First Person Account : Life with Dissociative Disorder

Presented by Kathryn Livingston,
Voluntary Co-ordinator, Trainer, Trustee & Treasurer for **First Person Plural**
A national survivor-led charity for adult survivors of childhood abuse & trauma who have dissociative identity disorder (DID), DID-like dissociative disorder not otherwise specified or other complex dissociative condition and their allies

The patient is a 17 year old white female, a GCE 'A' level student who will be 18 in six weeks time. She was recently transferred from a general ward to an adult acute psychiatric ward as a voluntary patient. She has no previous psychiatric history. She had been on the general ward for 3 days after 2 days spent on ICU following an overdose of over-the-counter analgesics. Initial psychiatric assessment on the general ward indicated she was a continuing risk for suicide.

She is the second of six siblings and lives in the family home in a deprived area of the city; neither her parents nor siblings have any known psychiatric history but there are two paternal aunts who are long term psychiatric patients (diagnoses unknown). The mother has grand mal epilepsy. Neither parent has visited the patient since her admission to the psychiatric ward. They excused themselves from attending this assessment, saying she was old enough and clever enough to know her own mind. Earlier, they gave their opinion that the overdose was due to exam stress and the recent death of a boyfriend, who their daughter disobediently continued to see after they forbade it; but they didn't think it was a real suicide attempt, just a 'silly teenage attention-seeking prank'.

The patient is overweight, wears baggy masculine clothes and no make-up. Her hair is greasy and tied back severely in a pony tail. Her broken spectacles are held together at the bridge with tape and the lenses are visibly greasy. She appears highly anxious, jumping at every small noise or movement. She sits tensely on the edge of the chair with her hands tightly gripping the arms and her legs constantly shaking. She does not make direct eye contact. Instead, her eyes dart rapidly around the room, occasionally scanning quickly over peoples' faces or focusing repeatedly for brief periods on the closed door. She is slow to respond to questions and speaks with a slight stammer but she shows no sign of disordered thought patterns.

With flat affect she tells of the recent suicide of her fiancé who hanged himself. She says they'd been planning on running away together after her exams were over. Asked why she wanted to run away she answered quickly – 'nothing really, just life, you know'; and then silently resisted any further attempts to explore this. She did not attend her fiancé's funeral because both her and his parents forbade it.

When asked to do serial sevens and other standard cognitive tasks she becomes suddenly animated and performs these exercises rapidly, with no errors and no stammer. When asked where her stammer has gone, she says she hasn't got a stammer. The anxious presentation, stammer and flatness of affect return and continue throughout the rest of the psychiatric assessment.

She responds negatively to questions about hearing or seeing things that others do not. She says she is unhappy that her suicide bid failed and still plans to kill herself as soon as she works out how to succeed; she says she wants to be with her fiancé; but later in the interview she says she doesn't want to die and asks to be discharged.

She becomes very agitated when first asked to undress for a physical examination but then suddenly becomes compliant, appearing edgy but resigned. During the physical she seems somewhat 'spaced out' but responds to instructions and answers questions promptly in a quiet, barely audible voice without stammering.

The examination reveals numerous small old scars of varying ages; some appear consistent with deliberate self-harm but she denies this. There is also some recent bruising. Her explanation, given assertively but somewhat robotically, is 'I was a very clumsy child, always having accidents, falling over and bumping into things, I guess I'm still clumsy – I don't even know how I got those bruises'

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Good afternoon, my name is Kathryn Livingston. Like every other person in this room I have multiple life roles and wear many hats. For this presentation I identify as an 'expert-by-experience', that is a mental health service user who has enhanced my core personal experience and knowledge of my subject through speaking to others with similar experience, reading, attending trainings and conferences and participating in discussions with specialist professionals. I am also a survivor of extreme sexual, psychological, emotional and physical abuse, neglect and deprivation from a very early age until, at least my mid-twenties. This abuse was perpetrated by the father and the mother, by multiple perpetrators within a pseudo-religious cult and through organised paedophile, pornography and prostitution rings.

The previous case study is representative of my first encounter with a full standard psychiatric assessment, 35 years ago. Subsequent to this I was a revolving door psychiatric patient for approximately 15 years, with some involuntary hospital admissions and time in locked facilities. Following a break of about 7 years consequent on moving to another city, I involuntarily re-engaged with services 13 years ago and have intermittently since then been a long-term outpatient with occasional admissions to residential crisis care. My complex needs require an enhanced care plan which has recently been reviewed under the FACS requirements and remains largely unchanged.

Thus, from the age of 17 I have experienced mental health services first hand as a patient and beneficiary. But sadly also as a captive, guinea pig and victim of systemic failures, poly-pharmacy, infusion therapy, ECT, professional disrespect, negligence and arrogance, closed-minded ignorance, repeated diagnostic errors and abusive practices.

In short, I have been traumatised and re-traumatised by many of my experiences in mental health services.

Very few individual practitioners have been knowingly abusive towards me; indeed most, I believe, were good people and good workers who intended to help me. But good intentions were not enough to prevent the harm done to me and from my perspective all of these traumatising experiences were (and are) unnecessary and preventable. Some of my recent experiences of psychiatry and mental health services have been marginally better overall. But I have once again had abysmal and traumatising experiences through the failure of the services since February this year culminating, just over one month ago, in a totally preventable admission to Home Treatment and the Recovery House. Happily, the service failures which precipitated this are now being resolved. Even a primary clinical need for specialist psychotherapy which has been identified in my care plan but unmet by the NHS for more than a decade may finally be met. I'm reluctant to get my hopes up but there has been a recent commitment to make an application to the Trust's independent case panel for funding for such therapy.

Tragically, my past and some current experiences within the psychiatric services, which are my only option for the complex support I need, have complicated, entrenched and exacerbated my primary mental illness, which is dissociative identity disorder. The most tragic part is that this childhood trauma – related disorder is eminently treatable. Like many severe mental illnesses, the best prognosis is related to early diagnosis and treatment. However, even after delayed diagnosis, those who receive treatment consistent with the International Society for the Study of Trauma and Dissociation's treatment guidelines have a good chance of making a full recovery or, at least, be able to take more control over their lives and reduce the frequency of crises so they become less draining on NHS resources. *[based on figures from the London Clinic for Dissociative Studies]*

Some clinicians mistakenly believe that DID is purely a North American phenomenon and not a valid diagnosis in the ICD10 classification. In fact, it is classified at F44.81 within the Dissociative (Conversion) Disorders section of ICD10 but the outdated label of multiple personality disorder is used, which may lead to the false assumption that it is a personality disorder. The DSMiv code for DID is 300.14.

Type 1 dissociative disorder not otherwise specified is a DID-like condition sometimes referred to as partial DID or partial MPD. Alters are less well developed, do not take executive control; there is no amnesia for the present, but amnesia for the past is usual.

In my opinion and that of most professionals specialising in trauma and dissociation neither the DSMiv nor ICD10 capture the complexity and experience of these disorders and thus they are profoundly unhelpful in guiding the average clinician to identify them correctly. ICD10 additionally perpetuates a myth of rarity and seems unfairly biased towards the sceptical side of the controversy about complex childhood-trauma related disorders. Correct diagnosis of DID and the related type 1 ‘dissociative disorder not otherwise specified’ becomes even less likely when clinician’s have little or no accurate knowledge or curiosity about the complex trauma-related dissociative disorders, so do not even get to the point of suspecting DID as a possible diagnosis. The standard mental health assessments used in the NHS give little opportunity to identify or explore the presence of dissociation, so do not encourage the necessary curiosity. I think the tragedy of non-recognition of complex dissociative disorders will continue until the average general clinician in psychiatry and other NHS mental health clinicians become aware of and trained in using specialist assessment instruments which can accurately screen for and diagnose these disorders.

The concept that DID is merely a North American phenomenon has been refuted in the past decade by research reports from diverse countries, including The Netherlands, Turkey, Germany, Israel, and Japan. Comparable studies have yet to be undertaken in the UK. However, a British point prevalence estimation study was published in 2005. It used the Dissociative Experiences Scale (a standard dissociation screening tool) and was undertaken on an acute psychiatric unit in Norfolk.

Its findings suggest a 15% prevalence of undiagnosed dissociative disorders (including DID) among inpatients. That translates to approximately 12 people on the mental health wards at Penn, of which 2 – 4 may have undiagnosed DID or Type 1 DDNOS. International prevalence rates for DID in non-clinical populations vary from about .1% to 1%. At 1% it is on a par with schizophrenia which is generally not described as rare, but even at .1% we are talking about an estimated 250 people in Wolverhampton (at 1% it's 2,500)

My Dissociative Identity Disorder was finally recognised about 11 years ago by a psychotherapist in private practice whom I paid from my own pocket to see. This diagnosis was subsequently confirmed by Professor Christine Dean, who some of you may remember, who was then my NHS consultant psychiatrist.

It remains my current primary diagnosis but, as I mentioned earlier the NHS has not yet fully met my care-plan-identified needs for effective treatment and care for either my extensive trauma history or this diagnosis.

I made significant progress in managing my DID and coping better with living a dissociative life during the psychotherapy for which I paid privately but the therapist was inexperienced with DID and extreme abuse. She did her best but when therapy ended due to her retirement more than 18 months ago, I had not achieved integration and resolution and remained prone to periods of destabilisation. I still have significant dissociative episodes; including switching between partially or wholly autonomous parts of my self, fugue states, amnesia, depersonalisation and derealisation and I continue to experience my 'self' as fragmented. A very recent assessment (May this year) by a specialist in the field of trauma, dissociation and cult abuse has re-iterated my previous therapist's opinion that with long term expert specialist psychotherapy I would be likely to make further progress towards resolution and integration, with an eventual reduction in my use of other mental health services.

This latest assessment has been accepted by my consultant psychiatrist, clinical psychologist and other members of the CMHT involved in my care. They have now committed to trying to get me the appropriate help, starting with making an application to the PCT for funding for a referral to an 'out-of-area' psychotherapist specialising in trauma, complex dissociation and the sequelae of cult abuse.

In the meantime, I continue to live with dissociative identity disorder. The following is a quote I wrote about my experience for the inside front cover of the new edition of the Mind booklet, "Understanding Dissociative Disorders", which I authored, in collaboration with other members of First Person Plural.

'For much of the time I look and act unremarkable, but inside there is almost always noise and chaos – it sometimes sounds like I've walked into a theatre foyer during the interval, you know, the buzzing of many conversations, none of which I can fully tune into and make sense of. I have other odd experiences - like when my arm doesn't seem to belong to me, or when I feel like I'm a cardboard cut-out that someone else animates, or when I seem to know something I don't remember learning. And when I fully switch to another self my life can become chaotic. If it is a child personality I behave like a child, often a very scared and traumatised child. Such behaviour looks bizarre because all you see is the adult body, but this isn't an act, it's not something I can control – my experience of myself at these times is that I am a child. Sometimes, I lose time, like one minute it's Monday and I'm at work, the next it's Wednesday and I'm in a hotel, 100 miles from home and my arms are bleeding. Only I don't know immediately that time has passed. I don't remember how I got there. Even though I know 'I' must have cut myself with the paper knife in my hand, I don't remember doing it and it feels like I have been attacked by someone else. It's very confusing, disorientating and distressing and it doesn't help when professionals and others don't understand about ~~DID~~ dissociative disorders ~~so~~ and think I'm attention seeking or acting out.'

So, with so much internal noise, chaos, disorientation and distress in my life how is it I'm able to stand up here today, seemingly normal, and hopefully competent in delivering this presentation?

Paradoxically, one part of the answer to that question is 'I dissociate'. Through therapy I have mastered the ability to zone out or dissociate from the internal noise but only for relatively short periods of time. I can also dissociate my intellect from the emotion stirred up when I am presenting, so that I do not become overwhelmed by affect which might trigger a switch. I have to balance this adaptive dissociation with making a commitment to spend time later attempting to hear what my 'others' are trying to communicate and attending to the previously dissociated emotions.

Other tools I use to facilitate being able to speak to you today, is an internal conference table and external writings on paper and white board. In my preparations, I invite all of my insiders to come to the table or participate in written discussion if internal communication is not possible, and I ask for their co-operation to give me the time and capacity to speak at this event. Not all my parts respond to such invites, some may not even hear them, since internal communication barriers still exist. But for those that do, there are negotiations leading to agreement that certain others can have time in executive control of the body at more appropriate times and in a safe place. Or, that we will wear or carry certain clothes or objects which have significance for a particular part or parts. For example, rainbow socks, a special toy or piece of rock. Or that we will do a leisure activity a particular part enjoys e.g. a cinema trip, meal out, or see a favourite pop star in concert. Similar preparation and pay-back or recovery time periods of varying lengths and intensity accompany most tasks I wish to accomplish, even banal everyday things, like taking a shower or washing the dishes. Some who don't attend the internal meeting or participate in written discussions will accept the agreements when they hear about them from those that do.

Others are not reachable but they may still have some awareness about what my intentions are and will co-operate. With others I am taking a risk because I do not know how they will respond to being here today or if they even know we are here, but it's a calculated risk based on the experience that once we turn up (occasionally we go AWOL on route – but that's another story) I have rarely been unable to complete a presentation, unless we are triggered.

For, even with all this preparation, there is still a risk that I won't be able to complete my presentation without switching, or otherwise being influenced by my others. If something triggers us then any such preparatory negotiations and agreements about who has executive control of the body are over-ridden by our automatic defensive response.

Then I'm likely to switch or otherwise dissociate and so lose the ability to continue this presentation. Whichever of us is deemed to be the most appropriate part to deal with the perceived threat and what it is assumed to mean, will take executive control. Unfortunately, as a consequence of our past traumas, we commonly misinterpret or misperceive threat in the present so the part who finds themselves in executive control may not have the maturity or capacity to deal with the situation, and may even be 'trapped in a past time and place' and completely unable to understand or even know where they are or what is happening.

So, I use adaptive dissociation, negotiation with my other parts and I make agreements and compromises in preparation for what I achieve today; but still I am taking risks. Having Jane, my personal support worker, with me when I do presentations helps to reduce the risks. But today Jane is not with me so I'll have to trust I'm amongst friends. I employ Jane, who has been a life-enhancer, if not a life-saver for me, with funding from the social services direct payments scheme. Having her (or another supporter, such as Jackie) with me makes it less likely that I will become overwhelmed with anxiety or fear and thus internally trigger a switch. Further if a switch or other unsettling dissociative experience does occur, it is likely to be less of a problem or turn into a crisis if I have immediate support to help ground me and ensure my safety. And all this is true whatever activity I'm trying to do – whether it be training, travelling, shopping, taking a shower, leisure or social activities.

But to return to the preparations we have to do to enable me to be here. None of it would work if I didn't keep my side of any bargains I've made; so at home later today it is unlikely that I am going to be spending much time in executive control or have a chance to start my preparations for my next challenge. My best hope is that I will stay aware of what happens from a co-conscious position but this isn't a given either. If I'm not co-conscious when others have executive control I 'lose time' and will have no memory of what occurs. But if you were a fly on my wall later what you might see is this adult body, sitting on a tiger print rug, cross legged (which is a contortion far beyond my own flexibility) surrounded by several stuffed toys, tossing small colourful plastic characters called 'Crazy Bones' to try to make just one of them land on it's feet to score top marks. What you'd hear is excited child-like giggles and, if Jane or another trusted person is with us, you'd hear this child-self speaking in an endearing child-like tone and speech pattern that is very different from how I have been speaking here as an apparently normal adult self.

This child-self is called Tiger Girl and we are very proud of her. When I first became aware of her she was a group of terrified child fragments of varying ages. They were known as The Angies and functioned both internally and when present in the outside world as a single entity. They were almost permanently trapped in a flashback re-experiencing of horrendous torture and abuse; they had no concept of this is now, not then; and believed they were still being abused.

They worked very hard and courageously for two or more years in therapy to resolve their own personal traumatic memories. This allowed the child fragments to blend so Tiger Girl is now experienced by me and experiences herself as an endearing, fun-loving child of eight years old, with whom I can usually be co-conscious without becoming overwhelmed. The abuse she suffered on our behalf is not forgotten but is placed firmly in the past where it belongs. But, a therapeutic task I have not yet completed is to fully accept as my own experience the abuse Tiger Girl (and other parts) suffered. And this is probably why Tiger Girl continues to be experienced by me as a separate person.

I was recently reading a chapter of the newly published book "Dissociation and the dissociative disorders – DSMv and beyond, edited by Paul Dell and John O'Neil. This chapter written by Paul Dell is titled 'The Long Struggle to Diagnose Multiple Personality Disorder : MPD'. In it he offers proposals towards achieving more clinically useful diagnostic criteria for Dissociative Identity Disorder. If you are academically minded (it's a pretty heavy read) I would recommend a full reading of the chapter; indeed I believe a perusal of the entire book would not be wasted time.

But for your immediate interest I refer now to table 24.1 on page 391 which lists thirteen well-documented dissociative symptoms of Dissociative Identity Disorder. These symptoms take us beyond the less than helpful descriptive criteria in DSMiv and ICD10, to consider what actual symptoms may be present. And interestingly they include 7 Schneiderian first-rank symptoms which historically have been associated with, even considered to be diagnostic of, psychosis. It seems that of the 10 Schneiderian first-rank symptoms only audible thoughts, thought broadcasting and delusional perceptions are not correlated with DID.

So, the symptoms of Dissociative Identity Disorder presented in the table mentioned are:- Amnesia; Conversion; Voices; Depersonalisation; Trances; Self-alteration; Derealisation; Awareness of the presence of alters; Identity confusion; Flashbacks and the following psychotic-like dissociative symptoms – Auditory hallucinations; Visual hallucinations; and seven Schneiderian first-rank symptoms, 'Made' actions, Voices arguing; Voices commenting; 'Made' feelings; Thought withdrawal; Thought insertion; 'Made' impulses.

These reflect many of the effects of dissociative disorders collated from my own and other dissociative survivors' experience, which I list in the Mind booklet 'Understanding Dissociative Disorders'. [Pause to refer to overheads]

Also in this booklet I outline Colin Ross's non-specific diagnostic clues for DID, which are a useful guide for when to seek a specialist assessment for dissociative disorders. It should however be noted that DID is also seen in men, children, adolescents and older women, and a DID individual may not be aware of having been abused because as we've seen one of the classical symptoms is dissociative amnesia.

Ross's clues are: a history of childhood abuse or other childhood trauma; female; age 20 to 40; reporting blank spells; hearing voices; believing there are external influences on the body; other unusual beliefs; reports of other people's thoughts intruding; a previous diagnosis or suspicion of borderline personality disorder; previous unsuccessful treatment; self-destructive behaviour; no though disorder.

I hope you now see that in the description of my first full psychiatric assessment with which I began this presentation there are several indicators that I had a complex dissociative disorder which were missed. The diagnosis I was given at the time was reactive depression.

Diagnoses and mis-diagnoses I have had since, include endogenous depression; general anxiety; borderline personality disorder; manic depression; atypical schizophrenia; paraphrenia; and post traumatic stress disorder. Of these, complex post-traumatic stress disorder and depression are currently co-morbid secondary diagnoses with my primary DID and, when certain of my parts have executive control; we may meet diagnostic criteria for borderline personality disorder. Other complicating factors include the extreme, prolonged and ritual nature of the abuse I suffered; and the complexity of my dissociative system of personalities. On the plus side there are a range of factors which offer hope for a good prognosis for us if we receive appropriate treatment for long enough.

These include:- being well aware of the extent of my difficulties; being safe from current abuse (but I can't be certain of this as I still cannot communicate with all my parts and I'm amnesic for extended fugue trips to places where I was abused in the past); able to make an attachment to previous therapist and the progress I made during this therapy; having some coping strategies; having good motivation, determination, resourcefulness and resilience; being knowledgeable about dissociation and its effects – both from personal experience and self-education; reasonable support networks through First Person Plural contacts etc.

35 years ago when I had that first assessment, dissociative identity or multiple personality disorder had not yet appeared in psychiatric classifications, although cases have been described in the literature for more than 200 years. That may excuse early misdiagnosis of my primary illness, but I've had many psychiatric assessments since DID has been a valid diagnosis and validated assessment tools have been available and yet my DID continued to be missed.

Two key messages have threaded their way through my presentation – one is that life with a complex dissociative disorder (whether diagnosed or yet to be recognised) is exhausting, often distressing and sometimes chaotic, but it's not all negative, and there is hope. My second message is you each have the power to support that hope and bring it to fruition. Be proactive in seeking and completing whatever continuing professional development you need to identify childhood abuse survivors in your care who may have DID or another complex dissociative disorders, then challenge colleagues to consider the possibility if you have to; do all you can to ensure they have the specialist assessment needed to diagnose them correctly; learn to identify and address the complicated needs that a survivor of prolonged childhood abuse who is living with a complex dissociative disorder may have (including considering any further complications from non-recognition by and re-traumatisation in mental health services in the past); and finally work to ensure that the services develop ways for those with complex dissociative disorders to access effective treatment to bring their hopes to fruition.

THANK YOU & ANY QUESTIONS