#### **INTERVIEW**



## Ethics and law continue to shape psychiatric practice and research



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Science Award program. Appelbaum was previously the AF Zeleznik Distinguished Professor of Psychiatry, Chairman of the Department of Psychiatry, and Director of the Law and Psychiatry Program at the University of Massachusetts Medical School (MA, USA). He is the author of many articles and books on law and ethics in clinical practice and research, including four that were awarded the Manfred S Guttmacher Award from the American Psychiatric Association (APA) and American Academy of Psychiatry and Law. Appelbaum is a past president of the APA, American Academy of Psychiatry and Law, and Massachusetts Psychiatric Society. He has served twice as chair of the APA Council on Psychiatry and Law, now chairs the APA Committee on Judicial Action, and was a member of the MacArthur Foundation Research Networks on Mental Health and the Law, and on Mandatory Outpatient Treatment. Appelbaum has received the APA's Isaac Ray Award for 'outstanding contributions to forensic psychiatry and the psychiatric aspects of jurisprudence', was the Fritz Redlich Fellow at the Center for Advanced Study in the Behavioral Sciences (CA, USA) and has been elected to the Institute of Medicine of the National Academy of Sciences. Appelbaum graduated from Columbia College (NY, USA), received his Doctorate in Medicine from Harvard Medical School (MA, USA) and completed his residency in psychiatry at the Massachusetts Mental Health Center (MA, USA)/Harvard Medical School in Boston.

## **Q** What initially drew you to psychiatry in general & then more specifically to forensic psychiatry?

I was attracted to psychiatry in medical school by a combination of things: an interest in the manifold forms of psychopathology that patients presented with; I was intrigued with how the mind and brain could generate those phenomena; and I was also drawn to psychiatry because, at the time, in the 1970s in the USA, there was an enormous ferment in the legal system and its regulation of psychiatric practice. So forensic psychiatry

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#### Interview

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"We have taken the notion of full disclosure and made it into an icon without asking what is the purpose of that disclosure, which should be that the subjects understand the nature of the choice that faces them." was never far from my mind in choosing a specialty of psychiatry.

## Q Is there a role you have particularly cherished or an achievement you view as a highlight of your career so far?

I was enormously honored to be elected president of the American Psychiatric Association (APA) to serve from 2002 to 2003. The opportunity to speak on behalf of American psychiatry and to attempt to contribute to the future of American psychiatry was a wonderful opportunity and a huge learning experience.

#### Q What changes have you observed in the ways that legal & ethical rules affect medical practice & research during your career so far?

As I mentioned, I came into psychiatry at a time when the legal system had turned its attention to the psychiatric care system in a very focused manner. Rules were evolving that governed the use of civil commitment, involuntary treatment, various forms of seclusion and restraint, and informed consent in psychiatry and, more broadly, medicine. This was part of what drew me in to the field originally, because I have a long standing interest in the law that dates back to my college years. Since that time, we have observed a steady increase in the regulatory structure that governs medical and, in particular, psychiatric practice. In general, both the proliferation of legal rules and a huge elaboration of ethical standards has been for the best, since it is unquestioned that there were various abuses that occurred in the lightly regulated environment that preceded the 1970s. However, we have also seen some of the downsides of intensive regulation, such as medical practice becoming burdened with layers of bureaucracy, paperwork and requirements that may sound good in principle but actually contribute little to, or sometimes detract from, the quality of care a physician is able to render.

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#### Q You have written at length about therapeutic misconception & proxy decision-making; what do you view as the key issues that need addressing in this area & how can they be overcome?

Both of these issues relate to the broader category of informed consent, which is something a lot of my research and writing has focused on. I think that there is no question and, in fact, hardly any need for any additional studies to demonstrate that we conduct informed consent quite poorly in general. This is certainly true with regard to consent for research, and was true more than 30 years ago when we described the therapeutic misconception, which is the tendency for research subjects to confuse the research setting with the clinical treatment setting and assume that the drivers of physicians' choices and behaviors are the same in both settings. Unfortunately, it is equally true today and, to a considerable extent, relates to some of the issues I was referring to with regard to the regulatory structures that can be ends to themselves.

Beginning in the 1970s, here in the USA, we elaborated quite a substantial set of regulations and a prospective review process for human subjects research that has, over the years, resulted in a growing number of requirements that must be included in the process of obtaining informed consent for research. So we have now, in some cases, 30 single spaced pages of consent forms that we hand to subjects, often written at a graduate school level of difficulty, and we expect them to understand them. In fact what we've done, I think, is overwhelm research subjects with information, much of it irrelevant to the decision that they really need to make, yet at the same time we have failed to address the very real misunderstandings and misconceptions that we know are endemic in the research setting. We have taken the notion of full disclosure and made it into an icon without asking what is the purpose of that disclosure, which should be that the subjects understand the nature of the choice that faces them.

#### Q Do you think the difficulties surrounding informed consent are amplified in psychiatry?

I think psychiatry is more similar to, than different from, the rest of medicine as far as consent is concerned. We see many patients whose decisional capacities are to one extent or another impaired; however, this is also true for those undergoing surgery, for example, although that fact may be less well known. By definition, seriously or medically ill patients are in pain, distracted and have difficulty engaging in decision-making processes, often as much difficulty as psychiatric patients do.

#### Q Much of your recent work has focused on the issues surrounding genetic testing in psychiatry: what are the main areas of debate & what is your stance on these issues?

I now run a center here at Columbia (NY, USA) that conducts research on the ethical, legal and social implications of genetics, particularly psychiatric, neurological and behavioral genetics, and much of what we focus on, and much of what I think represents the major challenges in the area, is how best to use the enormous amount of genetic information that is just beginning to become available. Genome sequencing is becoming more common - indeed, I heard an advertisement on the radio this morning for a health system offering genome sequencing. We each have 3.2 billion pieces of information, a massive amount, encoded in our DNA. Thus, the question arises as to how to use that information for the benefit of patients and research subjects without imposing crippling burdens on the research process and medical treatment system. These are really the major concerns. Are people better off, for example, knowing about relatively low probabilities of risk of serious illness, including psychiatric and neurological conditions, most of which cannot be prevented in a very assured way? Or are they not? Additionally, what about the use of genetic information elsewhere in society by insurers, employers and the legal system? Those are vital questions that we need to figure out the answers to quickly because, even as we speak, this kind of information is becoming more widely available.

# **Q** Following the Newtown (CT, USA) shooting you discussed the link between mental health disorders & the perceived risk of violence: how do you think the myths can be dispelled & what needs to be done by the clinical community to reduce the risk of further stigmatization of this population?

We're in a situation now where we seem to be making progress and sliding back simultaneously. At the cognitive level, the general public are now more aware of many of the myths that have long been associated with mental illness, including the link to violent behavior. I think decades of educational effort have made an impact in helping everybody understand that not everyone with a mental illness is likely to be violent, although there may be an increased risk that only accounts for a very small proportion of violence that occurs in our society. Although that, at the cognitive level, has been successful, at the affective level when a horrific violent event has occurred, as happened last year with the shooting at the elementary school in Newtown (CT, USA), the visceral reaction of many people is to assume a link between horrific violence and mental illness, and to presume if only we could protect ourselves from people with mental illness then we could be safe. Those are understandable but unfortunate reactions, and unfortunate not just because of the stigma that they convey and embody, but also because they lead us to poor decisions regarding policies for protecting the public. The debate in the wake of Newton, as with the wake of other awful massacres in the USA, turned very quickly to what reporting obligations should be required regarding people with mental illness - should we restrict gun access for people who have been voluntarily hospitalized, treated for a mental illness or received psychoactive medication? At the same time, this country has laws barring the creation of a federal database covering everyone who holds a gun. I think we have short-circuited the process of rational policy-making with regard to gun violence, by virtue of this affective response that many people have regarding the relationship between mental illness and violence. I think there is an

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enormous role that psychiatrists, and other mental health professionals and researchers in allied fields can play in terms of helping people understand that only a small proportion of violence is attributable to mental health issues. In the USA, it is between 3 and 5% and, in fact, there has been no study anywhere else in the world suggesting it is over 10%. The figures suggest that if we truly want to make our countries safer places, focusing on people with mental illness is not likely to be a very effective way of doing that. Those points I think need to be made and I encourage my colleagues to do that, not just in formal presentations, editorials or publications, but especially in the informal context. Those interactions can be even more important in terms of shaping people's attitudes, and in educating friends and relatives. If we each took it upon ourselves to educate friends and relatives it would be substantial step forward

#### Q You are the current chair of the APA's Committee on Judicial Action: what is the purpose of the committee & what does your role specifically entail?

The committee was formed in the 1970s, which as I mentioned was a pivotal decade in this country for the relationship between psychiatry and law, and was created to give American psychiatry a voice in major court cases that impact the field of psychiatry or our patients. The committee monitors activity in the court as it relates to psychiatry and recommends, in appropriate cases, involvement of the APA as an amicus curiae - a friend of the court – we provide the briefs that help the court understand the psychiatric background of the cases they consider, and the implications for people with mental illnesses in the decisions they are about to make. Much of our activity is at the level of the Supreme Court of the United States, where we participate in almost every case that touches on psychiatry in any way. We are also involved in the lower levels of the federal courts and state supreme courts, and it is tremendously gratifying when our briefs are cited in the opinions and have clearly helped the judges better understand what the issues are.

## • Where will you be focusing your attention on in the future & what do you hope to achieve?

For the foreseeable future a good deal of my research efforts will be focused on issues related to psychiatric, neurological and behavioral genetics. Although I have an interest in the use of this information in general, given my background in forensic psychiatry I have a particular interest in how this information will be used in the courts. In fact, we are actually conducting a series of studies on the impact of genetic and imaging information on jurors' decisions in a variety of different cases. From an academic perspective that will probably occupy a good deal of my attention in the upcoming years. From the perspective of organized psychiatry, which has been another big part of my career and life, I'm now chairing a workgroup for the APA on the DSM. The leaders of the process of compiling the latest DSM which was published earlier this year, declared henceforward that the DSM would be a 'living document' revised, in part, as new information and evidence came along to warrant revision. What it exactly means to take a massive tome like the DSM and make it into a living document is not easy to specify, so the work of our group is focused on helping the APA to develop a plan for future revisions to diagnostic classifications in an interactive and ongoing way. Given that effective diagnosis is essential to the task of psychiatry, I think that to be able to come up with the right answers here is critical for psychiatry's future.

### Q Do you have any closing comments or a message for our readership?

I'm sure that I'm not the only person to have said this but it is true and important to keep in mind: although day-to-day psychiatry is buffeted by many forces – economic, legal and social forces – and we can feel pretty bleak at times, this is an era of genuinely unprecedented growth in our understanding of the brain, the mind, their relationship and how it impacts the disorders that we treat, and I just feel grateful I can be part of it some small way.

#### INTERVIEW NEWS & VIEWS

#### Disclaimer

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