Dr Ken Zucker is the Head of the Gender Identity Clinic for children and adolescents at the Centre for Addiction and Mental Health in Toronto, and Professor in the Department of Psychiatry at the University of Toronto. His clinical and research interests pertain to psychosexual differentiation and its disorders. He was the Chair of the DSM-5 Work Group on Sexual and Gender Identity Disorders. He previously served as a committee member for the DSM-III-R, DSM-IV, and DSM-IV-TR. Since 2002, he has been Editor of the Archives of Sexual Behavior and is a Past President of the International Academy of Sex Research.

In this interview, Robbie Duschinsky questions Zucker about dilemmas encountered by the Sexual and Gender Identity Disorders Work Group. We hear about the process through which the three sub-Work Groups (Gender Identity Disorders; Sexual Dysfunctions; and Paraphilias) dealt with the dilemmas they faced. Zucker is also asked about the role of the consent and distress/impairment criteria for the diagnostic categories which appeared in DSM-5. The interview raises issues around the positions of sexuality and psychology in contemporary society.

**Robbie Duschinsky**

**How did you find the process of being Chair of the Sexual and Gender Identity Disorders Work Group?**

**Ken Zucker**

I first was part of the DSM-III-R subcommittee on Gender Identity Disorder of Childhood and Transsexualism. That was my first involvement with the DSM in the mid-1980s. And then I was part of the subcommittee on Gender Identity Disorders for DSM-IV and then I was responsible for making any text changes for Gender Identity Disorder in the DSM-IV-TR. So the DSM had been part of my life for a long time. When I heard that the DSM-5 was in the works, my fantasy was that I would be nominated to be the Chair of the Gender Identity Disorders sub-Work Group and, in fact, that was the initial offer because a psychiatrist by the name of Steve Levine had been nominated to be the Chair of the entire Sexual and Gender Identity Disorders Work Group. And so he had floated a preliminary offer to me which I said I was interested in – but before that was vetted it turned out that Steve was deemed ineligible to be the Chair of the Work Group because he was receiving a small amount of money from the pharmaceutical industry that he was using in his private practice clinic to support staff, thus not pocketing it himself. Nonetheless, that was deemed to be in conflict with the financial conflict of interest guidelines that the APA had developed. This was unfortunate. So then I was approached to be the Chair of the entire work group – and certainly I’ve never received a penny from the pharmaceutical industry; and, for better for worse, my nomination was approved and
I became the Chair. So it turned out that I was being asked to do something much broader than I had originally thought I might be involved with in the DSM-5.

So the first element of the process was for me to assemble essentially three sub-Work Groups: one on Gender Identity Disorders, one on Sexual Dysfunctions, and one on the Paraphilias. It was limited in how many people could be part of each work group just in terms of financial considerations. So it turned out there were four people on each of the three work groups. So in total there were 13 of us, along with the various advisers that we also nominated. But it was this core group of 13 that did the vast majority of the work.

So, with regard to how did I find the process, well I found it quite intellectually enjoyable and extremely stimulating. Over the floor of my home office, I still have piles and piles of files and notebooks and articles that I still have not packed away. When I think about all of that and the thousands upon thousands of email exchanges that took place, I look back on the process and reflect on how much work and time it actually took. It really, I think, was the most intensive work of any DSM edition, without a doubt.

Continuing with the process, it was complex in other respects. So, for example, I knew that the diagnosis of Gender Identity Disorder was likely to generate a lot of comment because there certainly is a constituency of both professionals and consumers who more or less have never been happy about the diagnosis being in the DSM. But until the DSM-5 Task Force was assembled, there was no real concrete opportunity to lobby for its deletion and certainly there was a very strong lobby that combined various criticisms: a little bit of scientific criticism, a little bit of clinical criticism, and a lot of political criticism. And I was certainly the target of a lot of personal criticism. I received a few death threats via email which I basically just ignored and deleted. There were online petitions that I should be removed as the Chair of the Sexual and Gender Identity Disorders Work Group. Another member of the group, Ray Blanchard, also had a petition saying that he should be removed.

When I think about all of the personal criticisms, the most favourite one was that one transgendered activist accused me of being a draft dodger from the United States during the Vietnam War and that I fled to Canada and was hiding out here. That wasn’t true. I’m in Canada, on a voluntary basis, and I never was drafted to serve in the US Army because I had a college deferment at the time.

Robbie Duschinsky
I'd be interested to hear about any conflicts you experienced in your role as Chair.

Ken Zucker
I'll start with the sexual dysfunctions and I would say that the conflicts that may have evolved over time with regard to the sexual dysfunctions were primarily scientific and perhaps divergent in clinical opinion. But by and large there wasn’t a lot of conflict in
the work of the sexual dysfunctions group. I would say that the most controversial element of that work group was the proposal for women to merge Hypoactive Sexual Desire Disorder and Female Sexual Arousal Disorder into one overarching category which is now called Sexual Interest/Arousal Disorder. I think that there was some external criticism that this merger of arousal and desire was premature but there were also good counter arguments. But I think that was the proposal that received the most criticism and therefore more internal discussion.

Robbie Duschinsky

*Just in order to give a flavour of these things, how was that ultimately decided? Was it four people in a room making a decision, was it a batch of emails going backwards and forwards? Were you involved?*

Ken Zucker

Well, I was always involved. I think it was more than four people because first of all we had a whole string of advisers, including those who were assigned the task of reviewing that particular proposal. And we certainly had support from them.

And then, in addition to all of those emails I mentioned, we had lots of conference calls through the process and there was usually a higher up on the DSM-5 Task Force listening in on these conferences, and then the Work Group would meet face to face twice a year in Washington DC and occasionally we had additional meetings if we could append them to a conference that all of us were attending, that was also face to face. So we were getting feedback along the way from the higher ups about the merit of, let’s say, this particular proposal. And then, of course, it had to get feedback from the Scientific Review committee and so on and so forth. So it went through the various hoops successfully and then ultimately it was up to the Board of Trustees of the APA to accept the proposal or not.

Robbie Duschinsky

*We’ll come back to the Board of Trustees.*

Ken Zucker

So I’m going to continue detailing the conflicts. We’ll talk next about the paraphilias. In the paraphilias sub-Work Group, there was more conflict with regard to two diagnoses: one was the proposal to add a new diagnosis to the new DSM-5 called Hypersexual Disorder, which was argued primarily by one member of the paraphilias sub-Work Group, Martin Kafka. The proposal was not for Hypersexual Disorder to be a paraphilia per se but actually the proposal was that it should become one of the sexual dysfunctions. Or at the end that it should be in an appendix for further study.

Hypersexual Disorder received lots and lots of attention in the media and by professionals because it certainly – at least, I would say, in the United States, the concept of hypersexual disorder or compulsive sexual behaviour or sexual addiction
Ken Zucker

has received an enormous amount of attention and there are many private clinics in the United States that treat people with so called ‘sexual addictions’. We took a theoretically neutral position: should this be considered a compulsion or an addiction by using in a sense a neutral proposed label Hypersexual Disorder. If so, then we should try to put into writing what the core phenomenology was, and try to come up with relevant data that would support its inclusion at least in the appendix for further study. People had been writing about this and treating patients for several decades now. Yet, there really has been no formal diagnostic place for this condition. In the end, the proposal was not approved – so it did not meet the final cut, so to speak. I thought it deserved to be in the appendix, but clearly the Board of Trustees did not.

And then the second paraphilic diagnosis that received a lot of attention was paedophilia. And here, the main proposed change was to make the diagnostic criteria more precise with regard to the age and pubertal status of the offender’s victims. If one reads the way it’s written in the DSM-IV, it talks about how a man in essence has an erotic preference or a preferred erotic attraction for prepubertal children, generally 13 years of age or younger. And the problem with that is there are many children under the age of 13 who are not prepubertal. They’re in the early stages of puberty: the Tanner Stage 2 or the Tanner Stage 3. So the proposal was initially to have these subtypes: the classic paedophilia subtype of an erotic preference for a truly prepubertal child, a Tanner Stage 1; a second subtype, which was termed haebophilia, which would have been an erotic preference for a child at Tanner Stage 2 or 3; and then a combined type.

At one point along the way, there was a lot of external discomfort about the term haebophilia which I found sort of amusing because the DSM uses a lot of terms that have Greek origins. In the end, the final proposal was to refer to these subtypes with regard to Tanner stages. So the classic paedophilia subtype for prepubertal children was simply referred to in relation to Tanner Stage 1; a second subtype specified Tanner Stage 2 to 3; and a third one a combined type. What I found completely surprising at the end of the process was that the Board of Trustees did not approve this proposed change and therefore in the DSM-5 the diagnostic criteria for paedophilia are identical to what they were in the DSM-IV. And of all of the things that happened, this was the most surprising outcome because I did not think that this proposal would be rejected. I thought it was based on a lot of very solid empirical evidence. In my view, the decision to reject the proposal was certainly not based on scientific grounds but with regard to some other issues, political or otherwise. Now I think I know why the proposal was rejected but I can’t talk about it because of the confidentiality agreement.

Robbie Duschinsky

When you introduced paedophilia just now you said “the main proposed change was to make the diagnostic criteria more precise in relation to the age and pubertal status of the offender’s victims”. The term offender situates this in relation to a forensic context. The forensic demand for changes to
Ken Zucker

classifications is perhaps something distinct from a clinical demand and perhaps again is a different thing to a scientific demand. Do you have any reflections on that?

Ken Zucker

Well, the DSM is a diagnostic manual that one hopes is based in part on the science of diagnosis, the science of phenomenology. It’s not a legal document; in fact, there is a disclaimer at the beginning of the manual that makes reference to that. And so the question that you’re asking is: Should the tail be wagging the dog or should the dog be wagging the tail? Yes, one has to think about forensic considerations and all diagnoses have the potential for misuse but, in my view, that would be a separate issue and not a scientific issue.

And I think that, of course, one of the issues that one could raise here is conflict of interest. So, for example, suppose you wanted to have somebody on the Work Group who is a forensic psychiatrist who happens to make tens of thousands of dollars testifying for the prosecution. Or testifying for the defence. In both cases, you would have a conflict of interest. We didn’t have that among members of our sub-Work Group. If we were starting over based on what happened, what I would certainly suggest is that—because the DSM-5 Task Force did, in fact, seek input from people with an interest in forensic issues, not just for the paraphilias but also for other diagnoses – that they should have been involved much earlier in the process so that potential forensic implications could have been discussed on a more systematic basis. And to also get a whole range of opinion about that.

In the United States, for example, one of the big issues are the so called ‘sexually violent predators’ statutes. One of the issues has been the whole idea that somebody can serve a sentence but if they’re deemed still dangerous, you can keep them in prison indefinitely. And so somebody might say, “Well, maybe your changes to the diagnostic criteria for paedophilia, by including males with an erotic preference for early pubertal children is going to result in them being detained indefinitely because now they have a clear diagnosis”. I personally think that argument is nonsense because 1) the prosecutor could say, “Well, maybe this person doesn’t have paedophilia but he has a paraphilia not otherwise specified in the DSM-IV.” And 2) courts in the US have ruled that there are differences in legal and psychiatric criteria in what constitutes a mental disorder. And some courts have ruled you don’t even need to have a DSM diagnosis to make the argument for retaining indefinitely somebody who is deemed very high risk to reoffend. So I think that whole issue was not handled very well and that that type of criticism came externally and it was a very political one, not a scientific one.

Robbie Duschinsky

You were saying about conflicts in relation to the third of your sub groups?

Ken Zucker
Right. So then with regard to the Gender Identity Disorder Work Group, in a way the overarching issue was should GID be in or out of the DSM-5? At the end of the day, the Work Group unanimously supported its retention in the DSM. I can’t tell you why each member came to that decision although if you read Jack Drescher’s literature review that’s in the Archives (Drescher, 2010), you can see why he supported its retention because he was public about it. For him, this was an argument primarily about access to care outweighing any other considerations. But the group certainly debated the pros and cons of retention and deletion. And certainly I’ve spoken publicly about some of the arguments and opinions that I have about the arguments.

So we renamed the diagnosis from Gender Identity Disorder to Gender Dysphoria. Gender Dysphoria was actually the second term proposed as an alternative to Gender Identity Disorder. One reason we moved away from the GID label was that some people didn’t like the fact that the word ‘disorder’ was in the name of the diagnosis because it was viewed as stigmatising. Now, on that point, I have mixed feelings because it is in a manual that ends with ‘of mental disorders.’ So you can’t sugar coat that. Now there are some diagnoses in the DSM, like anorexia nervosa where the word ‘disorder’ isn’t in the name – and encopresis and enuresis, for example. But I think a conceptual criticism is “What you’re really diagnosing is not gender identity per se but gender dysphoria, which is the disjunction between one’s felt gender and somatic sex.” And in that respect I like the term Gender Dysphoria because it is capturing phenomenology. A patient comes to see you and they say they’re in distress about a mismatch between their felt gender and their biological sex. We had initially proposed Gender Incongruence which is a very old term that John Money and Richard Green coined in 1960. But the feedback we got on that was that it was too vague and it could potentially be misinterpreted.

So the argument...as an example, some people have said, “It shouldn’t be a psychiatric diagnosis, it should be a medical condition; a non-psychiatric medical condition.” And the problem is: what is that medical condition? And to date I don’t think that there’s any evidence that it’s a non-medical psychiatric condition. There’s no evidence, for example, that there’s any gross hormonal abnormality from which one could therefore conclude it’s an endocrine condition, etc.

Robbie Duschinsky

When you were describing why Gender Dysphoria can be considered a mental disorder, you emphasise suffering. I’d be interested to pursue that just a little bit further. Can you say a little more about the role of the distress criterion in the thinking of your Work Group more generally? We suffer for all kinds of reasons: what makes this a marker of a psychological disorder? And you might think about Gender Dysphoria as the case for thinking this through.

Ken Zucker
That’s a great question and it immediately links up to the long standing discourse on what is a mental disorder. On that point, although the DSM provides its own definition, there remains a lot of philosophical debate as to what is or is not a mental disorder. And somebody like Jack Drescher would argue that deciding back in 1980 that transsexualism or Gender Identity Disorder of childhood were mental disorders was arguably not based on any evidence that they met the criteria for a mental disorder. But if you have patients coming to see mental health professionals and you have a diagnostic manual that only is considering psychiatric diagnoses, there’s no alternative. And if you don’t have a diagnosis then you don’t have access to care.

I know that for the ICD-11, which is now slated for publication in 2017 there’s a proposal to move all of the diagnoses in the DSM that were part of my Work Group, I think, to a new section called Sexual Health. So it would take them out of the mental disorder chapter of the ICD into a new chapter. And presumably if that happens, all of these conditions will still be covered. But I think the sexual dysfunctions and Gender Dysphoria certainly push the margins of what are considered mental disorders. So is premature ejaculation or what we’re now calling Premature (Early) Ejaculation...yes, it’s a sexual dysfunction if defined in a certain way but is it a mental disorder in the same way that schizophrenia is? The DSM includes an incredibly wide range of diagnostic categories and there is an ongoing debate about the extent to which they all easily map on to a person’s sense of what is a mental disorder or a mental illness.

Robbie Duschinsky
You were thinking about Gender Dysphoria, and considering whether it should be in or out of DSM-5. What role did the distress criterion play in your thinking?

Ken Zucker
Well, that requires a bit of a longer answer. So for DSM-III, Spitzer introduced a definition of mental disorder which included distress. And then in the DSM-IV, the APA introduced the so called Distress/Impairment criterion for almost all of the diagnoses in the DSM-IV so it became a boilerplate parameter. So you could meet the criteria for diagnosis A in terms of phenomenology but if you did not have distress impairment, in theory you don’t get the diagnosis.

At some point during the DSM-5 process, there was debate in the Task Force about whether or not the distress/impairment criterion should actually be removed from the diagnostic criteria and evaluated as a separate dimension. So if somebody met criteria for a diagnosis yet did not show distress or impairment then maybe there wouldn’t be much of a need for treatment. And so that could be evaluated separately. And we were certainly interested in that with regard to gender dysphoria. There are certain problems with that proposal but in favour of it, I mean if you think about medical conditions, suppose I have a wart on my nose but I’m not distressed by it: Does that mean I don’t have a wart? No, it’s ridiculous. I have a wart but
whether or not I want it treated depends on whether it bothers me and you could say that’s true for a lot of medical conditions. Or you could say it’s true for all medical conditions, you either have it or you don’t. The need for treatment or the extent to which you’re distressed by it could be evaluated separately.

But it is a very tricky issue. So for example: we know from epidemiological studies that the prevalence of women who don’t have sexual desire for a long period of time is pretty high but the prevalence drops substantially if you only include women who are distressed by it. So there one would say, “We really need that distress criteria or we’re going to be diagnosing a large number of women” and that gets into a whole range of other issues e.g. Why are all these women not distressed by not having sexual desire? Overall, the DSM-5 Task Force came to the opinion that it would be perhaps too risky to remove the distress impairment criterion at this point in time.

And so the distress/impairment criterion was preserved for the Gender Dysphoria diagnosis. Now, from a developmental perspective, the measurement of distress for people with a diagnosis of Gender Dysphoria is complicated, especially for children. Let’s say you see a 16 year old who comes in saying “I really feel more like a guy, having my period and having my breasts, not having facial hair, completely does not line up with how I feel about myself psychologically.” And a large number of kids are very distressed by this disjunction. Certainly in my clinic we see a lot of kids who self harm, make parasuicidal attempts. So I think with adolescents and adults, for a lot of folks, the distress is fairly palpable. Although the push back on that has been, “What really is the source of the distress? Is it stigma, is it rejection by family or friends?” And so one can ask the question, “If transgendered youth and adults were growing up in a completely supportive, non-discriminating environment, would there be any distress?” And I don’t think we’ve actually studied that very well. My own clinical impression is that there would still be distress about the mismatch between how one feels psychologically and the body one has.

**Robbie Duschinsky**

It’s distress about the mismatch which, for you, makes Gender Dysphoria a mental disorder?

Ken Zucker

Yes.

**Robbie Duschinsky**

And this could be a case even if this is distress were primarily, although perhaps not entirely, caused by sociological factors such as discrimination and rejection?

Ken Zucker

I’m now turning to the relevant page of the DSM-5 where it says ‘the condition is associated with clinically significant distress or impairment in social, occupational or
other important areas of functioning.’ So it’s a little vague about the source of the clinically significant distress. And so I think that gives people latitude in making a judgement about that. Personally, I think that the distress/impairment criterion has never been well studied when it comes to Gender Dysphoria or its predecessors. We need actually to do more work on that.

My own bias is I’m not sure how much attention it’s given in other areas. In some cases, it’s so obvious you don’t even think about it. But I imagine the average clinician simply reflects on whether somebody is in need of treatment. And presumably they’re basing that on how distressed or impaired somebody is by something.

**Robbie Duschinsky**

To zoom out slightly from these considerations we’ve been having, I’ve got a broader question, which is what role do you think that changing societal values have played in shaping the Sexual and Gender Identity Disorders in DSM-5?

**Ken Zucker**

I have to think about that. If I think about the Sexual Dysfunctions, one meta-issue has certainly been to what extent do we pathologise everyday problems in sexual life by classifying these as sexual dysfunctions. Other than eliminating one sexual dysfunction diagnosis, Sexual Aversion Disorder, because nobody’s studied it in decades, there certainly seems to be a stable population of people who come to mental health therapists for support around sexual problems and I think diagnostic categories have heuristic value and clinical utility value. Perhaps the major change would have been if Hypersexual Disorder was added to the mix but it didn’t go in that direction. So if you have low sexual desire, it’s a problem but if you have too much it’s not a problem.

I know that people who self-identify as asexual were worried that we were going to pathologise them in the DSM-5. Because, in fact, a lot of those folk would probably meet the criteria for Hypoactive Sexual Desire Disorder in males or the emergent category in females. But I think these are a very different group of people, who don’t go to sex therapists, for example, and they say they’re not distressed or impaired by being asexual. Therefore, we wouldn’t be interested in diagnosing them. So I could say that the emergence of asexuality as a possible sexual orientation or a new identity category was something we did think about. And nobody in the Sexual Dysfunction sub-Work Group or I had a particular interest in pathologising people where the evidence was unclear if it was warranted. But I think people who self-identify as asexual really are a different group just in terms of demographics than those who typically seek out sex therapists and the like.

Let’s say a person who self-identifies as asexual is seeking mental health treatment for some other issue, such as depression. And the clinician is talking with them about
their sexual life and the clinician says, “Oh, you know, this guy seems to have hypoactive sexual desire disorder, as he has absolutely no interest in sex but it doesn’t bother him. So I shouldn’t give him that diagnosis.” So in that sense I think it’s an important constraint of not pathologising something. That doesn’t mean one can’t be curious about why somebody has no sexual desire but it’s really a function of whether or not the individual feels the need to understand that better.

**Robbie Duschinsky**

What you say, however, would imply that the sexual dysfunction and the paraphilias are mental disorders on rather different levels or in different ways. Because the entry points of being a disorder for the sexual dysfunctions, from what you say, a core part of that would be self referral. By contrast, a paraphilia would be a mental disorder indelibly in part because of its forensic context.

**Ken Zucker**

Yes. Of course, the sexual dysfunctions have been studied quite extensively epidemiologically in the post Viagra era and also in sex survey studies in the AIDS era to resolve the sudden need to know much more about sexual behaviour. But there could be, let’s say, a man with paedophilia who seeks mental health attention not because he has committed a crime but because he’s distressed by having a sexual attraction to children and wants help in dealing with it. But I think you’re right that the majority of patients with certain paraphilias are because they’re also against the law and they get caught.

Now, to continue with our discussion of conflicts about the paraphilias, certainly there was a group of clinicians who felt that all of the paraphilias in a sense should be deleted from the DSM. The ones that are illegal, just keep them as crimes but why add on the excess baggage of calling them mental disorders. And then the ones that are legal, why pathologise them at all? What we did, which I think might be classified as progressive, is we made a distinction between paraphilias and paraphilic disorders. And that was approved and made it into the DSM-5. So we talk about ascertaining a paraphilia based on phenomenology versus diagnosing a paraphilic disorder based on distress and/or impairment. A good example of that are people who practise consensual S&M or BMD. And we’re basically saying if it’s consensual and it doesn’t cause you distress and/or impairment then you should not be diagnosed with a paraphilic disorder.

There is a group in the United States – one of the leaders is a woman named Susan Wright. That group is very happy about this distinction between paraphilias and paraphilic disorders. There have already been court cases around child custody where judges are saying, “Well, if the mother practises S&M but she is not distressed or impaired by it, she doesn’t have a mental disorder.” Susan Wright has a commentary in the October 2014 issue of the *Archives of Sexual Behavior* this year that talks about that development. So going back to your societal values question, I
think that we have partly de-pathologised atypical sexual interest by using distress and/or impairment as a demarcation point; and that’s particularly relevant I think for the paraphilias that are not considered against the law.

Now with regard to Gender Dysphoria, I think that the results of the sub-Work Group were certainly influenced by various criticisms of the diagnosis and I think we did a good job in fine-tuning it, trying to better label what the core phenomenology is, making the diagnostic criteria more precise. But I think it’s a good example of the ongoing debate on what is the boundary of a mental disorder. And it gets into non-scientific issues where there’ll be ongoing discussion about this. But certainly some of the input we received asked: “Well, if it’s not a diagnosis in the DSM, why would any insurance company pay for its treatment, including surgery?”

**Robbie Duschinsky**

*Was that a significant consideration for the work group and for yourself?*

**Ken Zucker**

Well, it was a consideration that Jack Drescher explicitly talked about in his review paper and I don’t think anybody on the sub-Work Group argued against that consideration. Whether access to care should be the only consideration in whether or not something should be considered a psychiatric diagnosis is a very complicated one. But one of the issues that we had to address was: will there be unintended consequences if we do X rather than Y? So a potential unintended consequence would be if there wasn’t a diagnosis of Gender Dysphoria in the DSM-5, would insurance companies all of a sudden say, “Well, we’re not paying for this treatment anymore.” But because we didn’t go that route we don’t know the answer to that question.

**Robbie Duschinsky**

*I’d like to push a bit on this. You’ve raised this issue of insurance services that are available to people who are experiencing distress. It would be good to know whether that was actually the determinative consideration in having Gender Dysphoria in rather than out of the DSM, in treating it as a mental disorder. From what you’ve said, you’ve implied that yes, it was on the table, but it wasn’t so determinative. I’d be interested to hear what you think was the determinative factor, at least in your thinking if you don’t want to speak for the Work Group as a whole.*

**Ken Zucker**

In some respects Gender Dysphoria is a good example of something that truly borders the mind-body division. So because one could argue, it’s a “disorder of the body as much as a disorder of the mind”, maybe it should be in a separate category of its own, so it would have some special status. That was something Heino Meyer-Bahlburg talked a lot about in his review (Meyer-Bahlburg, 2010). That didn’t go very far, I think, at the APA Task Force level at the top; I don’t think it was going to get
special treatment. For example, premenstrual dysphoric disorder is now an official mood disorder in the DSM-5. One could ask, “Well, why isn’t it an endocrine condition where one of the symptoms is depressed mood?” It’s the same dilemma.

I think another consideration was placement options. So we said, “Well, you know, maybe in the DSM-5, we should put Gender Dysphoria in the so called V code section,” which in the DSM-5 is called ‘Other conditions that may be a focus of clinical attention.’ So they’re not considered mental disorders per se. But that also had relevance to access to care because insurance companies don’t reimburse for V codes. So that argument was rejected.

If I think about it myself, and this is my own personal opinion, one reason that I was in favour of retention is that I do think that people who present with the “symptoms” of Gender Dysphoria do experience distress and suffering. And it is a syndrome, it consists of a set of signs and symptoms clustered together which I think is different from other types of distress. And by including it, it makes it easier for people to receive help if they want it. And I certainly myself feel that if you don’t feel you need help then you don’t need to come to see a mental health clinician.

Robbie Duschinsky
So on the basis of research indicating you have a syndrome you conclude that it is a relevant clinical phenomenon, on the condition that the person is experiencing distress?

Ken Zucker
Yes. Sometimes when I talk to graduate students about how did all of these diagnoses make it into the DSM, starting with the DSM-I in 1952, I think it’s based in large part on what is out there in the world; it’s phenomenology. What is it that people are experiencing that will lead them to seek the care of mental health clinicians?

Robbie Duschinsky
Or get arrested.

Ken Zucker
Yes. DSM-III in 1980 had a boom in the number of mental health disorders. I think one of Spitzer’s standards was: if this is something that people are seeing clinically, and that you can demonstrate that you have a set of signs and symptoms that form a coherent syndrome, then you have a foot in the door. Whether or not it will meet other standards is then the issue.

Robbie Duschinsky
Looking back on it, what do you think you’ve learnt about the position of sexuality or the position of psychology in society, from being involved in the Work Group?
Ken Zucker

Well, one thing I’ve thought about over the years is that the diagnostic categories that were the responsibility of the Work Group have always been on the border of mainstream psychiatry. They’re not bread and butter diagnoses; in a sense, they’ve been outlaw diagnoses, but there have always been a small number of clinicians and researchers, perhaps increasing, who are interested in these diagnostic categories and may turn out to be the specialists to think about these diagnoses and how to best help people who are struggling with them.

As a sidebar example to that, for a couple of the sexual dysfunctions, we had proposed that the diagnosis Sexual Aversion Disorder, which has been deleted, be moved over to the Anxiety Disorders chapter and be considered a type of phobia. So it’s really more of an anxiety disorder, not a sexual dysfunction. The Anxiety Disorders Work Group was not interested: “It’s not our kind of thing.” And we had proposed that, for example, dyspareunia (which got merged with vaginismus into ‘Genito-Pelvic Pain/Penetration Disorder or GPPPD) was a pain disorder as was vaginismus, and so maybe the Somatic Disorders Work Group should take it on. But they weren’t interested. And so at the end of the day, clinical utility turned out to be an important parameter. Sex therapists are the folks who are most likely going to see these patients and so keeping them in the sexual dysfunctions chapter had clinical utility. So going back to the question, I think that both sex and gender matter, that’s what I’ve learned.

Robbie Duschinsky

Say more...

Ken Zucker

I think that how things have evolved in the postmodern world is that for some people when they’re struggling with their sexuality, they turn to mental health professionals for advice. And so in some respects being an expert in the area of sex and gender confers a legitimacy to people’s worries and anxieties as they would in any other domain of modern life. That’s the best I can do for you right now.

Robbie Duschinsky

A final question: what do you think is going to happen from here, in relation to the Sexual and Gender Identity Disorders?

Ken Zucker

Well, you know one reason that the DSM-5 went to Arabic from Roman Numeral was the idea that necessary changes to the DSM-5 should take place as new data warrant changes so the idea is maybe there’ll be a DSM 5.1. And then a DSM 5.2 where changes to specific categories can be made because there are new data that
clearly warrant it. Or maybe we have now biomarkers that need to be added to specific diagnostic categories.

I do not think that there will ever be an overarching revision for the entire DSM because I think things have just become way, way too complicated and it would take way, way too long to have a repeat for a DSM-6. I have no idea whether there’s anything in the works for a DSM 5.1, I certainly haven’t heard anything. But I think this process was a very expensive process, it was a huge, huge undertaking and I referred earlier to the sheer amount of work involved between reviews, conference calls, face to face meetings, e-mail, external committees that one had to submit one’s proposal to. I think about my involvement with DSM-III-R which basically was a one day meeting in New York City and prior to that I wrote on a typewriter a one and a half page letter to Spitzer, making a suggested change for Gender Identity Disorder of Childhood and my proposals were accepted. It’s become way, way more complex and complicated. So we don’t know what’s going to happen post DSM-5. I think the next interesting formal development will be what ICD-11 does in 2017.

**Robbie Duschinsky**

**And what about informal developments?**

**Ken Zucker**

Well, the only concrete development that I can think of in the last year or so, as I say, is certainly that more insurance companies are authorising sex reassignment surgery for adults. And I’m presuming that they’re authorising it because there’s a diagnosis. Certainly, if I look at papers that are coming out in peer-review journals, people are already using the diagnostic term Gender Dysphoria, so I think people have accepted it as a new diagnostic term but I think it’s still too early to see how things are going to roll out over the next number of years.