



What to do when a diagnosis doesn't fit?

by Amy Druker

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Abstract

This article will explore 'the politics of naming problems'. Who should have the right to name the problems that we face? I will share from my work with a 17 year old, K who, despite really wanting a diagnosis, determined that the one selected for her was not a fit, and how we went about re-writing the 'diagnosis' to one that she felt suited her much better. Narrative therapists are interested in the meaning a person makes of a diagnosis. What about the label fits or does not fit? These questions demonstrate our belief in a person's expertise about their lives. In the asking, we hand over the 'authority' to the person consulting us to decide if a label fits, and if it does not, to choose a name for the problem that does. 'Therapy' becomes a collaborative exploration, in which the person's expertise about their own life is sought and valued.

Key words: naming rights, re-writing diagnosis, DSM, de-pathologising, externalising



Artwork: K

Foucault suggests that the real political task facing our society is to criticise the workings of institutions, especially those institutions that appear to be both neutral and independent. (Besley, 2001, p. 73)

Michael White and David Epston, who originated narrative therapy, were influenced by Foucault's ideas about the 'inseparability' of power and knowledge, and how 'the 'truths' of traditional notions of knowledge position one form of knowledge in ascendancy over another' (Besley, 2001, p. 77). Narrative therapists recognise that these claims to 'truth' can render other explanations, or other ways of being in the world, invalid – pathological even. Concepts like 'pathology' and 'normal' are seen as social constructs derived from those beliefs and values that prevail in a particular context, determined by those who have the authority to 'name' these things as such.

It was art that gave K and I an opening to speak about her hopes for a psychiatric diagnosis. I met K in our Walk-In

Counselling Service a couple of months before we began meeting regularly, about six months before sitting down to write this. Through conversations with K, she came to name the two problems that brought her to Oolagen as 'The Warming thoughts' (WTs) and the 'Angst, Angst, Angst', which later became known as Angst³.

Often times when a person comes to consult with us, they start out using a name that someone else put to the problem. Narrative therapists invite the person to name for herself the problem or problems that she is facing. By inviting the person to name problems in her own words, is to deliberately and, 'from the earliest possible moment ... assist the person to regain her sense of control over her life ... To name is to regain a little control; naming is taking the initiative, imposing a chosen identification on something' (Payne, 2006, p. 42.). By handing over the 'naming rights' to the person consulting us, 'therapy' becomes a collaborative exploration, in which the person's knowledge of her own life and that which she is facing, is valued. It is important to note, that if a person

tells us that a 'clinical sounding' name (or one that we might consider pathologising) for the problem actually fits with her experience of the problem, this is the name that we will use. In this case, we might ask questions like: 'What about this name fits or doesn't fit?' In the asking, we hand over the 'authority' to the person consulting us to decide if a label fits, and if it does not, to choose a name for the problem that does.

K described the effects of both of the WTs and the Angst³, and reflected that, of the two, the effects of the WTs were the more troublesome, exhausting and at times were capable of 'frightening the hell out of her'. K described how the WTs would 'push themselves in, digging; they're always there, sort of yelling at me, they won't leave me alone ... they're constantly judging me.' K spoke about how the WTs at times tried to recruit her into a belief that certain people and felines (namely her cat, Link, whom she adores) were capable of reading 'each and every one' of her thoughts. K explained how the WTs had even tried to convince her that certain people and Link were trying to hurt her, and that the only way to get to the bottom of it involved hurting these people, Link and herself.

K talked about how, with the help of her 'Reigning Myself In Skills', her 'Getting Out Skills' and her 'Super Human Abilities for Self-Reflection', she had managed to keep the WTs 'from crossing that line', but described this effort as 'exhausting, frustrating and really unpleasant.' We traced the history of these skills and abilities in K's life, and what they made possible now, and what they might make possible in her future. For example, K's 'Super Human Abilities for Self Reflection' have made it possible for her to 'reflect on what is right and what is wrong. It's removed any possibility of being self-entitled, being a martyr or believing in my own victimhood ... It's enabled me to connect the dots and this has helped me to repair myself'. K's 'Reigning Herself in Skills' and 'Getting out Skills' have helped her to 'keep the WTs pretty tame', without which she reckoned 'I'd be screwed royally. I probably wouldn't be here right now.' This realisation was important to K because she came to see herself as 'Super Humanly' able, on account of all that she faced in battling the WTs, as opposed to seeing herself as disabled by them.

Being an artist, K often brought along a sketch book and worked on her drawings in the reception area at Oolagen before we met, and sometimes continued to draw during our conversations. One day, K shared some of her work with me. A drawing entitled: 'You Can't Fix Me' brought to light K's desire 'not to wade around in the dark' and her 'hell-bent' intention to better understand what she might be facing both in the short term and in the future. In other words, it made visible K's consideration of seeking a psychiatric diagnosis. K reflected on how a diagnosis might make a difference in her life: 'Not having a diagnosis feels like a backwards step

and keeps me from moving forward ... I'm not a fan of feeling around in the dark. I need to know if this will be around my whole life, and how I'm going to combat it.' K mentioned that another thing that motivated her to consult a psychiatrist was her sense of how the WTs and the Angst³ were impacting on others: 'I don't like how much my uncle has aged, and I don't like that my cat wouldn't come near me because I scared him. Once your behaviour starts to impact others negatively, your right to choose (not to seek help) should be eliminated.' This opened up a conversation about the history of her value of 'not seeing people suffer', which K referred to as one of her 'core beliefs'.

K had some ideas about what a diagnosis might make possible for her, but she also expressed some reluctance about it because of her past mostly negative experiences with the mental health system. We spent a lot of time discussing the pros and cons of this decision, and eventually it was during a conversation that K reflected on how she would know that a psychiatric consult was something that she wanted to pursue, and she said: 'I would rather set myself on fire than experience another hospitalisation'. It was this revelation that ultimately led to K's decision to seek a psychiatric consult in the hopes of preventing a subsequent hospitalisation. Thus began our very careful exploration to find a psychiatrist who would be a good fit with K. Together we drafted the following email, which I sent out to a few prospective psychiatrists, in our pursuit of finding a person who was a good (or good enough) fit with K:

I am working with a young woman (age 16) and we have been discussing the pros and cons of seeking a psychiatric consult (we've been meeting since early December, once/week). She is aware and has given me permission to write this to you about her with the hope of finding a psychiatrist who might be the right fit.

About K: her mother took her own life when she was an infant, and she is being raised by her uncle. She would probably describe herself as unconventional, an out-of-the-box thinker, a rejecter of materialism in favour of making art (I believe she is an amazing artist). She is highly intelligent and has strong artistic abilities and self-reflection abilities.

She would probably would work well with someone who is maybe a bit unconventional and very respectful (obviously) of her own expertise and knowledge of herself and her experience of what she is facing. She's not a big believer in medication, but she is not strictly opposed either. She's had a couple of in-patient psychiatric experiences - not at all positive experiences.

It was a conversation, where K's hope and intension never to experience a subsequent hospitalisation

became known, that ultimately led her to make the decision to pursue a psychiatric consult. K has made a couple of suicide attempts and has experienced what she has named 'worming thoughts' that in the past tried to convince her to hurt her cat ... this was a terrifying experience for her. This happened about ten months ago and hasn't happened again since. She has figured out some really helpful ways of grounding herself when the worming thoughts creep back in, such as focusing on her sense of smell, taste, texture, etc.

I admire the thoughtfulness about which K is making this decision. She has expressed both reluctance about the prospect of a diagnosis, but also has reflected that understanding that which she is facing may make a big difference for her. When I asked her what would be important for a psychiatrist to know about her, she responded that it would be important that they know that she wants a concrete PLAN. She said that she would not want to be 'slapped with a diagnosis' without some kind of follow-up or treatment plan/options. She also thought it would be important that you know that she is being followed by Dr. L, but has not found this to be a good fit for her.

I hope this isn't too much information for you, but we feel it is very important to find the right fit for K in a psychiatrist. Looking forward to hearing from you. Please don't hesitate to call or email if you have any further questions and to let me know if you feel she may be a good fit with you as well.

After hearing back from two psychiatrists (who had been recommended to me by colleagues/friends) who were unable to see K, and a third psychiatrist whom K determined not to be the right fit, we settled on a children's mental health centre that could give us an appointment within two weeks. The initial meeting with the psychiatrist was about two hours long, and K detailed her history with the mental health system, the effects of the WTs and the Angst³ and her 'coping strategies'. At the end of the two hours, we were told that we would be contacted within six weeks for the psychiatric assessment. (We were both a little bit surprised that the two hour long meeting with the psychiatrist had not been the actual assessment). The assessment, we were told, would involve several people from various disciplines, including students of the various disciplines, some of whom would be observing from behind a two-way mirror. K expressed reluctance about this, but she agreed to go along with it because she really wanted to have the assessment done. We learned that the whole thing would happen over two three hour sessions. K would be given a series of psychiatric tests which involved both filling out questionnaires, interviews and an 'interpretation' of her art work.

Two months following the psychiatric assessment, K, her

uncle (by whom she has been raised since the age of two) and I were invited to meet with two of the students who had been involved in the assessment process (one from a Master of Social Work Program and a Psychology Intern). It was the students who provided K with the following diagnoses: Major Depressive Disorder, Generalized Anxiety Disorder and Borderline Personality Disorder (BPD) and the following treatment recommendations:

1. Abilify Medication
2. Dialectic Behaviour Therapy and
3. It was recommended that K's uncle attend a group for family members who are living with a person labeled with BPD. K made sense of it in the meeting (for her uncle): 'It's so you can talk to other people who have to live with a pain in the ass like me'.

The psychiatrist was not present at this meeting and the student interns were unable to walk us through the process of how the team selected the diagnoses for K, nor were they able to provide much information about the medication prescribed.

Returning to Oolagen after the meeting, more than a little bewildered by the BPD diagnosis, I went to consult with one of my colleagues with whom K had also consulted in our Walk-In Counselling Service. Her response to the BPD diagnosis was: 'Are you sure that they didn't get her paperwork mixed up with someone else's?' Everything that I knew about K had me questioning the fit of the BPD diagnosis. What was troubling about it for me was the careful and thoughtful process that K had undertaken to reach the decision to pursue a psychiatric assessment, and the time and energy that she spent actually participating in the assessment itself. I was concerned about what effect having this type of label might have on K (both in terms of how she experienced herself and in terms of how others might experience her), given how much stock she had put into the psychiatric consult. However, I knew (and my colleagues reminded me) that what mattered was the meaning that K made of the diagnoses. What about the diagnoses, if anything, was resonant with K's experience; and what, if anything, she found helpful, not helpful, both or neither?

K's response to the diagnoses when we were sitting in the room with the student and intern was: 'I guess it makes sense'. However, by the time we met the following week, K had had a chance to 'process the hell out of them (the diagnoses)' and when I checked in with her about her opinion of their opinion, her response was: 'First of all, I didn't need three diagnoses, I really just wanted one, and while I technically meet the criteria for it (BPD), it doesn't mean that I identify with it. I mean, I can fit into that box if I really cram myself in there, but I'll only last for about a minute.' K said

that while ‘they (the people involved in the assessment) were really nice, they didn’t get it on the mark’.

K walked me through her process of coming to this conclusion about their opinion. ‘I’ve processed the hell out of this... I did my research (read scholarly articles, stuff on the Mayo Clinic’s website, went on psych forums for the adult’s perspective and went on Tumblr for the young adult’s perspective). I’m very thorough ... I’m not the type of person to do things half-assed if it’s important to me. I weighed each thing that I read, compared all the stories and applied them to myself, but it was like, ‘this isn’t me’ ... then I had to ask myself if I was just trying to fit myself into a box that I didn’t actually fit into (because) I wanted it to fit. I tried to keep my feelings, the upset and indignation, out of the equation.’ K noted that because the people who assessed her were ‘really, really nice and cool’ it was that much harder to disagree with their opinion: ‘it would have been easier to reject something if they were mean’.

K reflected on what it had taken for her to keep the ‘upset and the indignation out of the equation’ and to hold onto her sense of herself, in spite of the combined years of education and ‘professional expertise’ of the team who assessed her. K said: ‘I’m an expert in common sense. I have a mind of my own and I’m smart enough to know.’ K reflected on her experience of her response to the diagnoses: ‘I’m surprised at how well I am taking it because I’ve been working for this for so long. I feel very proud for not completely and utterly losing it ... I actually think I’ve done a bang-up job in terms of coping.’

In terms of the ‘helpfulness’ of the diagnoses, K said: ‘The jury is still out on that’. K and I decided that it might be helpful to request a meeting with the diagnosing psychiatrist, as we had some questions that we hoped to get answered about how the team had selected the diagnoses for her, and how ‘sure’ they were when they made their picks. I consulted with K and together we came up with a list of questions, which I emailed to the psychiatrist prior to our meeting so that he might have some time to prepare. I also had the good fortune of consulting with David Epston, who happened to be visiting Toronto at this time, and some of the questions were influenced by this conversation and from conversations with Dale Andersen-Giberson and Marilyn Vasilkioti, colleagues at Oolagen:

1. *When someone or a team of people at your clinic make a diagnosis, are they usually 90% sure, 80% sure ... how does this work?*
2. *Could you help illuminate for us the process of selecting a diagnosis?*
3. *How sure do you have to be to give someone a diagnosis?*
4. *What do psychiatrists and their teams do if they’re not certain of a diagnosis? Can you walk us through the steps of how you would proceed?*

5. *Have there ever been times when people have gotten a diagnosis wrong? How would you know if you had gotten it wrong or ‘right’ for that matter?*
6. *What if the person and the people supporting that person did not feel that a diagnosis was the right fit? What, if anything, would that do to your sense of the fit of a given diagnosis?*
7. *Given that K had expressed her interest in receiving a diagnosis from you and your team, do you think that knowing this influenced your team’s decisions in terms of the diagnoses provided?*
8. *You mentioned to me on the phone that you and your team felt K was ‘impressive’ and that you felt she had a good chance of being successful. I was wondering what it was about K that stood out as impressive to you? What was it about her that had you speculating that she would be ‘successful’? Was there a particular moment during your interview with K that led you to draw this conclusion about her?*
9. *Is there a story you could share with us about what had you and your team believing this about her?*

During the meeting, the psychiatrist responded to most of our questions (with the exception of the last one), and K seemed to reposition herself in terms of her sense of the fit of the BPD diagnosis. She seemed to be questioning her initial conclusion about BPD not being a fit, and I sensed hopelessness moving in. I shared my concern about hopelessness moving in with Ruth Pluznick, the Clinical Director at Oolagen, and I also shared my early excitement about K’s initial response to the diagnosis: how she had drawn her own conclusion about the assessment team not having ‘gotten it on the mark’ despite having a positive experience of the people who assessed her. Ruth proposed re-writing the diagnosis. I loved this idea and thought it important to also re-invent what the D, the S and the M stood for. I was thinking about names whilst making a cup of tea in the lunch room, when my colleague, Emma Turner walked in. I asked for her ideas about what to rename our version of the DSM. I came up with the ‘D’ for Delightful, and almost immediately Emma came up with the ‘S’ and the ‘M’: ‘Simply Magnificent’.



Feeling duly invigorated, I set off to rewrite K's diagnosis. I decided to use the template of the BPD diagnosis, and went with Expert in Common Sense (ECS). I combed through my notes from previous conversations with K, where I wrote down word-for-word her response to questions, to come up with 'the categories'.

Expert in Common Sense (ECS) is manifested by a pervasive pattern of thoughtfulness in interpersonal and/or inter-feline relationships, and marked abilities to self-reflect beginning by early adulthood and present in a variety of contexts, as indicated by six (or more) of the following:

1. Markedly and persistently able to see both sides of a situation, in at least two domains that are potentially helpful. Note: This involves not seeing the world in black and white and an openness to understanding both sides of a given issue.
2. A pattern of showing interest in understanding how one's behaviour impacts other people/felines.
3. Aversion to negatively impacting others (e.g. frequent displays of caring about how one's behaviour may be impacting others). Note: Includes random acts of kindness, such as bringing home-made cookies, banana bread and/or art cards to people.
4. The ability to discern when one has 'crossed the line' and the willingness to 'own-up'. Note: the presence of this principle of living (owning up) derives from maturity, a good outlook, and the ability not to blame anyone else or oneself for the problem.
5. Chronic presence of super-human abilities to self-reflect. Note: The presence of this symptom in a young person can be seen as likely to prevent a 'mid-life crisis'.
6. The persistent ability to discern when to leave a situation (e.g., through employing 'getting out skills').
7. The persistent ability to discern when to 'reign oneself in' (e.g., through employing 'reigning oneself in skills'). Note: This should be seen as a 'testament to one's willpower'.
8. A pattern of planning things out and thinking things through.
9. Recurrent ability to assert oneself when it's important enough (e.g., this includes the ability to be firm and direct). Note: This requires tenaciousness.
10. Commitment to and determination to get the help that one needs.
11. A belief in the capacity to change.

I was excited to show the new 'diagnosis' to K, but again, I felt it was important to temper my excitement and first check-in with her about the meaning she continued to make of the diagnoses. To my surprise, in the time between the meeting with the psychiatrist and our next meeting (four days), K had returned to her original position (that the BPD was not a fit), and in fact, she seemed to be more firmly grounded in her stance: 'I don't agree with the label' and about the helpfulness or unhelpfulness: 'it really wasn't that helpful.'

K reflected on some of the things that she came to know about herself and the wider world through this experience: 'I've learned that any label can be debated because it's not an exact science...It's not so clear-cut as people think, otherwise they would not have to keep revising it (the DSM).' K said that she learned that: 'even if you were going through the worst identity crisis known to man, you know yourself better than anyone else ... and I feel quite sure that what's going on with me isn't (likely to be found) in the DSM... and I have the ability to apply my 'Getting Out Skills' and my 'Reigning Myself in Skills', so it's not debilitating.'

K talked about what sense she made of the fact that she managed to hold onto her sense of herself in spite of all of the years of education, professional experience of the individuals involved in the selection of the BPD diagnosis, not to mention the niceness and coolness of the people involved: 'I'm happy that I can think for myself. The best feeling about all of this – the silver lining – is that I'm pretty level (headed) about this. I feel pretty sure it (the BPD diagnosis) isn't a fit and I'm not feeling irrational, guilty or upset.' K reflected on what she makes of being free of guilt and upset: 'It's interesting to me ... I'm surprised by how well I'm responding to this because I've been working hard for this for a long time, and it wasn't exactly a pleasure cruise ... I've done all the research, all the follow ups, and the fact that I'm so level-headed about this proves to me that I don't have BPD because someone with BPD would probably be raging at the doctors even though it's not their fault. I'm demonstrating that I'm not what they stuck me with.'

K reflected on what she has come to know about herself through this process: 'that I have a mind of my own; that I'm open-minded; that I have the ability to weigh both sides of a situation; that I'm not impulsive; that I'm not selfish; and that I'm not that hell-bent on receiving a diagnosis.' K added that she felt the experience 'toughened her up' and taught her about 'going with my gut', and she joked that she also became an expert on BPD. K summed up her experience of her own response to the BPD diagnosis like this: 'I think that it's a testament to how well I can think about things. I've matured and my development is more important to me than getting a diagnosis.' K said this about the 'new diagnosis' of

'Expert in Common Sense': 'I love it, because it's like, 'This is me, I'm ECS'. It's way more helpful ... I'm just happy that my opinion is up on the gold pedestal ... and I feel certain of the fact that things will get better.' As for whether the renamed DSM worked or whether it should have a different name, K said that 'Delightful, Simply Magnificent' was 'perfect the way it is,' and she offered: 'the best thing about it is that it highlights what is right with you, as opposed to what is wrong.'

Update

K and I worked collaboratively for just under 18 months and we stopped seeing each other because it became clear to K that our work together was done. K described her new relationship with the WTs: 'they're still there ... they still pop up ... they're still really annoying ... but putting them into words (naming them) has been helpful in figuring out how they work ... I can do a lot more now and I can't afford to stop because if I stop, I won't be able to start again.' K said that the Angst³ is 'not really an issue any more', which she attributes to 'maturity' and 'getting out of puberty'.

After almost two years of attending a day program for young people facing mental health difficulties, where K was able to earn a maximum of two high school credits each year, she returned to the mainstream school system. In order to 'catch up' on her credits, the last time we spoke, K was taking night classes, in addition to attending school full-time during the day, and planned to attend summer school as well. K described 'enjoying the challenge' of her new art program at the public high school, but said that at times she found it a little embarrassing when people asked her what grade she was in because she was taking a mix of grade 10, grade 11 and grade 12 classes. She remarked that it probably bothered her less than she would have anticipated, and reflected on how she made sense of this: 'I've matured. I'm more secure. I'm more comfortable with myself now.'

K successfully applied and won a grant to create four drawings and have them displayed at a downtown gallery (competing with other young people up to age 29!). A few months later, she was hired to recruit other young people to apply for the same grant for the following year. K also participated in a show at the prestigious Art Gallery of Ontario and had a few drawings for sale in a *Nuit Blanche* pop-up vending machine.

In a recent correspondence, K forwarded me a link to an article by Allan Frances, in which he questions the 'reliability, validity and usefulness of the DSM – 5'. I asked K about her reaction to reading the article: 'Yep, this is what I want my outlook to be like, and this is how I feel about the DSM.' I asked K if it was worth speculating about why this way of positioning herself suited her better: 'It's more suited to what I believe in ... It goes back to my core belief in looking at both sides of an issue and using my critical thinking skills and my super human powers of self-reflection to decide for myself on a given issue ... The DSM, with all of the revisions that have been made to it, helps me understand that it's not set in stone. A lot of people take it like it's the "Tablet of Moses" but to me it's just wishy-washy ... And besides that I'm not sure how helpful it is to have it pointed out what is "wrong" with us as people.'

K reflected on the kinds of possibilities she had created for herself by keeping herself going in these ways: 'I might be able to work in the mental health system and I think I'll be pretty damn good at it ... I will be a useful asset to the system because of everything I learned from my own experiences, both with the system and with having a mother who took her own life ... and I think that will translate in my work with people.'

Sharing her story

In terms of why it was important for K to have her story made available to other young people and to individuals working with young people who may similarly be faced with a diagnosis that does not feel like a fit, it comes back to K's core belief to 'not see other people suffer'. It comes from her hope that her story will make a difference in the lives of other young people and adults who may feel saddled with a diagnosis that doesn't fit, and that through her story they may come to know that there exist possibilities for recreating a 'diagnosis' that is not only fitting, but hopeful and transformative. Michael White wrote: 'There now exist a simply fantastic number of opportunities that are available to mental health professionals for the pathologising of people's lives' (White, 1995, p. 112). K and I, and my colleagues at Oolagen, see the DSM – O as one way to de-pathologise people's lives. We hope to collect enough re-written diagnoses to fill the DSM – O to the brim, and then to throw a party for its launch.

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