

# Living with dissociative identity disorder: A client's and therapist's perspectives

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*This article is co-authored by a person (the client) who has been diagnosed with dissociative identity disorder (DID) and a clinical psychologist who treats this condition (the therapist, Mike). The client discusses her experience of growing up with DID before it was formally recognised, the difficulties she has experienced within NHS mental health systems and her progress during therapy. Mike then adds his perspective on the understanding and awareness of DID as well as the method and potential for successful treatment. The client wishes to remain anonymous.*

## **The client's experience**

FIRSTLY, I need to explain why I developed dissociative identity disorder (DID). I'm not going to go into detail – just enough so you understand the story that follows.

I was physically, sexually and emotionally abused by my Dad from as far back as I can remember. 'I' would switch off in my head and 'someone else' would come out and take care of things. I was a high achiever in school and

a bright, happy child. No one knew what was going on because 'I' didn't know myself.

Things started to fall apart in high school when the normal experiences of growing up began to open up doors that previously had remained shut. I stopped eating as a way of coping and teachers at school noticed.

Sent to the GP, I was diagnosed with atypical anorexia and referred to child and adolescent mental health services, where weekly

family therapy sessions began, alongside individual work. I had a wonderful key worker who knew something wasn't right but couldn't do anything because I wasn't able to tell her. The family sessions were a farce, with my dad being able to control and manipulate both the situation and everyone around him.

One day I turned up and said I was very sorry but I was going to kill myself. I didn't want my death to come as a shock to her, but was exhausted and couldn't go on. I was referred to an inpatient adolescent unit on a three-week emergency admission.

The ward manager explained that the aim was to do the work to change my behaviour and then leave to go back home. None of my internal parts (alters) felt safe enough to say anything, so we tried to deal with it on our own – mainly through cutting, burning, bingeing and purging.

This continued throughout my admission(s) and I was labelled a 'difficult patient'. Looking back, I can see that I dissociated a lot during this time – different parts would come out and take over my behaviour and I'd come back from leave with things I didn't remember buying. I could never explain my thought processes when it came to self-harm, and staff often thought I was being obstructive.

Many attempts were made to discharge me and every time a suicide attempt would land me back. These were a mix of genuine, desperate attempts to end my life, and others just to get back into hospital. I didn't like being institutionalised, but going home was terrifying. I had dialectical behaviour therapy, cognitive behavioural therapy and cognitive analytic therapy. Never a diagnosis, but the other patients and I figured out we were being treated as 'borderlines'.

What had started off as an emergency admission turned out to be a cycle of inpatient care that lasted almost three years. Adult services were becoming more of a possibility, (that, or actually making a 'successful' suicide attempt), and something had to happen.

'J', promised to do some outreach work, saying if I went home temporarily she'd help find us an adult foster placement. She'd started

a group in the unit which was essentially play therapy for adolescents, and it gave my 'insiders' a safe space to express themselves. This helped to bridge the gaps between the amnesia and I was able to disclose about my dad.

The police were involved, even though I didn't want that and completely wasn't ready for it. Next to useless during the interview, I was zoning in and out of memories and struggling to follow lines of questioning. I've never seen the tape but understand how it would never have stood up in court.

'J' finished her transition work with me and I moved over to the local community mental health team. I was assigned a fantastic community psychiatric nurse (CPN) who believed me when I spoke about the DID, and did her best to help. She would read my diary filled with everyone's handwriting and listened to how distressed I was. The consultant psychiatrist, however, refused to acknowledge my 'self-labelled' dissociative disorder, and refused to engage in discussion about it whatsoever.

At this point I was living in the foster placement scheme – although none of the placements worked out. They broke down because neither the carers nor myself had any real support in place – I was losing time left, right and centre, and the behaviour of different parts wasn't always easy to cope with.

We tried many more hostels, bedsits and housing projects for young people, and all of them failed – either because of my repeated hospitalisations or my inability to work within their programmes.

Aged 18, I started attending a drop-in and counselling centre for young people 'not in education, training or employment'. The drop-in was helpful – somewhere to go – but sometimes I feel the counselling did more harm than good. (My therapist wasn't trained in dissociation or trauma, and would often trigger me without meaning to, leaving me lost and spacey after sessions.)

Still trying to help, my CPN organised for me to live in supported accommodation for adults with mental health problems. Staff there accepted my diagnosis to a point, but would not (or did not know how to) work

with it. It was a case of 'don't listen to the voices', and although they encouraged me to undertake voluntary work, things did become difficult. My struggles were seen as a refusal to engage and in the end, out of frustration, I left and rented alone.

I had been involved in NHS mental health services for eight years by this point. I wasn't achieving what I knew I was capable of in life and had to do something.

An internet search took me to a specialist centre which enabled me to find a suitably experienced clinical psychologist in my area, Dr Mike Lloyd. He seemed to understand what we said and could provide me with the answers as to why I was the way I was. He also gave me hope that life could get better with the appropriate treatment and support.

Out of my own pocket I completed the SCID-D (see below) with Mike and started therapy with him a week after my 22nd birthday. I have paid for therapy and fought for it since then.

Life has changed so much since seeing Mike – I am living independently, I can drive, I can hold down a job and I can think straight. All of my parts write in a diary so we can see what we're up to, and we talk to each other about what we're thinking and feeling. Traumatic stuff gets worked through in therapy (or even at home, now that we're getting better at it), and we're learning all of the self-care stuff that we never learned as a child.

As brilliant as all of this is, my transition into a 'normal' life has been difficult – over the last few years I've had several emergency visits to GPs, walk-in centres and A&E, all of which have been incredibly stressful and unsupportive. (I would really like to thank the nurses at the walk-in centres, who did treat me like a human being.)

I relocated from my town to another county in order to fit the catchment area for a different clinical commissioning group (CCG), hoping that a different mental health team would be better able to assist. This work is hard enough as it is, without having to fight for it and justify it every step of the way. Every time I slipped or struggled, it was because

'therapy wasn't working' or the 'treatment wasn't appropriate'. It felt as though anything I did reflected on my choice to recover, and that the normal pitfalls of this journey were used against me as justification to not help. Mental health teams would not engage with what I was trying to achieve, with one psychiatrist saying to me, 'Who are you to deserve this funding?'. I know there's a finite pot of money available, but the fact that other people have been given it, with no clear reasoning why I haven't, is what makes it so difficult to accept. Surely two-hour train journeys to therapy showed my dedication to 'recovery'.

There were times in the past when I've literally not known what to do or why I'm carrying on, but I made a promise to myself that if we got through this then we'd make it better for other people. I'm not the only one going through this, and I don't want anyone else to have to go through what I did to access therapy.

Things need to change.

### **The therapist's perspective**

The client begins by helping us understand how DID for her occurred as a result of abuse sustained in childhood. We will use the term DID in this article as this is how the client wishes it to be referenced. Abuse is a common causative factor of DID, though it can also be due to neglect within the context of attachment dynamics, and where an aspect of a complex trauma experience is more likely. For DID to be present, according to DSM-V (American Psychiatric Association, 2013) and the ICD-10 (World Health Organization, 1992), there has to be the presence of two or more personalities, each with their own set of characteristics and behaviours (e.g. the person and one or more 'alters' or emotional personalities, as described within the model of structural dissociation (Van Der Hart et al., 2006)). This has to be present outside of any consequence of substances, disease or head injury, not be part of a cultural/religious system, have elements of amnesia and be distressing to the individual. The prevalence of DID, the most severe form of dissociation, is thought to be between

0.4 and 1.7 per cent (Akyüz et al., 1999) in the general population; the prevalence of dissociation in general is much higher.

The client writes about how her behaviour needed changing, with 'atypical anorexia', self-harm and suicidal thoughts becoming the focus of attempts to treat. This is noted in many people's accounts of their journey with dissociation, with other explanations being offered instead of dissociation, such as autism, ADHD, eating disorders, conduct disorders or emerging personality difficulties. For a broad overview, see Brand et al.'s (2016) dispelling of the myths about DID. In this case, the group therapy was offered without an indication that her father was critical in the cause of her distress. Being able to see past the behaviours for a full understanding of why she may be dissociating was not possible. In DID, there are internal parts, or 'alters', who may have very different behavioural patterns, or 'actions systems', some of which can be seen as persecutory punishment and others more focused on protection, defence or retreat (Van Der Hart et al., 2006).

A key element of DID is amnesia. The client describes finding things she has no awareness of buying. In this case, a dissociated part may have 'taken over' the body, pushing her into the background and gone out to buy things. It can be challenging for family, friends and professionals to understand this. Being able to explain thoughts and behaviour is therefore problematic, and can further promote secrecy about the dissociative experiences as well as the abuse. The 'barrier' between her internal world and hospital staff trying to make her safe led to years of frustration from both sides, with many techniques being tried to little effect.

The presenting behaviours of DID can be confusing and disorientating to watch, with rapid changes of voices, mannerisms and movements. It is not uncommon to see many dissociated identities within the space of a few minutes. Due to a lack of understanding, this can lead to strong rejecting reactions in others. Under such circumstances, foster placements would be nearly impossible to maintain if the

carers were unaware of dissociation. Education and employment can suffer and the potential for quality of life can be quickly lost.

The client points out how frustrating it was to not be able to engage in discussions about her dissociation with staff, and has found this occurring in different areas over the years she has sought therapy. The importance of raising awareness of DID and general dissociation is paramount, and voiced by many people seen within specialist trauma clinics. Locating dissociation at the centre of treatment can prevent further triggering of traumatic memory and behavioural response. She is appreciative now of how difficult it must have been for people to 'hold her', but she could easily have taken on a perspective that she is 'a failure, a lost cause'.

When the client contacted me, we followed the assessment guidelines recommended by the International Society for the Study of Trauma and Dissociation (ISST-D, 2011). This included the self-report screening measure, the Dissociative Experiences Scale – II (DES-II) (Carlson & Putnam, 1993) and the Structured Clinical Interview for DSM-IV Dissociative Disorders – Revised (SCID-D) (Steinberg, 1994). These are internationally validated tools; however, as she points out, even with a diagnosis there was no help to be found within NHS settings.

The client shows how she has changed following the therapy being set up. It began with stabilisation, then trauma exploration and then integration – of the self and into life (ISST-D, 2011). The potential for the client is well on the way to being fully realised, demonstrating how a 'disorder' does not have to be a 'disability'. It is one of the great ironies that a condition like DID, which can be so debilitating at times, can also offer the chance of a wonderful life. Some therapists work toward full integration (i.e. merging all parts into a whole); others work with the parts remaining as support and company.

NHS England and the National Institute for Health and Care Excellence have not developed UK versions of the ISST-D guidelines, despite requests to do so. Self-funding for therapy is costly and beyond the resources of many, especially considering the general

long-term nature of therapy. We continue to work closely with the local CCG to develop service level agreements for assessment, diagnosis and treatment pathways.

Evidence is emerging that offering therapy for people with DID may be very cost effective, as it has been demonstrated that providing therapy focused on working with DID reduces the use of services in more traditional mental health settings, such as inpatient admissions and out of hours crisis contacts (Lloyd, 2011, 2016; Myrick et al., 2017), yet people like this continue to 'fall through the net'. With increasing awareness of dissociation and DID, there is room to hope that such an experience will be less often seen.

For this client to describe her experience in this manner is both courageous and informative, and helps us understand the unique

and individual journey for every person with mental health or trauma difficulties, improving our understanding of how we seek to help. Co-authoring such papers as this builds a joint approach to the literature, which mirrors the process we recognise as being essential in the therapeutic relationship. Writing by following the client's lead (whose article was the first written) helped me as a therapist to understand the need she had for the experience of DID to be accepted, as much as the overwhelming frustrations about lack of access to funded treatment.

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