

The Voice of Someone with Dissociative Disorders Not Otherwise Specified

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There is not a lot written or for that matter said about the experience of complex dissociation that does not fit in with what is known as Dissociative Identity Disorder (DID) formerly Multiple Personality Disorder. Recently the criteria for the diagnosis of DID has changed so that what was previously known as Dissociative Disorders Not Otherwise Specified is now included. If you happen to be coming to terms with the realisation that complex dissociation could have something to do with your own experience of life and all that you come across does not bear much relationship to your own experience, then feelings of being cut off, different, perhaps not part of the human race....these can be exacerbated. Below is a voice, a viewpoint, of my own personal experience in this largely unmapped territory of human experience. There is nothing definitive about this voice, it seeks to open a doorway through which a light might shine on this different lived experience of severe dissociation. This voice is also seeking to join other voices in the sharing of our own experiences.

Dissociative Disorders Not Otherwise Specified brings us into an arena of lived experience of profound dissociation that affects our lives in the world, our relationships, our inner world and our very experience of our self or selves. And yet, in the true experience of dissociation it apparently does not fit in with definitions of other dissociative disorders. And so we are left in a landscape "not otherwise specified". It is as if we find ourselves alone in a house at an unknown location, the house is in darkness and new to you and do you think you can find where any of the light switches are?

Each person's inner world is undoubtedly unique. It was not until I had left my parents home and lived with others at University that I discovered that my inner world seemed to be different to that of those other young, growing adults that were around me.

My experience of trauma from when I was born until when I was 9 left me in severe dissociative states that meant I was not able to be fully in relationship with myself or others. Reflecting on this title of our workshop "Trauma and Relationship" over many months, has helped me realise that for myself, and I suspect others who have survived trauma through dissociation, trauma has meant not being in relationship and it is through learning to come into relationship that healing the wounds of trauma has been able to happen.

To return to my time at University, it was through forming relationships with others (as best as I could) that I saw reflected back to me how different I was from them in my inner and outer world and I began to realise my alienation from my whole self and other people. Whilst living at my parents house until 19, either I did not feel safe enough to realise this or maybe I just had not encountered others people's outer lives and inner worlds and so was unaware of any differences. As a family, apart from my father, we were alienated, in fact dissociated from others. And so I, so to speak, entered the darkened house in my 20s and started to explore. Actually that sounds more gentle than it was. I felt forced to explore what was going on, as states of rage causing me to kick walls when I was training as a nurse also caused me to leave my training, (this all came to a head when I was on placement on a ward where it seemed to me that the doctors were unable to let people die in dignity and with grace), ~ also as my body became increasingly allergic to various things and I had more and more difficulty breathing due to asthma, that threatened to escalate to needing hospitalisation myself which I was determined to avoid ~ I felt unable to function in the world, my body and other parts of me were reacting, over reacting and forcefully demanding attention.

A couple of years after I left University ~ any reference to timescales is always a bit vague for me as I can't seem to be able to measure time accurately to this day ~ I experienced a breakdown, a break through in many ways. This took me to a level of consciousness of myself/myselfes that I had never experienced before. It was as though just some of the walls of the house became broken so that fragments of memories, body sensations, emotions, leaked out of sealed rooms that previously secured their isolation, their quarantine. A friend said that it was like I had walked into a mirror and I would say that the resulting fragmented image was a more accurate one. How I was became less hidden to myself and those around me. These fragments are not a whole self with personalities of their own, defence mechanisms, body armouring and body patterns of their own but they are like shards of the mirror, holding say the body memory of the pain inflicted on the body when swung at a door frame ~ another shard might hold the intermingling smells of cigarette smoke and lipstick ~ another intense, destructive rage.....

In your minds eye put one tiny fragment into one of the darkened rooms, sealed off, enclosed and then deconstruct the house so that each room is blasted far away from each other, in fact scattered all over the Earth. If you can imagine this then maybe your mind can touch on this human experience, one not unknown to those who lived thousands of years ago in Egypt where the ancient story of Isis and Osiris, Ast and Usari Nepra arose ~ the latter being the names by which they were known in their own tongue rather than that of the Greeks but many of us don't know this, these names, this story and so we have to discover and rediscover ourselves and our connection to each other and the stories we weave. We have to search the "ends of the Earth" as Isis/Ast searched for the body parts of her dismembered lover ~ we have to search in this hearts desire for healing, wholeness where no-one and nothing is excluded. The fragments are painstakingly gathered and woven together like many threads, placed in positions like little squares of a mosaic that when you step back and look at it you can say, "yes, this is Sandra Sunfire".

I have spent a lot of time and energy on wondering what I want to say to you today and how can I communicate this. If how I am speaking is confusing, jumping about from this to that, you may be feeling some of the gaps in between thoughts, emotions, sensations, in between woven threads in this gathered "self", as I try and weave some of my wordless experience into something I can communicate in words. As I was preparing myself to talk with you, I heard on Woman's Hour about a report on autism in the UK. They naturally focused on women and autism and it was fascinating that women are often not diagnosed until late in life and often after misdiagnosis because as women we "present" differently to men. It was commented on about how good women are at mimicking and I wondered if those of us who are dissociative (men and women) use these same skills to learn to "pass as normal", or near enough anyhow! We may appear as a "singleton", a single self, at least some of the time if nothing untoward happens that triggers a different response. This ability that a woman with Asperger's described as being able to learn social skills from watching Coronation Street, is one many people with dissociative disorders may be able to identify with. The ability to mimic, taking you to edges in friendship, in intimacy, in real meeting, where the script runs out and leaves you in one of those gaps, really not knowing what to do, how to respond, how to reach out, how to reach in, when everyone has hidden within those darkened walls again, or maybe all that remains in the no-man's land between us, is the wordless urge to run, to hide. As I prepared to come here today it was these gaps I had to leap, to risk, to find the solid ground of words to build a bridge, the reality of body sensations in this present moment, to find a way to reach you, to come into relationship now, with you. I am motivated to do this as I carry on taking each step in my own healing journey, one with dissociation (I did write "from" dissociation and realised that all though I dissociate far less than I used to it certainly still has a major effect on me, my life, my body and relationships) ~ so as I move more from isolation into relationship which has brought me to a place of my own acceptance of being part of humankind ~ interesting to use that word particularly because it has

been the accumulative effect of gradually being able to let in human kindness that enabled the acceptance of being human to happen. With this realisation, with this real experience I have come to know that so many people on this Earth have suffered atrocities inflicted on them by other people ~ in states of war, in Bosnia, Serbia, Iraq, Afghanistan, Palestine, Israel ~ in so called states of peace, in families, in paedophile rings, in human trafficking And so we perpetuate these cycles of abuse, of human cruelty that is hard to believe or imagine, that can not always be survived. And so at 49 I realise that I am not alone, people especially when young are surviving atrocities using our natural mechanism to do so, severe dissociation. We have been surviving such atrocities, such calamities for millennia as the mythological stories of Isis and Osiris testify. It seems to me that this human experience really is not all that uncommon and as such it needs to be recognised, ideally at that first point of contact, when someone asks for help. We may need to do more research to fully identify the prevalence of severe dissociative survival mechanisms but if we are unaware of their existence now, when we meet someone daring to ask for help now, then we are unable to help them as fully as we can. We are increasing our understanding of DID, which is wonderful and we need to realise that severe dissociation also exists in "unspecified" ways that we know less about collectively. I have been a Trustee of FPP for a number of years and ironically one of my purposes is to hold "continuity" as our board of Trustees changes over the years. Continuity has become something that I treasure as such a precious jewel in my own experience after having experienced it in these later parts of my life, as parts of myself, shards of my experience, find how we can fit together and the gaps lessen, they can be bridged ~ or at least some of them. Another purpose I hold as a Trustee of FPP, is to remember and try to find a voice for those of us who don't fit in with the DID experience of being. I have tried to share some of my personal experience of severe dissociation with you today, to hopefully give voice to what it can be like to perhaps have DDNOS. I'm sure others may experience DDNOS in different ways but in ways that don't fit in easily with either being multiple or singleton. In recent years I seem to have used the phrase that I am "multipley inclined".

Thank you for reading, for listening.