate harm reduction strategies. This represents a wasted opportunity to use a global mechanism of data collection to examine more problematic use and the extent of drug-related harm experienced by young people.

## Inadequate Data Collection Methods

Across high-, middle-, and low-income countries, the majority of studies examining the prevalence of drug use among young people rely on self-reporting from an accessible group of young people, normally school students. These school-based surveys are often

cost-effective, drawing on a large number of participants, and when the same methodologies are used researchers can make cautious comparisons over time and between countries. For example, within Europe, similar national reporting mechanisms have allowed some cross-national comparisons of patterns in young people's drug use.<sup>20</sup>

However, there are important limitations to the reliability and representativeness of data collected via school-based surveys. These limitations include practical problems in using school-based surveys to collect reliable self-report data about students' use of drugs.<sup>21</sup> For example, a fear of a lack of anonymity, or of potential repercussions for an admittance of drug use may bias results due to underreporting. A recent American study comparing data collected via self-completion questionnaires with biological markers found that teenagers' hair specimens were *fifty-two times more likely* to identify cocaine use than their self-reporting of drug-use behaviors.<sup>22</sup> In addition, while large-scale surveys provide the "big picture" in terms of the prevalence of youth drug use, they are depersonalizing and largely ignore the meaning and social context of young people's actions: drug use is now an extremely important source of recreation and identity for many of these young people.<sup>23</sup>

Perhaps most significantly, school-based surveys provide insights only into the drug-taking behaviors of young people *attending school*, therefore omitting those who are not attending school or have been excluded from school. Where studies have surveyed vulnerable young people they find much higher levels of drug use. In the Netherlands, for example, researchers found that while 8 percent of twelve- to sixteen-year-old school students reported recent cannabis use, this increased significantly among students referred to truancy projects (35 percent) and homeless young people (76 percent).<sup>24</sup> It is these most vulnerable groups of young people—such as those who are not in education or training, and homeless, runaway, and street youth—whose drug use is less likely to be transitory and subject to norms of self-control, and more likely to progress to more problematic patterns of use, such as injecting drugs and sharing injecting equipment, which can transmit infections such as HIV and hepatitis B and C. Surveys of "street" youth in the United States found that 45 percent had injected drugs,<sup>25</sup> while in Canada, this figure was 36 percent.<sup>26</sup>

Street-based surveys of young people, such as the Sydney Street Intercept Survey<sup>27</sup> and the Vancouver Youth Drug Reporting

System,<sup>28</sup> are extremely rare at present but could be more widely implemented to complement existing monitoring systems. Countries in Eastern Europe—which are experiencing a process of social and economic transformation, including high unemployment and poverty rates—using such street-based survey methods, have begun to identify very high rates of HIV infection among young people as a result of shared injecting equipment and unsafe sexual practices.<sup>29</sup> For example, a recent citywide survey of more than 300 street youth in St. Petersburg, Russia, found 37 percent HIV prevalence.<sup>30</sup> These drug-involved young people who are living and working on the street, and who are at risk of HIV and hepatitis C, also often report a history of parental drug use, incarceration, and “survival sex.”<sup>31</sup>

Another potential source of data on young people’s drug use is routine records kept by drug-treatment and harm reduction service providers. When a new client comes to a facility, their age may be recorded and this can later be used to examine which drugs and methods of use are bringing people of different ages into contact with services. These types of data are particularly useful for analyzing problematic drug use among young people at the population level. However, it is clearly limited to assessing patterns among those young drug users who are able and willing to access services, and this, again, may leave out the most vulnerable young drug users who for a variety of reasons may not be able to access services. Indeed, age restrictions applied to harm reduction services may inhibit such data collection outright.

## The “War On Drugs”: Prioritizing Prevention and Hiding the Harms

Responses to drug use among young people continue to be dominated by individually focused and group-based prevention strategies, such as school-based drugs education, mass media campaigns, and youth development programs.<sup>32</sup> In turn, surveys on young people’s drug use focus on those questions most pertinent to informing such *drug prevention* efforts, such as “have you ever used an illegal drug?” And herein lies a further, major problem for informing the next generation of harm reduction approaches. Prioritizing prevention through policy and practice inevitably means that it tends to be similarly prioritized at a research level,

especially where research is funded through governmental sources. This has led to a situation where a full and accurate assessment of harm reduction needs is not available.

From those rare studies that have focused on understanding and uncovering drug-related harms experienced by young people, it is apparent that many young people require a harm reduction approach *tailored to their needs and the nuances of youth drug use*. For example, problematic drug use is often defined as encompassing injecting and/or long-term heroin or cocaine use, but a recent UK report by the charity DrugScope on drug use among vulnerable young people concluded that the definition should be revisited for this population.<sup>33</sup> Heroin and crack cocaine were less common among this group than polydrug use, particularly the mixing of alcohol with cannabis and other drugs. Cannabis is now the most frequently reported “main drug of misuse” by under-eighteens attending drug-treatment agencies in the UK: in total, 11,582 young people (75 percent of all clients) received treatment for cannabis misuse in 2005–6.<sup>34</sup>

However, these crude population-level data regarding young people’s “main drug of misuse” provide only limited insights and, more important, DrugScope’s consultation recommended a review of data-collection practices in order to gather more valid and responsive information on problematic and harmful drug use within the youth population.<sup>35</sup> Another important recommendation made in this report was the establishment of a new national “radar” service to provide early warnings of new youth drug trends and emerging harms, enabling policymakers and services to make timely, effective responses. Such systems would have uses outside of the UK, and perhaps at a regional or global level, given the ever-evolving nature of drug use, particularly among young people.

In ninety-three countries around the world, harm reduction is featured in national policies (often in relation to HIV prevention) or is used in practice,<sup>36</sup> and there is a wide-ranging body of evidence that harm reduction services such as needle and syringe programs have been effective in preventing unsafe injecting and the transmission of blood-borne viruses such as HIV, including among young people.<sup>37</sup> However, without adequate research into problematic drug use and drug-related harms among young people, public health policymakers and practitioners lack the data necessary to inform, and provide impetus to and support for, these

highly effective harm reduction interventions. The extent of drug-related harm and young people's needs remain hidden in the fog of the "war on drugs."

## The Next Generation of Research

Currently, evidence regarding young people's drug use is focused on certain regions of the world, and particularly concerned with preventing experimental and recreational drug use. This leaves significant pieces of the puzzle missing. Furthermore, the extent to which young people are experiencing harms associated with their drug use is largely unknown. Nonetheless, small-scale studies from low- and middle-income countries have powerfully illustrated how young people are engaging in problematic drug use and the resulting need for new support and treatment services. In particular, in Central Asian and East European countries, it is thought that a quarter of all people who inject drugs are now under age twenty,<sup>38</sup> and a recent assessment found that initiation into injecting begins as young as age twelve in countries such as Romania, Russia, and Serbia.<sup>39</sup>

By missing crucial pieces of evidence, the current research agenda and the methods and ideologies underpinning it further reinforce existing inequalities in health. The research process could itself be conceptualized as part of the broad "risk environment" in which drug-related harms occur within the youth population. Globally, there is a need for a mix of national surveillance and complementary small-scale studies focusing on the most vulnerable young people and problematic drug use, with three particular priority areas needing to be addressed urgently.

First, emerging data from low- and middle-income countries indicate that youth drug use is a present and growing concern in many regions. In the short term, the WHO GSHS provides the opportunity for more reliable monitoring of patterns of drug use behaviors around the world, but greater attention needs to be focused on how these surveys are undertaken. Further high-quality large-scale epidemiological studies are also needed.

Second, the focus on school-based surveys means that those young people who are most "at risk," such as those who experience school exclusion and homelessness, remain largely invisible in official statistics—as does their involvement with drugs. Street-based surveys

are feasible and should be implemented more widely to complement existing monitoring systems, including in those developing countries where street-based drug-using youth are a particularly neglected and vulnerable group.

Third, “war on drugs” discourses translate into drug policies, practices, and research that are largely centered on prevention, particularly in relation to young people. There is a need to break this cycle and to increase the focus on problematic use and the harms associated with it, in order to fuel and inform the necessary harm reduction responses. Definitions of what should be termed “problematic” will vary according to drug trends and this should be monitored at the population level, with early warning systems in place to quickly highlight new patterns of drug use among young people.

The limitations of current insights into young people’s drug use directly inhibit an effective response, particularly in relation to the most problematic kinds of drug use. Young drug users worldwide remain extremely vulnerable to harm, a situation that is unacceptable from both public health and human rights perspectives. It is imperative that policymakers and those funding and conducting research address the gaps in current investigatory approaches into drug use among young people, in order to build and support an effective harm reduction response.

## Endnotes

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# 13. Taking Drugs Together: Early Adult Transitions and the Limits of Harm Reduction in England and Wales

*by Michael Shiner*

## Introduction

The failings of prohibition and the need for alternative modes of regulation were highlighted by British sociologist Jock Young some forty years ago. Drug laws, he argued, had proved “damaging” and “unworkable” because they cannot stamp out consumer demand or illicit supply and inadvertently create spirals of “deviancy amplification.” “The problem in a nutshell is that if there is strong demand for an illicit activity, then legislation, far from removing that demand, will merely pervert and distort it.”<sup>1</sup> “Like it or not,” Young insisted, “we live in a society which makes extensive and repeated use of psychotropic drugs. Effective controls must be instituted if we are to avoid a vast amount of unnecessary misery and hardship.”<sup>2</sup> “We must,” therefore, “learn to live with psychotropic drug use” because “it is only by treating citizens as responsible human beings that any sane and long-lasting control can be achieved.”<sup>3</sup> Drug policy did not, of course, move in the direction Young favored. In the very year his work was published, Richard Nixon, then president of the United States, declared a “total war on drugs,” while in Britain the introduction in 1971 of the Misuse of Drugs Act signaled a shift toward a more explicit enforcement-led approach. Even without the benefit of hindsight, this move was noted with a sense of foreboding by liberal critics. Young warned that more punitive policies could only exacerbate the problem, while Edwin Schur maintained: “It is reasonable to predict that if the British do move significantly in the direction of American policy, the consequences of doing so will be unhappy ones.”<sup>4</sup>

The past four decades of global prohibition have confirmed that the criminal law cannot stamp out consumer demand or illicit supply. Despite a flurry of activity that aimed to strengthen international prohibition in the early 1970s, there followed an “explosive worldwide growth in the production and trafficking of virtually all types of illicit drugs.”<sup>5</sup> Consequently, the drug trade is now “a global problem of enormous proportions,”<sup>6</sup> providing “the largest and most

successful form of criminal activity ever developed.”<sup>7</sup> According to recent estimates, illicit drugs account for 3 percent of world trade, making it the third largest sector behind oil and arms.<sup>8</sup> International comparisons also indicate that the global distribution of drug use is not straightforwardly related to drug policy, since countries with stringent regimes do not have lower rates of use than those with liberal regimes.<sup>9</sup> In the United States, for example, the “war on drugs” has been escalated by almost every presidential administration since Nixon’s<sup>10</sup> and yet it has a drug problem worse than that of any other wealthy nation.<sup>11</sup> A similar paradox is evident in Britain, which has developed one of the harshest drug regimes in Europe, yet is host to one of its largest drug markets.<sup>12</sup> This paradox is examined below, first, by considering the place and meaning of illicit drug use among young people in England and Wales, and second, by considering the narrowness of official approaches to drug prevention.

## Taking Drugs Together: From Counterculture to Consumer Capitalism

The now well established link between young people and drugs can be traced back to the 1960s. This was, lest we forget, a decade of unprecedented visibility for British youth, during which society’s defenses against drug use were “decisively breached.”<sup>13</sup> When Mick Jagger and fellow Rolling Stone Keith Richards were prosecuted for drugs offenses in 1967 the case became “symbolic of a wider contest between traditionalism and a new hedonism, the focal point of which was society’s attitude towards recreational drugs.”<sup>14</sup> As youth culture became more visible and increasingly permeated by drug-friendly references, official policy began to take the form of a recurring “moral panic.” After the “sixties drugs” of amphetamines and LSD, a string of substances were added to the list: “designer drugs, PCP, synthetic drugs, ecstasy, solvents, crack cocaine and the new associations: acid-house, raves, club culture and ‘heroin chic’ supermodels.”<sup>15</sup> With the rise of ecstasy culture, and related talk of the “democratization” of drug use, a raft of surveys during the early 1990s began to show that youthful drug use was no longer a minority experience.

The emergence of widespread youthful drug use in Britain, and across much of the late industrial world, has been facilitated by broader processes of social change.<sup>16</sup> Accelerating globalization has stimulated

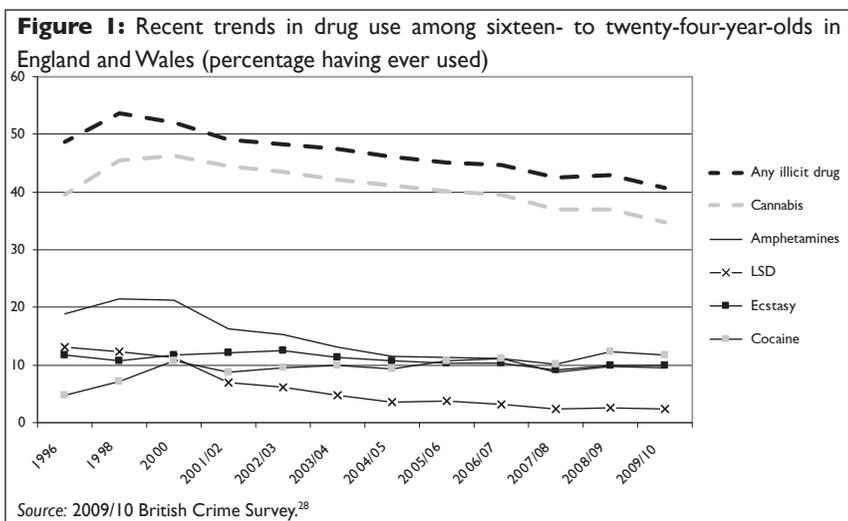
supply, while various factors have combined to accentuate demand. Crucially, the expansion of postcompulsory education beginning in the mid-1950s, augmented by the collapse of the youth labor market during the 1970s and 1980s, created the conditions for an extended adolescence. As a result, young people from all social classes began to experience a greater gap between leaving school and “settling down,” providing more room for hedonistic pursuits. Having previously made little effort to court the youth market, moreover, the drinks industry began to target young people from the early 1960s, with the result that “pub culture” and alcohol were quickly installed as “central pillars” of youth-oriented leisure.<sup>17</sup> The economic pressures that undermined the youth labor market also served to elevate the significance of leisure, both as a form of consumption and source of economic growth. Repeated urban-regeneration initiatives stimulated a massive expansion of the nighttime economy, which was, by the end of the past century, responsible for creating one in five of all new jobs.<sup>18</sup> Greater competition between outlets resulted in heavy discounting, making alcohol much more affordable, while various marketing strategies (such as happy hours, chasers and shots, etc.) actively encouraged the transgression of traditional drinking norms. With an explicit emphasis on adventure, intoxication, and release, the nighttime economy has become the primary site of “subterranean play” and its expansion has encouraged the growth of a distinctly hedonistic leisure style, which has, in turn, helped to create a platform for accelerating rates of illicit drug use. As a result, recreational drug use has become firmly established within the late industrial leisure complex, offering young people a means of celebrating freedom from adult roles and responsibilities.

Patterns of youthful drug use have changed somewhat since the high tide of dance culture in the early 1990s.<sup>19</sup> Overall rates of use plateaued toward the end of the decade, with prevalence rates for most substances leveling off or falling during the years that have followed (see Figure 1). What has caused these fluctuations is not entirely clear though it is likely to have involved an interplay of multiple factors, including changing tastes and fashions. While much of the overall decline in drug use has been driven by reductions in cannabis use, neither law enforcement nor prevention programs appear to have played a significant role in this regard.<sup>20</sup> LSD and amphetamine use have fallen sharply as ecstasy and cocaine have become the party drugs of choice for young adults,<sup>21</sup> though they may, in turn, be losing out to alcohol as the expansion of the nighttime economy

and the liberalization of licensing laws have been accompanied by an increase in “binge” drinking and “determined drunkenness.”<sup>22</sup> Reduced availability and purity of ecstasy and cocaine have also been linked to the recent emergence and rapid growth in the use of “legal highs” such as mephedrone (now banned) and methylone.<sup>23</sup>

Even allowing for recent reductions, large numbers of young people continue to engage in illicit drug use. According to recent estimates nearly two and a half million sixteen- to twenty-four-year-olds in England and Wales have used cannabis, with more than a million having done so in the past year and more than half a million having done so in the past month.<sup>24</sup> In addition, an estimated three-quarters of a million sixteen- to twenty-four-year-olds have used cocaine, with 374,000 having done so in the past year and 175,000 having done so in the past month. Young people from all social classes are well represented among those who engage in such drug use, though the vast majority stop doing so by their mid- to late twenties as they form stable relationships and start families of their own.<sup>25</sup> From a developmental perspective, illicit drug use is, for the most part, one of a range of behaviors that make up the dominant trajectory of “adolescent limited” offending, through which young people test boundaries and assert their independence. As an “adaptation” to the “maturity gap” between biological maturity and the acquisition of adult status, such behavior is “ubiquitous” and it is “statistically aberrant to refrain from crime during adolescence.”<sup>26</sup> There may even be something reassuring about rule breaking during this phase of the life course as such behavior is indicative of social integration with peers. Nonengagement in deviance, by contrast, may be suggestive of interpersonal difficulties: young people who abstain from trying drugs, for example, have been found to be “relatively tense, overcontrolled, emotionally constricted . . . somewhat socially isolated and lacking in interpersonal skills” while those who had experimented, mainly with cannabis, were said to be “the psychologically healthiest subjects, healthier than either abstainers or frequent users.”<sup>27</sup>

The prevalence rates shown in Figure 1 are indicative of a clear hierarchy of use, which is, in part, a function of perceptions of harm. Normative concerns about managing risk and reducing the potential for harm inform various decisions that young people make about what to use, what not to use, when to use, and how to use. Such concerns have also been found to constitute a more significant source of self-regulation than symbolic or instrumental concerns about



the law.<sup>29</sup> Youthful drug use typically involves a limited repertoire of substances, most of which are less harmful than alcohol.<sup>30</sup> Cannabis is both the least harmful and most widely used illicit drug, while ecstasy and cocaine tend to be used more fleetingly in the context of a “calculated hedonism” regulated by boundaries of time, space, company, and intensity.<sup>31</sup> Use of the more harmful illicit drugs, such as heroin and crack cocaine, remains much more limited. Most young people continue to be thoroughly convinced of the potential harmfulness of illicit drugs other than cannabis,<sup>32</sup> and many disapprove of, even, recreational drug use.<sup>33</sup>

## Tackling Drugs Together: The Limits of Harm Reduction

Drug policy has toughened into a “war” at a time when increasing levels of consumption point to a less inhibited popular culture.<sup>34</sup> The 1971 Misuse of Drugs Act was implemented in the wake of the newly emerging drug “problems” of the 1960s and has been central to British drug policy ever since. Under the terms of the act, controlled substances are divided into three classes (A, B, and C) according to their perceived harmfulness, and are linked to a sliding scale of legal penalties. Substances that are newly identified as a risk can be slotted into the established classification, so, for example, amendments were recently made to include “legal highs,” such as mephedrone and

naphyrone, in Class B.<sup>35</sup> Since the mid-1980s, what was already an enforcement-led approach has been codified in a series of strategic documents, including *Tackling Drug Misuse* (1985), *Tackling Drugs Together* (1995), *Tackling Drugs to Build a Better Britain* (1998), and *Drugs: Protecting Families and Communities* (2008). While combining enforcement and prevention, the national strategy clearly prioritizes enforcement.<sup>36</sup> Prevention has been defined in fairly narrow terms and, though significant steps have been taken toward harm reduction, the vast potential of this approach has “barely been explored.”<sup>37</sup> Officially sanctioned harm reduction practices were introduced as a pragmatic response to the threat of HIV and are almost entirely configured around the needs of injecting heroin users, with needle exchange, opiate substitution treatment, and some innovative moves toward heroin-assisted treatment and drug-consumption rooms.<sup>38</sup> The overriding policy imperative driving the national strategy remains one of “demand reduction,” which, applied to young people, means enforcement, primary prevention, and “treatment.” There is, in short, no official conception of harm reduction responses to recreational drug use. Remarkably, the 2008 drug strategy makes no reference to “pubs,” “bars,” “clubs,” or “licensing.”<sup>39</sup>

Given that recreational drug use is so strongly tied up with the activities of the drinks industry, it follows that the nighttime economy should provide one of the main focal points for youth-oriented harm reduction efforts. While some moves have been made in this direction, toward something we might call situational harm reduction, these remain largely informal. “Best practice” guidance has been issued for those concerned about drug use in the nighttime economy, which addresses issues such as overcrowding, air conditioning, ventilation, the availability of drinking water, the demeanor of door staff, transport home, the availability of information and outreach services, and access to health services.<sup>40</sup> While such guidance highlights many useful interventions, the lack of enforcement remains significant. According to a review of the health-care implications of clubbing:

*There are easily identifiable initiatives that could significantly reduce the impact of clubbing on the NHS [National Health Service]. They include the use of unbreakable drink containers, the elimination of discarded glass in or around clubs, a national registration and training scheme for club doormen, improved first aid provision at larger venues, limitations on crowding in clubs, and the abolition of drinks promotions that target young people.*

*All of these measures form the basis of voluntary codes of practice (such as that published by the London Drug Policy Forum, Dance till dawn safely). We suggest that they should urgently become a national legal requirement if good clubs are to thrive.*<sup>41</sup>

Best practice could be enforced through various mechanisms, including by-laws, health and safety legislation, and/or licensing conditions.<sup>42</sup> Consider, for example, that recent amendments to the Licensing Act 2003 ban “irresponsible promotions,” including the dispensing of alcohol directly into the mouth, and require that customers have access to free tap water so they can space out their drinks.<sup>43</sup> The revised conditions also ensure that customers have the opportunity to choose small measures of beers, ciders, spirits, and wine.

As well as being largely voluntary, good practice guidance has been limited by a narrow conception of harm reduction. Despite concerns about drug purity and adulterants, for example, the original “Safer Clubbing” guidance refused to recommend the use of ecstasy testing kits because, among other things: “It is hard to maintain a policy that discourages drug use at the same time as offering a pill testing service.”<sup>44</sup> Such a stance seems strangely at odds with the legalized distribution of injecting paraphernalia and the prescription of heroin substitutes. A similar tension is evident in the way the Select Committee on Home Affairs supported the piloting of heroin prescribing and safe-injecting houses, but refused to endorse the principle of legally regulated supply more generally on the grounds that to do so would be a “gamble” and a “step into the unknown.”<sup>45</sup> While recognizing the need for realistic drug education, moreover, the committee singled out *Lifeline*, a voluntary sector drugs project, for particular criticism, arguing that its comic-book harm reduction materials, which promise to “tell the truth about drugs”<sup>46</sup> “cross the line between providing accurate information and encouraging young people to experiment with illegal drugs.”<sup>47</sup>

## Conclusion

Much like the characters in the film *Groundhog Day*, the architects of British drug policy seem to be caught in a time loop, reliving the same experiences over and over again, repeating previous mistakes and failing to learn from the past. Phil, the central character in

*Groundhog Day*, broke the cycle by doing good, which leads us to the ultimate question, what would make for a good response to young people's drug use? The central problem, it seems to me, is not so very different from the one Jock Young identified some forty years ago, and nor are the solutions. We must take seriously both the limitations of the criminal law and the harmfulness of illicit drugs. In practical terms, this means accepting that the elimination of drug use is an impossible task and focusing instead on establishing a system of regulation that concentrates on reducing harm. What is required, in other words, is a more effective system of regulation than prohibition is able to provide. It remains strongly dysfunctional to harass and undermine existing drug subcultures because to do so dislocates the most viable source of norms and controls. We should, rather, seek to maintain subcultures and encourage controlled use through the dissemination of "positive propaganda," or accurate information phrased in terms of the values of the subculture, alongside an expanded set of harm reduction practices. The ultimate solution may well require a system of state-regulated supply, which enables consumers to know precisely what they are getting, while constraining suppliers—criminal, corporate, or otherwise—from pursuing profit at the cost of human well-being.<sup>48</sup>

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# 14. Drug Testing in Schools: A Case Study in Doing More Harm Than Good

by Adam Fletcher

## Introduction

As drug use has spread more widely through the youth population, it has become a public health priority to reduce the harms associated with it. Secondary schools continue to be the focus for policies aiming toward reducing drug use and drug-related harm, although traditional classroom-based drugs education has proved insufficient for changing students' behavior and reducing harm. Drug testing in schools is now also a prominent part of school life for many children around the world. In the United States, school-based drug-testing programs are commonplace, and in 2004, President Bush authorized the use of federal funds for school-based drug testing in the No Child Left Behind Act, placing testing at the heart of the "war on drugs."

This practice of random, suspicionless drug testing is not confined to American high schools. A study by the European Monitoring Centre for Drugs and Drug Addiction found that drug testing in schools has become an issue for public and political debate throughout Europe, and is now implemented in schools in the Czech Republic, Finland, Norway, and Sweden, and also takes place sporadically in the United Kingdom and Ireland, Belgium, and Hungary.<sup>1</sup> In 2009, Russia's antinarcotics agency announced that teenagers will now be tested for drugs during regular medical examinations at school, and drug-testing schemes are being piloted in schools in Kazakhstan and Hong Kong. This chapter is critical of these policies because of the practical and ethical problems associated with them, because of the lack of evidence or logic to support them, and because they will *do more harm than good*.

## School Drug Testing, Consent, and the Right to Privacy

As drug-testing programs in schools have gained political support in America and been exported to other countries, the range of technologies used to test for the use of drugs has also expanded and now includes methods for the collection and analysis of blood, urine,

saliva, hair, nails, or sweat samples. These surveillance practices represent an unwelcome and expensive extension of invasive surveillance into school life. It has been estimated that programs routinely cost as much as US\$70 per student tested,<sup>2</sup> amounting to as much as US\$36,000 per school each year.<sup>3</sup> New “point of collection tests” for use in schools can reduce the overall costs by avoiding sending specimens to an outside laboratory, although this requires procedures for testing and storing data securely on school sites, and risks the confidentiality of results.

Nonlaboratory points of collection tests also limit the reliability and accuracy of drug testing, greatly increasing the risk of “false positive” test results, and they cannot distinguish between licit and illicit drugs. For example, codeine in painkillers or prescribed medication can cause a positive test for opiates. Over-the-counter decongestants can also produce a “false positive” test result for amphetamines. How will young people’s right to privacy about medical conditions be maintained under such circumstances? Young people and parents should be consulted and asked to consent to a program of invasive testing; however, it is not unheard of for a parent or guardian’s refusal to consent to equate to the same disciplinary action as would be the case if a positive test were recorded.<sup>4</sup>

This invasion of privacy, potential for highly misleading results, and the lack of consent often associated with mandatory drug testing have meant that schools have been subject to high-profile legal challenges in the United States and elsewhere regarding their legitimacy. Indeed, the spread of mandatory drug testing in schools is further evidence of “an international environment within which human rights violations connected to drug policies are less likely to be raised and addressed” as the “war on drugs” trumps young people’s rights.<sup>5</sup> The UN Convention on the Rights of the Child requires that state parties take “appropriate measures” to protect children from the illicit use of narcotic drugs and psychotropic substances (Article 33). However, the process of coercive testing and the assumption of guilt where consent is withheld raises serious concerns in relation to other articles of the convention, including Article 16, which states that “no child shall be subjected to arbitrary or unlawful interference with his or her privacy,” and Article 3, a general principle of the convention requiring that in all matters affecting the child, the child’s best interests shall be “a primary consideration.” These protections are difficult to reconcile with

random school drug testing, especially given the lack of evidence of any positive health outcomes of such programs.

## In Search of the Evidence

Researchers have searched for evidence of effectiveness to support the proliferation of drug testing in schools—and have failed to find any. Neil McKeganey of the University of Glasgow undertook a comprehensive search of studies published in major bibliographic databases to assess the effects of drug testing in schools. He found that the current evidence base is limited to a few small-scale, methodologically weak evaluations.<sup>6</sup> Where studies have suggested that student drug testing “works,” they have lacked any control group, and often have also been politically motivated. A 2008 study commissioned by the Australian National Council on Drugs to review the evidence relating to drug testing in schools and its effects concluded that:

*While there is a large volume of literature about drug testing programmes for school-aged children, the overwhelming majority of articles comprise anecdotal evidence and journalistic comment. Few studies have examined specifically the effectiveness of drug testing programmes for school students and none has been conducted rigorously in a controlled, unbiased manner.<sup>7</sup>*

The largest study to date was undertaken by Ryoko Yamaguchi and her colleagues at the University of Michigan. They draw on data collected from more than 75,000 students across 410 U.S. high schools as part of the Monitoring the Future Study to assess the effect of drug-testing practices on drug use between 1998 and 2001.<sup>8</sup> A total of 74 out of the 410 schools surveyed reported implementing a drug-testing program during the study *but there were no differences* in either the prevalence or frequency of cannabis or other drug use reported by students depending upon whether or not drug testing had been taking place in their school. In the absence of any prospective, controlled studies, this analysis represents the best available evidence at present regarding the effectiveness of drug testing in schools and concludes that such policies do *not* deter young people from using drugs.

Meanwhile, studies exploring the views of young people, their parents, and education and health professionals consistently find that drug testing is unpopular. Young people dislike it, with those

who are subjected to it becoming more negative about school following testing.<sup>9</sup> A study of American parents and high school officials found that the majority opposed drug testing programs.<sup>10</sup> Even a survey of 359 American physicians found that 83 percent were opposed to high school drug-testing programs.<sup>11</sup>

## In Search of a Theory

Without any evidence and little popular support to underpin further drug testing in schools, it is worth reflecting on the philosophy and theoretical justifications that have allowed such practices to gain momentum. It is not unusual for new policies and practices to emerge without a clear theory or logical model underpinning them. For example, despite its widespread adoption, peer education has been described as a “method in search of a theory.”<sup>12</sup> Drug testing in schools is based on naive misconceptions about what influences young people’s behavior, and then *further limited* by misunderstandings about the potential for and extent of drug-related harms arising due to their drug use.

The policy relies on the premise that a fear of detection and punishment will deter teenagers from using drugs, or encourage them to stop using. Like many preventive interventions, it is based on the principle of modifying individual young people’s perceptions of the risks regarding drug use and assumes that they rationally weigh the costs versus the benefits of their actions in *isolation*. They do not, and therefore it is not surprising that the threat of drug testing has no impact. There are many other, more complex, social, economic, and environmental factors that are beyond young people’s immediate control and that shape their attitudes and actions relating to drug use, such as who their friends are, with whom they live, where they live, and what their school experiences are.<sup>13</sup> We should not ignore the importance of choice and individual responsibility but we must recognize these broader social and contextual determinants. As Richard Wilkinson and Michael Marmot put it:

*Trying to shift the whole responsibility on the user is clearly an inadequate response. This blames the victim, rather than addressing the complexities of the social circumstances that generate drug use.*<sup>14</sup>

Drug-testing advocates claim that such an approach is also

justified in order to refer young drug users to “treatment.” Yet youth drug use is characterized by “sensible” experimental and recreational patterns of use throughout Europe, North America, and elsewhere. Drug use with friends is now relatively normal, and part of a broader search for excitement, pleasure, and a sense of identity within the context of consumer-oriented and increasingly complex transitions to adulthood. Testing for the use of cannabis or “club drugs” is not like screening for cancer: the vast majority of young people experience no serious harms associated with these drugs. Yet, school-based drug tests cannot distinguish between experimental, occasional or regular, heavy use, or determine in what context a drug was used, to assess the likelihood of harm. Furthermore, surveillance does not work unless it is underpinned by a degree of social consensus regarding what is inappropriate or “deviant” behavior; but through the process of “normalization,” recreational drug use has been accommodated into mainstream youth cultures.<sup>15</sup>

## Toxic Schools: Doing More Harm Than Good

Not only is drug testing in schools theoretically misguided but it is likely to have unintended, harmful consequences. The first way in which harm is likely to arise is via “labeling” those young people identified as “drug users” by testing and identifying them as needing additional support. This process is likely to reduce their confidence, happiness, and self-esteem at school as well as to lower aspirations, and thus may lead to escalating drug use.<sup>16</sup> While drug testing cannot distinguish between occasional, recreational drug use and more problematic patterns of use, there is a danger that youngsters at very little risk of harm will be “labeled” and drawn into the net of counseling services, “treatment” centers, and the criminal justice system, potentially introducing them to networks of more “risky” drug-using peers.

The consequence of a positive test result also often involves suspension or school exclusion.<sup>17</sup> Reduced involvement in education and early school-leaving are associated with more chaotic and problematic drug-use practices, both in the short and long terms.<sup>18</sup> For example, a study published in 2008 of Irish young people who were using heroin found the one thing that nearly all of them had in common (eighty-one out of eighty-six) was that they were no

longer attending school.<sup>19</sup> In many cases drug testing will punish the *most vulnerable* young people—such as those from the poorest neighborhoods or those whose parents misuse drugs—who most need a supportive school environment, and whose drug use is most likely to escalate if they are excluded from school and their economic opportunities are further limited. Drug dependence and injecting drug use is also concentrated in the most disadvantaged areas and strongly linked to economic and social exclusion, both as a cause and a consequence, in high-income countries such as the United States,<sup>20</sup> and also regions such as Central Asia, Eastern Europe, and Russia.<sup>21</sup> Excluding large numbers of vulnerable young people from schools in already disadvantaged areas will only serve to increase drug-related harms in these “risk environments.”<sup>22</sup>

As with all surveillance systems, drug testing in schools is also vulnerable to “concealment.” There is potential for such a policy to do more harm than good where young people decide to change their patterns of drug use or school attendance to avoid detection. For example, drug testing can inadvertently divert young people to substances that are likely to be more harmful but less easily identifiable than cannabis, such as alcohol, amphetamines, or volatile substances (e.g., fuel or paint). This is of particular concern given the greater acute risks and long-term harms associated with excessive alcohol consumption. Furthermore, just as young people can switch substances, they can also vote with their feet and some may skip school to avoid the possibility of being tested. This increases the likelihood that they will fall behind at school and that they may become involved with older peers and a wider range of drugs, which are likely to present much greater risks than occasional cannabis use.

Drug-testing procedures also incur costs that represent a significant and unnecessary diversion of scarce resources in any education system, and the time involved in organizing these procedures is an additional burden for school managers. This time and money would be much better spent on creating a more supportive school environment in line with the principles of the health-promoting schools movement: social support, engagement, fairness, and democracy.<sup>23</sup> Schools with a positive, inclusive ethos that foster positive teacher–student relationships and promote school engagement have the lowest rates of drug use.<sup>24</sup> But drug testing only serves to damage relationships between students, teachers, and parents, and increase psychological distress.<sup>25</sup> Young people may also avoid participating in out-of-school,

extracurricular activities that help them to form positive relationships with teachers, and can divert and protect them from engaging in drug use at a young age.<sup>26</sup> These dangers associated with a poorer school ethos and diminished trust are likely to be compounded further by the harms associated with creating a false sense of a drug-free environment through drug testing, and limiting the potential for schools to create “safe spaces” for young people to learn about, and discuss issues to do with, drug use.<sup>27</sup>

### Drug Testing in Schools: “Just Say No!”

Schools are not an appropriate battleground for the “war on drugs.” The role of schools is not to police and punish young people. Schools are places where young people should be happy, build positive, supportive relationships, and have access to information about drugs, developing the skills they need to grow up safely in a world in which they face myriad risks. Drug testing breaches young people’s right to privacy and is inadmissible with the principles of school-based health promotion; it constitutes a policy of *harm promotion* rather than harm reduction. It does harm through labeling students; through excluding students from school; through creating perverse incentives to switch to more harmful substances; and through the costly disruption to school life and the loss of trust, ultimately undermining the principles of a healthy school environment. It does not address the social determinants of drug use but rather reproduces the contexts via which drug-related harms occur. And as with all wars, the most vulnerable young people are most likely to be the victims in the “war on drugs.”

School-based drug testing also provides *an exemplary case study of why drugs policies that do more harm than good are implemented*. It is a policy built on rhetoric and anecdotal evidence, and driven by technology rather than a coherent theory of human behavior. It is an example of *political interventionism*. As with military interventionism, such interventionism in schools involves aggressive state activities. Stephen Ball of the University of London has documented the flood of government initiatives and “concomitant interventionism” in education, highlighting how twenty-first-century schools are subject to directives from a local level and global trends, in addition to having to implement a wide range of policies and practices

determined by national government.<sup>28</sup> Reflecting on this phenomenon of interventionism, professor of pediatrics at the University of Oklahoma, Mark Chaffin, explains:

*Once taken to scale, once institutionalised and heavily funded, and once imbued with a sense of mission and mass commitment, programs take on lives of their own and subsequent hard data on program effectiveness are welcomed only if the news is good.*<sup>29</sup>

Yet, we have better, evidence-based policy instruments already: school-wide interventions that promote school engagement and positive connections between staff and students, and reduce disaffection have been found to be effective in reducing overall levels of substance use and supporting students' development and well-being.<sup>30</sup> These health-promotion approaches, which focus on ensuring that schools are safe, trusted, and inclusive social environments and also recognize and promote the rights of the child to privacy (Article 16 of the Convention on the Rights of the Child) to education (Article 28), and to health (Article 24) should be prioritized. These, rather than new surveillance and control technologies, are more "appropriate measures" (Article 33) to protect children from drugs.

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# 15. “I’ve Been Waiting for This My Whole Life”: Life Transitions and Heroin Use

*by Jovana Arsenijevic and Andjelka Nikolic*

## Introduction

One of the most significant aspects of drug abuse is that it affects the most vulnerable of demographics, namely, youth. The transition from adolescence to adulthood is a crucial period, during which a person is most likely to begin experimenting with drugs. Drug use can strongly affect young people who start searching for their own identity and a sense of independence. This age group is more prone to several issues that make them more susceptible to drug use. Curiosity and the search for new experiences, peer pressure, resistance to authority, low self-esteem, and problems with forming and maintaining positive interpersonal relationships can all be factors that make young people more vulnerable to drug use and dependence. Furthermore, drugs can be used as a strategy to deal with problems that include neglect, unemployment, violence, sexual abuse, and shell shock.

Various research data confirm that drug use is more common among the populations of youth living in vulnerable conditions (such as families with low socioeconomic status, large families, households with conflict and violence, alcoholism, etc.).<sup>1</sup> This group needs support and encouragement for the development of individual capacities. At the same time, drug use is also present among socially integrated young people. This is partially caused by the fact that many young people grow up under the influence of pop culture, which has a tolerant attitude toward drug use. Growing up under this influence is becoming even more risky in combination with a lack of knowledge about the risks and consequences of this lifestyle. Moreover, there are indicators that first experiments with drugs and the initiation of young people into injecting practices is happening at earlier ages than was previously the case.<sup>2</sup> Considering the developmental and psychosocial characteristics of youth, they have less ability to assess the risks and possible consequences of this behavior. Therefore, the development of individual mechanisms for resolving these issues is extremely important.

According to life-course theory, life trajectories are intersected by

various transitions that can affect the period of growing up—either in an affirmative way by helping us find constructive solutions to our future problems or in a negative way by causing stagnation or regression in the development of our personality. Our study presents the main aspects of transitions that take place in childhood or early adolescence and that can affect the lives of adult heroin users. Using descriptive analysis of eight life stories, we focus on the first memories from early childhood, family environment, peer relations, the beginning of sexual development and first sexual intercourse, the first encounter with psychoactive substances, and age at the time of first use of heroin. Most of the eight people on whom we focus also had experiences of war.

These life stories differ in many ways: from the environment in which childhood was spent, to the beginning of involvement with subcultural groups, to first experiences of love and sexual intercourse, and the first use of psychoactive substances. A particular factor, however, the introduction to heroin, is stable in all eight regardless of age differences among participants. The only variant involves the first encounter with heroin, which, nonetheless, is almost always connected to late adolescence.

The stations along the trip to the final destination—the world of heroin—are the main subject of this chapter. Following the tracks that led us there, we were told many stories that all ended in a similar sentiment, exemplified in the following quote:

*I have only one girl, I make love to her every day. It's heroin. The risk is too great, the price you have to pay is too high for a little satisfaction that lasts an hour or two.*

## Characteristics of Young Injecting Drug Users

In order to better understand the characteristic behavior of this demographic we studied forty-one injecting drug users, of which thirty-four were male and seven female. Through the Get Connected! project run by the nongovernmental organization Veza, in Serbia, which targets young injecting drug users aged fifteen to twenty-one, an initial questionnaire was used to collect information on the characteristics of our clients. The average age was just over seventeen (17.66). The age at the initial ingestion of any psychoactive substance, regardless of gender, was twelve (12.21), while the average age of first

use of heroin by injection was, again, just over seventeen (17.59) for thirty-four participants. At the time of the study, all of the participants were heroin users.

Just under a third of participants (31.71 percent) had used some form of psychoactive substance between the ages of nine and twelve, while over two-thirds (68.29 percent) had used some form of psychoactive substance between the ages of thirteen and seventeen. This implies a particularly young age of first usage of these substances. The majority of participants had their first experience with a psychoactive substance through marijuana (78.05 percent), followed by glue (12.19 percent), and heroin (12.10). Considering the more prevalent use of amphetamines in the club scene, however, this short survey does not accurately depict their usage.<sup>3</sup>

From the data gathered, the earliest case of heroin use was at age eleven. Day-to-day work with injecting drug users led us to the conclusion that individuals among the Roma population are most likely to begin using heroin at younger ages. In the general population, young people rarely, if ever, have their first experience with drugs through heroin—in most cases it is marijuana. On the other hand, the majority of young people from the Roma population are not directed toward any particular substance; rather, they begin experimenting with whatever they are most likely to encounter in their community. In the past, this was glue, but today heroin is becoming more prevalent. Upon inquiring into their family life, we concluded that the majority of participants live with their primary family (68.29 percent) and a considerably smaller proportion (9.57 percent) with their secondary family, defined as family gained by marriage. Some of those studied (7.32 percent) lived under conditions that substitute for a primary family, defined as any type of foster care. Considering the age and size of the data sample, the proportion of young people who are living on their own is significant at 14.63 percent.

In another study that took place at Veza, the social and health status of participants as well as their experiences with police were investigated. The sample size was fifty-seven participants, of whom forty-five were male, eleven female, and one who identified as transgender. One important topic that was investigated was the degree of education achieved, and why no higher education was pursued. Seven categories can be created from the responses received,

one of which includes the percentage of participants who completed a form of higher education. The variance between categories is shown in Table 1.

Category	%
Problems in school and lack of motivation	27.6
Beginning drug use	13.8
Joining the workforce	17.2
War period, sanctions, and bombing	6.9
Family problems	19.0
Other transitions in life	10.3
Have completed a higher education	5.2

These data imply that regular schooling most often ceased due to problems in school and a lack of motivation. Second in significance was family problems followed by joining the workforce, which participants attributed to a poor economic situation within the family (this makes it worth debating whether or not to include this factor within the “family problems” category or to separate it out). Drug use was the fourth most likely reason.<sup>4</sup>

## Life Trajectories of Eight Injecting Heroin Users

Following on from this snapshot of the characteristics of the relevant demographic, by using the case study method, we have mapped the life trajectories of eight individuals who told us their life stories—six male, two female. The ages of the interviewees today vary from twenty-five to thirty-two, and one who is now forty-two. To introduce these life stories, Table 2 compares the socioeconomic status of the participants while they were still living in the primary family and that in their later lives when they were living independently. The table shows a clear decline for most.

Socioeconomic status	Life in primary family	Independent living
High socioeconomic status	2	1
Middle socioeconomic status	5	2
Low socioeconomic status	1	5

In order to understand the differences shown in Table 2, it is important to consider that only two of the participants were currently employed, three were homeless, two were sex workers, and three were involved in acquisitive crime to support themselves financially. The decline in socioeconomic status happens parallel to heroin use, mostly because of family rejection and unemployment.

## First Memories

Each interview began with an inquiry into the participant's first memory. However, the first memory of most of those we interviewed was deeply repressed and unavailable for interpretation. As far as first memories go, family relations were often mentioned, or some knowledge the interviewee gained while growing up. This did not actually have to be a real memory, but information they considered to be memories diluted by the experiences of others, or other experiences and emotions that they had come to associate with a particular story. The answers indicated some degree of understanding that they simply could not remember events from their early childhood. The following is the only story focusing on early memories.

*I remember a series of memories, a series . . . Very nice ones. My favourite is when I come home wet, it's snowing outside, I lean on the radiator and watch cartoon movies. . . . That was Sundays at the time.*

## Family

Family descriptions and the relations within each of these microsystems<sup>5</sup> showed a lot of variance. In six of the eight cases, parents divorced during the participant's childhood. Complete cessation of relations with the father was present in five cases. The reasons for divorce were heterogeneous and were accompanied by new lives for the parents, leaving the children in a shadow of neglect.

Family descriptions were particularly confusing, leaving room for the interpretation that the individuals themselves were not completely clear on when their family situation transformed with the introduction of a stepfather, grandparents, or foster parents as caregivers. Their adaptation to this new situation was not complete, and several years down the line they tried to contact their biological parents.

Through two stories we found instances of attempted sexual abuse by stepfathers, and one case of rape by a biological father. The individual was fourteen years old at the time.

The remaining three recollections told the story of functional family relations. One of these included a foster father, but the story indicated a history of caring and acceptance. In all but two cases, maternal relations were unstable. Often, the mother had a passive role in the family, aiming toward a life that discontinued the primary instinct of protecting a child. It is important to note that these women were themselves the victims of abuse within the family, in multiethnic marriages, and it is obvious that they could not conquer their own trauma, which prevented them from dedicating themselves to their children.

The following excerpts exemplify some of the participants' experiences:

*I have a mother . . . I have a mom, no dad. Dad's not there, I've never seen him. I'd better never see him or hear from him ever.*

*When I was little I had a good time, I didn't have any brothers or sisters. Only a mom and dad. They didn't really argue when I was young, but they got divorced when I was in the eighth grade. They killed my old man after the war. They killed my father. They killed him over money.*

*I haven't lived with my mom or dad, I am the child of divorced parents, they left me when I was six months old. Because my mom is Muslim and my dad Serbian. I grew up with my grandparents, they put me through school. My mom and stepfather lived separately from us, I couldn't live with my stepfather . . . when I came to their house before my brother was born, . . . I mentioned I was going to change my clothes, he opens the door, you know, and "Oh, I didn't know you were there." And that's how it was for a while . . . then I stopped coming.*

*The absence of an open conversation with my father left its mark, which will influence my future psychological development. When I confront him, his reaction was like, go on back to bed, something like that as far as I remember. Anyways, I was just shrugged off.*

## Peer Relations

There were significant gender differences when it came to relationships with people in their own age group. Two of the individuals interviewed were female. They described relationships with their peers as meager at best, mentioning that they had one female friend, if any. The role of friends to them was particularly significant; it was their only way of compensating for the emotional deficit caused by a lack of communication with their families, especially with their mothers.

Male subjects, on the other hand, mentioned that their friends belonged to both a subculture and the mainstream population. We found different explanations for belonging to a subculture. There was the aspect of revolt, belonging to the group due to issues of identity, or simply due to an attraction to the activities of the group. It is evident that membership in these groups lasts for an extended period of time, further alienating them from the rest of their peers. An extreme case of this was being friends with children within an orphanage, where the ability to choose with whom you spend your life is gone.

With initiation into drug use, the circle of friends narrowed significantly for those interviewed. From then on, their friends were almost exclusively drug users:

*Parallel groups of friends, that I spent time with, that I met up with, well when I started doing drugs more, I started spending less and less time with the people that weren't a part of that world and that's normal, every idiot knows that.*

## First Love

Stories about first love were told with a different expression and a small smile, even after years had gone by. Regardless of whether their relationships with these people were long or short, it is obvious that they left a very meaningful impression. First experiences with love happened between the ages of fourteen and twenty. This was also the time of initiation into sexual relations. We consider it significant that four of the individuals had an experience with heroin not far from, or as part of experiencing love for the first time. In addition, two individuals are homosexual, and their first partners were of the same sex.

*I got married right before the war, somewhere over there, more or less near the end of 1988. To my English teacher. Nine years older than me. I got high with her before we hooked up. It was really simple, drug addicts recognize each other, always.*

*I fell in love with him and though he wouldn't give it [heroin] to me, I asked him for it. He said no. Once I tried snorting it, I jacked my guts out. I didn't like it the first time . . . I never said that he got me hooked. I wanted to try it because I'm an idiot. You know what I said? If you're gonna kill yourself [by using heroin], I'll kill myself too.*

*He was a dealer. In order to spend time with him, I bought heroin and threw it away.*

## War

All of the subjects were of different ages but despite this their life trajectories all included war. Whether during the time that the former Yugoslavia split up or when NATO bombed Serbia in 1999, by telling their life stories it was inevitable that they all included at least one segment of war stories. Other than the stress that was caused by a constant state of danger and a lack of public services such as a police force, war exacerbated many problems, particularly within already weakly integrated and noncohesive families. This was more influential with multiethnic families and families living under multiethnic conditions. War also brought about decreased control within each individual state, and with it a decrease in societal care for young people and family care for children, and more readily available weapons, drugs, and opportunities to commit crime.

Four characteristic examples of wartime experiences are presented. The first concerns a part of the former Yugoslavia that was only indirectly affected by the war, while the next three involve territories that were more directly affected.

*Her brother Fuad, me and Fudo were lying down and watching the news. It felt like it was still Yugoslavia. The speakers were Senad Erzefejdzovic, Ljubomir Ljubovic, Ivica Puric. So three nations, multiethnic. And then an argument broke out. Like Mr. President stop your green berettas. Karadjic said, why don't you stop the Chetniks, let him stop that, then Mr. President. . . . And I*

*see clearly how the war's starting, I can hear the shooting outside. And we're inside, lying down and listening to the war start . . . What comes after the war, what then, what . . . Nobody's talking, it's awkward for everybody . . . What you did to them here, what you did to them there.*

*A mountain. Night, the moon makes it as bright as daytime. You can see the deer running. . . . Two girls tried to escape from Bulgaria, they have light border control there. They shot at those two girls like it was a battle at Neretva, you know, they killed the two girls, who weren't to blame for anything. You should be ashamed, how are you not ashamed?*

*Then in 1995 I went to Kosovo. Why did I decide to? Drugs. And it's all the same to me, I ride my bike at 3:30 a.m. as the sun is coming up. There's a guy with a broken knee, this guy with no hands, with no legs, I'm riding around on my bicycle . . . All the drugstores are mine, all the morphine you want. And I'm cruising on my bicycle, on drugs and having a good time. You come into whatever house you want and take their drinks, take whatever you want, what do you care? People are running away. I don't care. Up ahead these guys are burning Albanian houses, those guys are burning Serbian houses, burning this, burning that . . . I don't care. 'Cause I've already seen it twice, I saw it in Croatia, I saw it in Bosnia and it's all normal to me, I know what's going on, I know what's going to happen.*

*So I was in Tuzla during the war, for a while, the first two years, then I was in Sarajevo for a year and that's how I caught shrapnel a couple times, I was injured in the legs twice.*

## Initiation into Drug Use

The first contact with drugs happened for the participants between the ages of thirteen and twenty, but most at about age sixteen. This corresponds to the survey described above. Glue, marijuana, and prescription medication were listed as the first drugs they came into contact with. Only one girl did not pave her way to heroin with other drugs. Heroin was her primary choice.

Among the male participants, introduction into the heroin scene on average happened at about seventeen years of age, and within their

peer group, again corresponding to the survey above. Both females who were interviewed were initiated into heroin use through young men with whom they were romantically involved. The use of heroin significantly affected their life, narrowing the friends in their social circle, and eventually completely ending relations with their family and pushing them toward criminality.

First experiences with heroin use were sometimes positive and sometimes negative, but in any case did not inhibit future use. The participants' whole world quickly narrowed and became concentrated on heroin and how to acquire money to obtain it. Attempts at abstinence and recovery were short-lived. A lack of motivation or the inability to perceive their lives without heroin influenced long years of use. Among the eight interviewed, only one had achieved long-term abstinence (four years, following seven years of heroin addiction). He was then employed, and had a family and a very active social life.

*I remember that first time, of course. I thought, I've been waiting for this my whole life. I dreamed of this a long time ago, I've been waiting for this my whole life.*

*I remember the first time I saw it (heroin). I remember the stench of death, I'd call it like that. I remember the physical experience . . . when he opened the package, I simply felt something . . . It was a thrill. Djole was like: "Did you feel it?" "What was it?" It was the stench of death.*

*No one is perfect enough not to get hooked on heroin. There is no perfect person that can resist getting hooked on heroin. It can literally find something that is bugging anyone, something that makes any person feel great, something with which anyone could be bought. You will be bought very fast. At the moment you are not aware of what is happening, you are not aware that you sold yourself. You sometimes think about it, when you feel withdrawal symptoms, but you finally become aware of it when you stop using it and when some time passes.*

*As soon as you get caught in a circuit with the devil (heroin), strange things start happening. You decide to stop using it, you go to the seaside, where you don't know anyone and it shows up the next day. Some incredible guy appears, or dealer calls to bring you some. You don't have a chance. It is always going to find you.*

*First you start to compromise with yourself. You say ok, I'll do it*

*once a month. Then you do it twice a month, then every weekend and the next second, you are taking it every day.*

## Criminality

A wide spectrum of reported criminality could not be completely attributed to heroin. A fair amount happened before the first use of heroin. Examples included smuggling cigarettes, committing robberies with underage gangs, violent behavior, selling psychoactive substances, and prostitution. In one very extreme case a murder was committed (explained further below). Motives for such criminal acts included gaining material possessions, rebelling against one's social circle, and lack of acceptance of sexual orientation. Heroin use, however, completely changed the motives for criminality with participants moving between two points—gaining the money for heroin and using it. Crimes specifically attributed to heroin use were robberies and prostitution.

*At seventeen years old I had my first robbery. I did it with a sort of bomb, so they didn't want to run after me, to grab me by the arm, instead they shot at me. Then I realized you really shouldn't do that 'cause you can end up losing your head.*

*I stole and I took, that's how I supported myself. At eighteen years old, in my second robbery we stole 16 million dinars. They quickly arrested us. In jail I befriended a guy from some gang, he died in my arms. He died from heroin.*

The following example refers to the murder noted above. The person involved was in a romantic homosexual relationship with the victim. The victim insisted that this individual had to accept his sexual orientation and “come out of the closet” so they could reveal their relationship in public. He rejected this but continued seeing the victim as well as his official girlfriend in their social circle. He defined their relationship as loving and full of common interests. The love he was talking about, however, turned into possessiveness and obsessive persecution.

*I took a cable and strangled him . . . I sat there beside him, I don't know, a certain amount of time, five minutes, ten, fifteen minutes, I don't know how long I sat there beside him. So I sat with him without being bothered . . . I felt casual. Without any emotions,*

*absolutely none. He never protected himself, not this time either. . . . Before that he told me that he loved me. I looked him in the eyes when I strangled him.*

While he was telling this part of the story, he was expressing certain forms of sociopathic behavior: manipulating and redirecting the conversation, shifting all blame onto the victim, and not showing emotions. He did not seem agitated. It is important to stress that this is a unique and extreme case. It is included here to give a full view of the experiences that the interviews uncovered.

## Conclusion

There is no universal explanation for addiction to heroin. The reason lies in a complex range of factors that influence the development of one's addiction. On the other hand, there are number of factors that come up in the life stories of most users.

In order to understand the lack of the first memories, we tried to find a connection between heroin use and memory deficiency. Heroin is a substance that causes memory deficiency, causing certain information to be inaccessible.<sup>6</sup> Merely applying any findings regarding the effects of heroin on brain activity, however, would be inadequate in this case. The unavailability of first memories can also be caused by various influences such as powerful systematic defenses including suppression, or the use of other psychoactive substances. As was previously shown, only one individual interviewed had particularly vivid early memories. This individual had spent his childhood in a functional family, so the aforementioned memories were associated with strong emotions.

Even though there are discrepancies regarding the influence of the family setting on boys and girls during the periods of childhood and adolescence, the general conclusion is that children from single-parent homes, as with step-parent families, show lower self-esteem and more symptoms of loneliness and anxiety, as well as other dysfunctional behavior on the social and psychological levels.<sup>7</sup> Parents' lack of attachment and their nonresponsiveness to the needs of a child are risk factors that, depending on other factors, can have differing effects. As we found through the stories of these individuals, a need to develop parental attachment existed for many years, and therefore, as adults, the participants yearned to compensate for this

missed period and to come to terms with their own emotional injury during their childhood.

The strategic process of selecting peers is based on certain attributes, such as similar interests, personal skills, attitudes, and behavioral predispositions.<sup>8</sup> Initiation into drug use happened within peer groups for all the males interviewed. For the females it was through an intimate relationship. During adolescence, young women are more prone to forming intimate relationships with their peers than young men are. In the absence of peer attachment, the potential for emotional investment emerges with first love. As with boys, drug use was seen as an accepted norm.

Regarding the social context in which these interactions take place, affiliation with a subculture was manifested in persistent clashes with accepted norms. The social context and the norms changed during the war. A system of values formed in these conditions, allowing for involvement in illegal activity, which in turn became “normal” and socially accepted. A wide spectrum of criminality is not exclusively tied to heroin use and may also be seen as the product of accepting this system of values during the period of war.

In society, drug users are, for the most part, represented as weak, with no moral values, rebellious, and incapable of fitting in. On the other hand, it is expected that these “weak” and “bad” people should change and become useful members of society. Ignoring the risk factors that influence personality development, as well as the lack of acceptance of heroin addiction as an illness, puts all of the blame on the individual. Heroin addiction is often differentiated from other illnesses in that the individual is seen as “choosing” to become ill. From this, it follows that it is up to you to decide whether or not you will be “cured.”

Considering the life stories above and the multitude of factors involved, the question that arises is whether there is enough understanding and support from the family and wider social environment to assist those who decide to seek help. Based on previous experience, in most cases, such support is either unavailable or fictitious. As much as the user’s personality may be “weak” and unable to fight against addiction, the personalities of people in the user’s closer and wider social context are just as weak and unable to accept the stigma that their child, sibling, partner, or friend carries. Conservative views and the ignorance of society in Serbia are the main

causes of intolerance toward drug users. The question that needs to be answered is whether heroin, as a substance, is so addictive that it makes dependence almost incurable, or the reaction of our social environment makes it seem that way. This is reflected in a common phrase used in Serbia: *Once a junkie, always a junkie*.

## Endnotes

1. For example, *Rapid Assessment and Response Guide on Psychoactive Substance Use and Especially Vulnerable Young People* (Geneva: World Health Organization, 1998).
2. See, for example, Eurasian Harm Reduction Network, *Young People and Injecting Drug Use in Selected Countries of Central and Eastern Europe*, 2009, [www.harm-reduction.org/library/1301-young-people-and-injecting-drug-use-in-selected-countries-of-central-and-eastern-europe.html](http://www.harm-reduction.org/library/1301-young-people-and-injecting-drug-use-in-selected-countries-of-central-and-eastern-europe.html).
3. [See also chapters 12 and 13.—Ed.]
4. These data were gathered from a small number of participants, but we are confident that the findings will not stray far from the conclusions of a broader study, with it being equally unlikely for the existing seven categories to be inadequate.
5. A microsystem, consists of complex relations between the person and the immediate setting (e.g., home, school, workplace). See R.E. Muuss, *Theories of Adolescence*, 6th ed. (New York: McGraw-Hill, 2006).
6. F. Nyberg, "The Role of the Somatotrophic Axis in Neuroprotection and Neuroregeneration of the Addictive Brain," Department of Pharmaceutical Biosciences, Division of Biological Research on Drug Dependence, Uppsala University, S-75124 Uppsala, Sweden.
7. N. Garnefski and R.F. Diekstra, "Adolescents from One Parent, Stepparent and Intact Families: Emotional Problems and Suicide Attempts," *Journal of Adolescence* 20, no. 2 (April 1997): 201–8.
8. T.J. Dishion, G.R. Patterson, M. Stoolmiller, and M.L. Skinner, "Family, School and Behavioral Antecedents to Early Adolescent Involvement with Antisocial Peers," *Developmental Psychology* 27 (1991): 172–80.

# 16. Why Should Children Suffer? Children's Palliative Care and Pain Management

by Joan Marston

*There can be no keener revelation of a society's soul than the way in which it treats its children.*

Nelson Mandela<sup>1</sup>

## Introduction

Children's palliative care is a professional and compassionate response to suffering caused by life-limiting or life-threatening conditions. It is a combination of excellent assessment of the child's body, mind, and spirit; management of pain and other distressing symptoms; and emotional, developmental, spiritual, and social support of the child and the family that continues into the bereavement period. Many of these children, with conditions such as cancer, AIDS, neurological conditions, genetic anomalies, metabolic conditions, severe disabilities, organ failure, and neonatal conditions, experience pain throughout the course of the disease, and often more severely toward the end of life.

Children cannot make pain an existential issue or understand the cause and effect of why they are experiencing it. When a child has pain, that is his or her whole world, and there is no understanding, just a desire to be comforted and pain free. They also cannot advocate for themselves and need a compassionate community to see their pain and feel outrage at their neglect. Older children may have the courage and the opportunity to speak on their own behalf, but what of the neonate, the infant, and the young child?

Palliative care is an answer to childhood pain. It is not just end-of-life care, or care when "nothing more can be done," but should be available from the time of diagnosis of any life-limiting or life-threatening condition, and can be given alongside potentially curative treatment. Treatment of pain is an essential element of palliative care, and access to medicines for this is crucial. Chronic pain is common in cancer and

in AIDS. Research has shown that between 60 percent and 90 percent of people with advanced cancer will experience moderate to severe pain,<sup>2</sup> as will about 80 percent of people with advanced AIDS.<sup>3</sup> While there are at present no similar studies that involve only children, we assume that the percentage of children with pain would be similar to that of adults. While they have many elements in common, however, the World Health Organization recognizes palliative care for children as different from that for adults.<sup>4</sup>

The special vulnerabilities of children, their right to health and freedom from inhuman or degrading treatment are recognized worldwide, as children are born into a world where most countries have ratified the UN Convention on the Rights of the Child; where the world is striving to reach the Millennium Development Goals, a number of which influence the health and development of the child; where the UN and strong international partners have a Global Strategy for Newborn, Maternal and Child Health;<sup>5</sup> and where most countries have special laws and policies protecting children and their rights. But in almost every part of the world, children continue to suffer with life-limiting conditions and untreated moderate to severe pain. This chapter provides a brief overview of the global state of child palliative care before considering the many barriers to improving access to controlled medicines for pain treatment, including the impact of overly restrictive or burdensome narcotics laws. It goes on to highlight the human rights case for addressing this issue, and sets out a series of recommendations necessary to ensure that children in pain have the chance of being free from unnecessary suffering.

## The Global State of Child Palliative Care

The good news is that most pain can be controlled with relatively simple-to-prescribe and inexpensive drugs, all of which are on the World Health Organization's Model Formulary for Children (2010) and updated Essential Medicines for Children (2010).<sup>6</sup> The WHO Pain Ladder has been used as the universal guide to the management of pain, and has three steps that are followed as the pain increases.<sup>7</sup> At each step of the ladder, adjuvant drugs (drugs that enhance the effect of opioids and other analgesics) can be given alongside the pain-relieving medication.

**Step 1** is nonopioids such as paracetamol and nonsteroidal anti-inflammatory medicines.

**Step 2** is weak opioids such as codeine and tramadol.

**Step 3** is strong opioids such as morphine.

All of these drugs are relatively inexpensive and easy to use. The WHO Ladder has been shown to be effective in widely different parts of the world,<sup>8</sup> but it cannot be implemented when any of the steps are missing because there are no medicines for that step.

The bad news is that child palliative care is severely underdeveloped worldwide. An as yet unpublished research project by Caprice Knapp of the University of Florida, Michael Wright of the International Observatory for End-of Life Care in Lancaster, England, and the Scientific Committee of the International Children's Palliative Care Network (ICPCN), carried out in 2010, indicates that, at present pediatric palliative care development in countries can be assessed at one of four levels:

**Level 1** No known hospice or palliative care activity for children;

**Level 2** Some capacity-building activity;

**Level 3** Localized pediatric hospice and palliative care provision with some access to morphine and other palliative care drugs;

**Level 4** Reaching a level of integration with mainstream health providers, with access to morphine and other palliative care drugs.<sup>9</sup>

Of the 192 member states of the United Nations, the researchers found that 66 percent were at Level 1; 18 percent were at Level 2; 10 percent at Level 3 and a mere 6 percent were at Level 4. Only in 16 percent of the world's countries would children have any chance of receiving palliative care that could include access to pain relief.

Europe has the best spread of palliative care programs for children, with 27.9 percent of countries at Level 3 and 11.6 percent at Level 4. Oceania has the highest percentage of countries at level 4 with 14.3 percent, but has no countries at Levels 2 and 3, and 85 percent at Level 1. Africa, with the highest burden of disease and 2 million

children infected with HIV, has only one country at Level 4, South Africa, and 83 percent of countries at Level 1.

The United Kingdom is probably the most successful country in the world in implementing palliative care for children. The first children's hospice, Helen House, was started in 1982 by Sister Frances Dominica, in Oxford, and the movement has since spread across the country. The UK has two national associations working closely together and very effectively to promote children's palliative care—the Association for Children's Palliative Care ACT and Children's Hospice UK. Government has supported the movement and committed relatively large sums of funding, providing some funding to children's hospices each year. Pediatric palliative care as a discipline and as a speciality has been taught at Cardiff University and Great Ormond Street with University College London for many years. The first True Colours Chair of Palliative Care for Children and Young people was established in London in 2009; and the community in the UK is very supportive of the children's hospices. Children's hospices are places where children receive high-quality palliative care and respite, in beautiful child- and youth-friendly environments with wonderful activities and well-trained and qualified staff and volunteers.

Scotland has an excellent model of a countrywide, well-managed children's hospice movement: Children's Hospice of Scotland, or CHAS, as it is fondly known. CHAS carried out a national survey to identify the number of children needing palliative care in 2002, assessed the requirements to care for these children, and built two beautiful units (Rachel House and Robin House) to provide respite and end-of-life care for them. Both houses have outreach teams working in the community, and there is a home-care team working in the north of the country.

But it is not just rich nations where such positive developments have taken place. Belarus has a national network of branches of the Belarusian Children's Hospice. Uniquely, in this country, the children's hospice movement was responsible for developing the adult hospice movement. Poland also has an extensive network of children's hospice services throughout the country and a strong chaplaincy program. South Africa has expanded the number of children's palliative care programs from six in 2007 to 62 in 2010 thanks to the vision of the Hospice Palliative Care Association of South Africa to implement a pediatric portfolio with a national manager; the support

of international donors; and the acceptance of the importance of palliative care programs for children by the member hospices.

And yet, with all that, many children are still not receiving palliative care. Why are there still barriers when, clearly, so much has been achieved?

*“Mind the Gap!”*

If you have traveled on the London Underground, you will have heard the voice over the loudspeakers continually warning commuters to “mind the gap” between the train and the platform. In the children’s palliative care community we are aware of the gap in development between adult and pediatric palliative care. St. Christopher’s Hospice in London, the first modern hospice for adults, was established in 1967, while Helen House, the first children’s hospice was opened in 1982—a fifteen-year gap that we are working to close. Indeed, it must be closed if we believe that children have the same right as adults to good palliative care.

When the development of children’s palliative care was compared with the development of (mainly adult) palliative care in the world as assessed by the International Observatory for End-of-Life Care, the disparity was highlighted:<sup>10</sup>

Level	Observatory	Pediatric
1	33%	66%
2	18%	18%
3	34%	10%
4	15%	6%

Even in the palliative care world, a world known for its compassion and commitment to the relief of suffering, children have been neglected

In the WHO publication *Achieving Balance in Opioid Control Policy*, it states that “Most, if not all, pain due to cancer could be relieved if we implemented existing knowledge and treatments. . . . There is a treatment gap: it is the difference between what can be done, and what is done about cancer pain.”<sup>11</sup> This statement could equally refer to all chronic pain in children. The treatment gap—the difference between what is and what should be in the treatment of pain in children—can take many forms. When countries do not

accurately assess the level of need, and order stock accordingly, there will be a gap in provision for pain management and the danger of too little stock to treat pain. When countries provide stock only to one or very few hospitals in the country as in Cameroon and Tanzania, patients living far from those centers will have an unacceptable gap between pain being diagnosed and pain being treated. When there is no effective supply chain there will be a gap between procurement and supply. And when pain medications are available only at limited sites in a country and families need to travel great distances to obtain the prescribed medicine, there will be significant gaps in accessibility.

So how do we close the treatment gap and go on to ensure access to all children in need?

### Barriers to the Provision of Palliative Care and Pain Management

To make palliative care work, a range of complex components are required simultaneously:

- Access to opioids and palliative care drugs.
- International and national laws and policies that support access to these medicines.
- Government support for palliative care.
- National Association that supports pediatric palliative care.
- Training courses for professionals, caregivers and families.
- Donor support.
- Model children's palliative care programs for training and mentorship.
- A national advocacy strategy.
- Hospice and palliative care organizations that include children's palliative care.

With all of these components in place, a child has a *chance* of receiving palliative care and having chronic pain managed. But considerable barriers block the way. They are legion and operate at the local, national, and international levels:

- Intergovernmental forums for drug policy discussions that have neglected access to controlled essential medicines.
- Governments that do not recognize the need for palliative care and opioid availability to treat pain, and that see palliative care as an unaffordable luxury, not an essential part of the health-care system.

- Lack of health policies that include palliative care.
- Health systems that do not include palliative care.
- Failure of governments to order sufficient opioids to meet the need in the country.
- Failure of supply chains for opioids.
- Failure to take seriously international legal obligations to ensure access to medicines.
- Overly restrictive narcotics laws and regulations.
- Failure of health-care professionals to prescribe opioids, or underprescribing of opioid dosages.
- Training of undergraduate health-care professionals that does not include palliative care and has little content on pain management.
- Health professionals who have not received any training in palliative care and pain management and still have fears concerning the use of opioids, addiction, and respiratory suppression.
- Community members who retain fears of using opioids and equate the use of morphine with death.
- Beliefs that neonates and babies do not feel pain.
- Traditional health practitioners who use traditional medicines and block the use of opioids.
- Social barriers that prevent children from accessing palliative care and pain relief, such as poverty, orphanhood, homelessness, and vulnerable caregivers such as the elderly or youth.
- Traditional adult-focused palliative care practitioners who do not recognize the different palliative care needs of children, or are not trained to provide palliative care to children.
- National palliative care associations that do not ensure that children receive the same attention as adults.

We need to identify and fully understand these and other barriers that prevent children from receiving the care they require before we can move forward. But many cannot see the need, or understand the human effects of the word “pain.” The issues above seem clinical and legalistic when read in isolation. It is therefore vitally important to illustrate the importance to children of surmounting these obstacles.

## A Tale of Two Children (and Two Countries)

### Bongani's<sup>12</sup> story in Bloemfontein, South Africa

Bloemfontein is the judicial capital of South Africa, situated in the center of the country in the Free State province. It is home to one of South Africa's few children's hospices, St. Nicholas Children's Hospice, which has a children's in-patient unit, Sunflower House, and a large home-based care outreach program.

South Africa's consumption of opioids is below the world mean but is still the highest in sub-Saharan Africa.<sup>13</sup> Morphine and all basic palliative care drugs are on the Essential Medicines List for the country.<sup>14</sup> South Africa has training programs for doctors, nurses, social workers, and spiritual care workers in palliative care and, more recently, pediatric palliative care. While there is as yet no adopted national policy on palliative care, a policy has been developed, and the government sits together with a number of national organizations on a National Alliance for Access to Palliative Care.

Meet Bongani—she is nine years old, diagnosed HIV positive when she was five and presented with severe pain in both feet and in parts of both hands when she was eight. Bongani was one of the 14.1 million children orphaned by AIDS in sub-Saharan Africa, and cared for by her elderly grandmother who first took Bongani to a traditional healer who was unable to manage her pain.

When Bongani came to the district hospital she was in severe pain, and both feet, two fingers on her right hand, and three on her left hand, were cold and blue. She was diagnosed with a rare circulatory problem in her extremities, and with advanced HIV disease. Bongani was seen by a medical doctor who was trained in pediatric palliative care and who was also the medical director of St. Nicholas Children's Hospice and Sunflower House, where Bongani was admitted for pain management and palliative care. Cared for by a multiprofessional team trained in pediatric palliative care, Bongani was started on antiretroviral therapy, oral morphine and other palliative care drugs, and other nonpharmacological interventions such as play therapy and massage. Bongani's pain was well-controlled and she was able to play with the other children and even go out for special treats.

However, the hands and feet did not improve and Bongani needed an amputation of half of both feet, and the affected fingers of both

hands. She was supported throughout the time in the hospital, and the palliative care team ensured that she continued on her morphine and had adequate pain control. Her grandmother was kept informed of her progress and brought in to visit her granddaughter.

Bongani lived for two months after the amputations, played happily with her friends until the day she died, and died peacefully in Sunflower House, without pain, and with her grandmother and the hospice chaplain next to her. Before she died she spoke openly to the chaplain of her mother and her wish to be with her, and said that she did not fear dying.

Where opioids are available and on the Essential Medicines List and this is linked to a pediatric palliative care team whose members understand the correct use of opioids, with a doctor trained in pediatric palliative care, a child's pain and suffering can be effectively relieved and that child can enjoy and participate in life. But all elements need to be present for this to succeed. Having opioids without staff trained to use them correctly, or having trained staff without access to opioids will leave children in pain.

#### Michael's Story in Kisumu, Kenya

Michael<sup>15</sup> is eight years old, orphaned by AIDS, and living with his elderly aunt in Kisumu. He has sickle cell anemia, a life-limiting blood disorder characterized by episodes of severe pain.

The over-the-counter pain medicines that his aunt buys for him are not strong enough to relieve the pain. This causes him to lose out on schooling and he is not able to play with his friends. Michael says the pain makes him unhappy and at times he wishes he could die to get away from it. Michael is suffering in his body, mind, and spirit. Good pediatric palliative care with access to oral morphine to control his pain would give Michael back his childhood and improve his quality of life.

Kenya is a country with morphine on its Essential Medicines List<sup>16</sup> and a strong national palliative care association, the Kenyan Hospice and Palliative Care Association, which has made big strides in the development of palliative care in the country. Unfortunately, as with many countries in the world, government policies actually block access to morphine for pain management. According to a recent report by Human Rights Watch,

*the Kenyan government has erected legal and regulatory barriers to using morphine to treat severe pain. The Kenyan narcotics law focuses on the illegal uses of morphine and other opioids and makes illicit possession punishable by life imprisonment and a heavy fine. There are exceptions for medical use, but no detailed guidelines about lawful possession by patients and health care workers. . . . Consequently, the medicine is unavailable at the vast majority of public hospitals in Kenya, in contravention of the country's international legal obligations.<sup>17</sup>*

In other words, the government is more concerned with controlling drug trafficking than with ensuring a supply of morphine for pain management. Added to this, pediatric palliative care is almost nonexistent, although with some interest and the support of the national association for development (Level 2). And there is inadequate training of health-care professionals in pain management of children. Meanwhile children suffer unnecessarily—Michael continues in pain and suffers from depression.

## International Commitments and National Narcotics Laws

### International Obligations Relating to Drug Control

The major barriers to children's receiving pain management and palliative care lie with national governments operating at home and on the international stage. There must be political will and an unwillingness to stand back and watch children suffer. But governments, especially in poorer countries, often prioritize other public-health emergencies, and fail to see that pain and suffering *is* itself a public-health emergency. They are quick to sign international conventions that protect human rights and require access to medicines, but slow to live up to these obligations. On the global level, the "international community" has been far more concerned with recreational use and supply reduction than with ensuring access to essential medicines.

The Single Convention on Narcotic Drugs was adopted in 1961 and has to date been ratified by almost every state in the world. It is a treaty best known for its approach to "illicit" uses of narcotic drugs, but in its opening paragraphs the treaty also proclaimed that narcotic drugs were "indispensable for the relief of pain and suffering." While morphine is strictly controlled under the international drug control

system, the obligation relating to palliative care could not be clearer. States' parties were instructed to ensure they had sufficient stock to meet the medical needs in each country.<sup>18</sup> The International Narcotics Control Board (INCB) was mandated to monitor this obligation. However, in 2008, the WHO estimated that despite the international acceptance of the Single Convention, 80 percent of the world's population still had little or no access to pain relief.<sup>19</sup> For the past twenty years, the WHO and the INCB have reminded governments of their obligations to ensure access to medicines for pain treatment, but with little effect on children. Meanwhile, vast sums have been spent on law enforcement and supply reduction in the decades since the adoption of the Single Convention, eclipsing by far the efforts to ensure access to essential medicines. While the shortfall in access is mainly in middle- to low-income countries, it is not exclusively so. The ICPCN is, in 2010, advising some very high-income countries to develop their first children's palliative care services.

#### Opiophobia and the “Chilling Effect” of Restrictive Drug Control Laws

Many people fear that morphine may be addictive, and believe that it is only given when the patient is near death. Health professionals often state that they fear morphine will suppress respiration, and show a lack of understanding of use of opioids in the treatment of chronic pain. This became clear in Human Rights Watch's study in Kenya in 2010, according to which:

*In Kenya, morphine is widely viewed not as an essential, low-cost tool to alleviate pain, but as dangerous. . . . Until recently, medical and nursing schools taught that morphine must only be administered to the terminally ill, because of unwarranted fear that it would cause addiction, and hospitals often only offer the drug when curative treatment has failed. . . . Even at the seven public hospitals where morphine is available, doctors and nurses are sometimes reluctant to give it to a child, because they believe it amounts to giving up on the fight to save the child's life, and because unwarranted fears of addiction remain.<sup>20</sup>*

For many years messages about opiates have, for the most part, been rooted in scare tactics aimed at deterring recreational use and preventing addiction. While that aim has not been achieved, the fears instilled in relation to these drugs remain. Those fears

are closely related to narcotics laws that can act as barriers to full access to palliative care medicines. In the 1961 Single Convention, within which access to essential controlled drugs is included as an obligation, addiction to drugs is referred to as an “evil,” threatening the fabric of society.<sup>21</sup> There is certainly an imbalance within the text, and this is reflected in international drug control efforts in recent decades. In Kenya, narcotics laws have had a “chilling effect” on access to palliative care medicines. As documented by Human Rights Watch, Kenya’s 1994 Narcotic Drugs and Psychotropic Substances Control Act (Narcotic Drugs Act) regulates morphine and other opioid pain medicines and is widely seen among health-care professionals as prohibiting these drugs. Heavy penalties are imposed for illicit possession, and, for medical workers, this can mean a loss of their license. According to the Kenyan Pharmacy and Poisons Board, “Due to the punitive nature of the 1994 Act, most providers have shied away from selling opioids.”<sup>22</sup>

While morphine is safe, effective, easy to use, and usually inexpensive, there is the potential for abuse. For this reason morphine is a controlled medicine, and the manufacture of morphine, its distribution and dispensing are controlled internationally and regulated in each country. But governments can and often do order relatively small amounts of morphine, inadequate to meet the need for pain control in their country, as they fear that it will be diverted for illegal use. This is despite the fact that the INCB states that diversion is relatively rare. Each government has a responsibility to ensure the safekeeping of morphine, to prevent or minimize diversion, but those regulations also need to facilitate the medical use of morphine and not prevent its availability and its use. Where governments see control of illegal trafficking and diversion as more important than the relief of suffering, children will continue to suffer. We must set our priorities straight.

### Access to Medicines for Pain Treatment as a Human Right

Recently human rights monitors have increased their focus on access to medicines and pain treatment. The argument is, for the most part, made under two headings—the right to health, and freedom from torture or cruel, inhuman, and degrading treatment. Both, of course, are recognized in the UN Convention on the Rights of the Child as well as other international human rights treaties. Nongovernmental organizations such as Human Rights Watch and the Open Society

Foundations have made the issue a focused campaign, while UN human rights mechanisms have also begun looking more closely at the problem.

In 2009 the UN Human Rights Council adopted a resolution calling on member states to ensure access to medicines as a component of the right to the highest attainable standard of health.<sup>23</sup> This echoed the view of the UN Committee on Economic, Social and Cultural Rights that access to medicines is a core minimum obligation of the right to health<sup>24</sup> as well as previous resolutions of the UN Economic and Social Council.<sup>25</sup> In October 2010, the UN Special Rapporteur on the right to health, Anand Grover, submitted a report to the UN General Assembly in which he recommended that all states “amend laws, regulations and policies to increase access to controlled essential medicines”<sup>26</sup> in order to “improve the quality of life of patients diagnosed with life-threatening illnesses through prevention and relief of suffering.”<sup>27</sup>

In December 2008 the UN Special Rapporteur on torture and other cruel, inhuman, and degrading treatment or punishment, Manfred Nowak, together with the UN special rapporteur on the right to health, wrote the following to the UN Commission on Narcotic Drugs in the lead-up to the adoption of the 2009 political declaration and plan of action on drug control:

*Governments also have an obligation to take measures to protect people under their jurisdiction from inhuman and degrading treatment. Failure of governments to take reasonable measures to ensure accessibility of pain treatment, which leaves millions of people (including children) to suffer needlessly from severe and often prolonged pain, raises questions whether they have adequately discharged their obligation.*<sup>28</sup>

In 2010, the commission, for the first time in its 53-year history, adopted a resolution on access to controlled medicines, calling on member states to “identify the impediments in their countries to the access and adequate use of opioid analgesics for the treatment of pain and to take steps to improve the availability of those narcotic drugs for medical purposes.” It should be noted, however, that the fear of diversion and addiction was still very clear, and included in the very title of the resolution.<sup>29</sup>

The Open Society Foundations have taken up the challenge of access to palliative care drugs as part of a new campaign called the

“Campaign to Stop Torture in Health Care.” Many children’s palliative care practitioners and the ICPCN are supporting this campaign as we believe children who experience inadequate pain relief for both chronic and procedural pain are subjected to inhuman and degrading treatment. According to the Open Society Foundations:

*at a time when many governments are regressing on their health commitments, using a torture framework to address human rights violations in health settings mandates immediate state action to stop them. A torture framework provides health advocates with an opportunity to connect with new, potentially powerful partners, including mainstream human rights and anti-torture organizations that may neglect vulnerable populations subjected to torture and ill treatment in health care settings, and traditional civil and political rights organizations that have yet to engage in health and human rights issues. A torture framework also places responsibility for patients’ suffering where it belongs: with governments, who too often place health workers in a dynamic where they are enlisted in violations of human rights. In practical terms, the Campaign to Stop Torture in Health Care is not a campaign against individual health workers as such, but against the failure of governments to protect all people (patients and providers) in health care settings.<sup>30</sup>*

These are strong statements, and we hope that governments will be forced to listen and to act accordingly; and that children will be among the beneficiaries of this campaign.

## A Country with a Vision: Progress in Uganda

Uganda is a country in East Africa with a population of 31 million, of whom 1 million people are infected with HIV. Much of the population lives in poverty and in rural areas, and more than 50 percent of the population is under the age of eighteen.

Uganda has a government that recognized that its people had the right to palliative care and pain relief, and it became the first country in Africa to recognize palliative care as an essential part of their health service. Working together with a visionary team of advocates from Hospice Africa Uganda, and in collaboration with the WHO and nongovernmental organizations, Uganda developed a five-year National Palliative Care Strategy that included the development of nurses and clinical officers who would be able to prescribe oral

morphine, and looked at introducing drug regulations to promote an adequate supply of morphine that could reach those in pain quickly and effectively. Along with most African countries, the number of health-care workers is low and the country has lost many of these professionals to more developed countries. Therefore, this was an innovative and effective way of increasing the number of prescribers to meet the need for pain control.

While there are still challenges to the implementation of this strategy, Uganda has increased access to oral morphine for adults and children, and become a model for other African countries. South Africa has a regulation at government level, supported by the South African Nursing Council, to allow nurses trained in palliative care and prescribing, to prescribe and dispense all palliative care medicines.

## Conclusion and Recommendations for Action

*Children and adolescents with life-limiting conditions have very specific palliative care needs that are often different from those of adults.*

*If the physical, emotional, social, spiritual, and developmental needs of these children and adolescents are to be met, the caregivers require special knowledge and skills.*

*We ask that the voices of these children and adolescents be heard, respected, and acknowledged as part of the expression of palliative care worldwide.*

The ICPCN Statement of Korea on Palliative Care for Children,  
2005

How do we close the treatment gap? How do we ensure access for all children in need to palliative care and pain treatment? We must start with the belief that the suffering of a child is unacceptable and that this can and must be changed. From there, we have much work to do:

- We need to continue to advocate for the rights of each child to relief of pain—with governments, educational institutions for health care providers, donors, medical and nursing associations, palliative care organisations, drug

suppliers, and international agencies—working together with organisations that are advocating to improve opioid availability.

- The voice of children themselves should be the most powerful voice in that movement. It is, however, seldom heard.
- All health care workers must receive training in palliative care for children as an integral part of their undergraduate training. This training must include pain management and use of opioids; as well as assessment of pain, and communication with children.
- Governments must be held responsible for setting in place properly funded policies and procedures to ensure an adequate supply of opioids, especially oral morphine.
- These policies and procedures must take precedence over concerns about diversion (which is, in any case, rare).
- Drug control laws that restrict access to opiates for palliative care must be amended to ensure that they do not operate as a barrier to the relief of suffering.
- Where there is a lack of doctors to prescribe, the government should look at alternative models, such as nurse prescribing (e.g. as in Uganda).
- Prescription procedures should be simple and not impede access to pain relief.
- Tools used for assessing pain in children should be available, simple to use, culturally acceptable and be used correctly.
- Donors must be encouraged to provide funding for palliative care for children—at present very few do so.
- Manufacturers must be encouraged to develop child-friendly formulations.

The UN Commission on Narcotic Drugs must direct more of its attention to this issue, reflecting the true balance of its mandate.

In the words of the Beatles ballad, we have been on a “long and winding road” to get where we are in developing palliative care for children. The road ahead promises to be long and winding as well, with many obstacles along the way before we reach our vision of quality palliative care for all children wherever in the world they are. We acknowledge our failings in not advocating as vociferously as we should, whether with governments, international bodies, other nongovernmental organizations, or within the palliative care community itself. And we end with words from the community we

work for, a child who had pain and who received good palliative care, morphine, and supportive therapies. Rosie is six years old, with an osteosarcoma:

“I was sad and cried because I had pain like a knife in my leg. Now I have the pain medicine and the kind nurse to visit me, I can sing again, even if I can’t dance”

## Endnotes

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## Discussion Questions

1. “Drug addiction is a choice.” Discuss with reference to children and adolescents.
2. What are the differences in the ways young boys and young girls begin using drugs? What are the implications for early intervention?
3. To what extent are laws and policies relating to drug use driven by morality? How can this be reconciled with scientific evidence-based responses?
4. The majority of young people use drugs recreationally. What are the consequences for this majority of focusing policy on problematic use? What might be involved in a harm reduction response to recreational drug use?
5. Fletcher argues that random school drug testing does more harm than good. What are the harms he identifies and what is the potential “gain” intended by such policies? Is there a hierarchy?
6. It is now a greater imperative to ensure access to controlled drugs for medicinal purposes than to restrict access for recreational use. Discuss.



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