Robert Bernstein, Ph.D., Executive Director, Bazelon Center for Mental Health Law

I am honored to be here. When I came to the Bazelon Center in Washington three years ago to be executive director, I heard "ivory tower" talk, from all sides. One thing I heard was that Bazelon is disconnected from the consumer/survivor community. I was very concerned: rightly or wrongly, we haven't done a good job of connecting with the consumer/survivor community. Without such a partnership, we have no validity at all. We have to do things differently.

We have a tremendous amount to learn from the consumer/survivor community, and we have been working hard to connect differently and better. For that reason, when I was invited to present on Sally Zinman's panel at the National Summit in Portland, it was a badge of honor. When I came today, I was hoping to see the same kind of passion and enthusiasm as in Portland, and it is in the room today.

Other "ivory tower" concerns were that Bazelon has lawyers who know nothing about the needs of people, and that, because of an obsession with rights, people are dying in the streets with their rights on. That caused me to spend time defining what we're all about, why we're not seeing the outcomes we had hoped to see.

One of the main pillars of our work is that you can't construct a mental health system on broken promises and see visions realized without services and supports. What you're seeing in the streets is neglect. We have to get that message to the public. Homelessness is not a symptom of schizophrenia; it's a symptom of neglect.

A trend increasingly evident in Washington and the states is to look at gaping holes and broken promises and try to plug those holes with coercion. Most evident as an example is involuntary outpatient commitment. The Bazelon Center has taken a strong position against IOC for a lot of reasons.

In New York, where Kendra's Law was sold based on the notion that there are 10,000 New Yorkers who need to be forced into outpatient treatment, we now only have a handful of people committed under Kendra's Law. Kendra's Law has polluted the system by introducing the very coercion that characterized the psychiatric institutions of the past into the community, where it was not supposed to be part of the picture. Michael Allen has been spearheading the effort at Bazelon to build consensus among consumers and various organizations in Washington about IOC and the way media deal with reports of violence, which they attribute to untreated mental illness. There are people in this room involved in a discussion group that talks about the impact of IOC and how they too are

concerned about violence. Nobody wants people, with or without mental illness, to be walking the streets and harming others.

Our work is not about having killers on the loose, it's about being able to accord people the rights and privileges they ought to have. Michael Allen, with the consumer/survivor group, has developed consensus statements, and we are sharing them with various organizations and seeing what they have to say about IOC and consumer principles. We're finding that many organizations look at the statements and say, We can buy into that. We're doing this so that, as the push for coercion and IOC laws continues, we're able to rely on a broad array of allies in Washington and locally to combat it.

Tammy Seltzer has started a listserv called "stop IOC" <u>stop_ioc@egroups.com</u> that has factual information so that local advocates can draw on that resource and make their arguments locally.

Third, we have on our Web site a state-by-state analysis of IOC laws. The next phase is to analyze what's going on at the ground level: the meaning of those laws. Some laws are like a Catch-22, where it's unclear what you're supposed to do to reverse that order, if you're admitted as an inpatient because you're a danger to self or others.

[Bazelon has been active on the] Joint Commission on Accreditation of Healthcare Organizations (JCAHO) Task Force with J. Rock Johnson, pushing the Joint Commission to adopt rules consistent with what the Health Care Financing Administration put out around seclusion and restraints. We fought valiantly, but we're not happy with the outcome. Our position is, if you feel an individual needs seclusion and restraint, call a doctor. But the provider organizations say, what if the facility if 50 miles from Topeka at 2 a.m. in the snow, how can we get a doctor in here? We say, let's stop talking about these ridiculous situations. Some public psychiatric hospitals have become seclusion-and-restraint-free. If they can do it, why can't you?

The third big issue is criminalization; the way that people are being incarcerated because of non-violent crimes, crimes of survival, where people are trying to live in the streets because the services and supports that were promised are not there, as a result of neglect by the systems that are supposed to serve them.

The vision of deinstitutionalization was supposed to be a vision of opportunity, inclusion and self-sufficiency for people with mental disabilities. That takes work and money. Bazelon found that, if you look back to 1955, when states were operating big institutions, and you correct for inflation, they're spending fewer dollars now than then. So we can see that the promise that the money will follow the patients was not fulfilled.