The Dissociative Disorders Alliance Strategic Plan

2025-2030

Introduction

Purpose (Our charitable 'Objects' clause)

The Dissociative Disorders Alliance exists for *"the improved quality of life and relief of distress for people in the UK living with a complex dissociative disorder."*

Vision and aspirations

We are working towards *"an improved quality of life, healing and recovery for those living with a complex dissociative disorder in the UK. We also hope that our work will contribute to the existence of a UK-wide preventative strategy for childhood trauma and abuse. "*

Mission

To achieve our purpose our objectives will be focused on four main areas:

1. The advancement of education and provision of accurate, culturally appropriate evidence-based information about trauma, dissociation and complex dissociative disorders.

2. The advancement of supportive and empowering peer led initiatives for those with complex dissociative disorders.
3. The advancement of awareness, understanding and quality of care regarding complex dissociative disorders among health and social care practitioners and other frontline services.
4. The establishment of alliances and relationships with national and international practitioners and organisations.

Our structure and ethos

The Dissociative Disorders Alliance (The DDA) aspires to be a supportive and psychologically safe charity which promotes emotional wellbeing for its beneficiaries, allies, Trustees, volunteers and any employees that it works with. Our current volunteers and future Board of Trustees (Trustees) are a mix of people with lived experience, practitioners and allies. We have chosen to form as a Charitable Incorporated Organisation (CIO) - this structure gives us the greatest freedom and flexibility in our operations. We have chosen a Foundation Model; this means that the Trustees will be responsible for making decisions. For further information please see our Constitution. The DDA is committed to transparency and accountability in all its dealings and our Constitution, Policies and Procedures will reflect this. Trustees have a legal obligation to act in the best interests of The DDA and in accordance with the charity's governing documents. Relevant trustee training will be undertaken, and knowledge proactively sought out to help us implement trauma-informed approaches and practices.

We want any content we produce and language we use to be as clear, inclusive and accessible as possible. Our content will be co-produced by knowledgeable and respected practitioners and experts-by-experience, drawing on the expertise of both. We will limit signposting of information and resources to those which we have been able to sense and quality check (or be clear if we have not been able to do so). We will seek external help and input in any areas where the Trustees, volunteers and any employees have gaps in knowledge.

We are hopeful The DDA will become a charity that those with Complex Dissociative Disorders and their allies feel safe to turn to. We will strive to foster and enable an ethos of inclusivity and diversity to build a community that people want to connect with and receive support from.

What are Complex Dissociative Disorders and who are our ultimate beneficiaries?

There are a range of different Dissociative Disorders which can be seen as being on a spectrum of complexity. The DDA's work in the main will offer support for adults experiencing distressing and complex trauma-related dissociative conditions. For the purposes of this document, we will refer to these as Complex Dissociative Disorders (CDDs).

Research suggests that CDDs typically follow the experience of chronic and extreme early childhood trauma, along with the absence of a safe attachment figure, ie the absence of appropriate comfort or care (McQueen, D et al (eds. 2008) *Psychoanalytic Psychotherapy after child abuse: the treatment of adults and children who have experienced sexual abuse, violence and neglect in childhood*: London, Karnac Books Ltd). As such, The DDA will aim to establish strong alliances with existing charities and services working with children and adolescents.

Our primary beneficiaries are adults who meet the diagnostic criteria for Dissociative Identity Disorder (DID) or Other Specified Dissociative Disorder (OSDD). It is not necessary to have an official diagnosis to benefit from the services of The DDA, an individual can self-identify based on their lived experience of symptoms.

We are aware that some people identify as being plural / multiple without having a trauma history and/or experiencing DID or OSDD. This group of people are not our target beneficiaries, but we will signpost and stay connected with allies in the community who work under the umbrella of 'Plurality'. It is important to note that some may not recognise the link between extreme trauma in childhood and the development of alternate identities. This may be due to not remembering their full experiences; or not feeling ready to confront the reality of a traumatic childhood. As such it is important to The DDA that all resources available on our website do not exclude and are accessible to this group.

For further information about CDDs please visit Clinic for Dissociative Studies (CDS UK) at https://clinicds.org.uk/. There is also a PDF available from MIND on their website about Dissociation and dissociative disorders.

The current situation

Treatment and training

It is rare for an appropriate treatment pathway to exist within the NHS for CDDs and where it does it is unlikely to be sufficient or long-term. In the UK, the National Institute of Health and Care Excellence (NICE) publishes guidelines on physical and mental health conditions. These guidelines are a standard for NHS treatment. At the time of writing there are no NICE guidelines on dissociation or CDDs. Therefore, access to diagnosis, therapy, support and care is often non-existent unless an individual can self-fund.

Treatment guidelines and recommendations are available from the International Society for the Study of Trauma and Dissociation (ISSTD) and the European Society for Trauma and Dissociation (ESTD) based on current scientific knowledge and informed clinical practice.

Widespread anecdotal evidence suggests that most healthcare professionals do not understand Dissociation or CDDs. Additionally, denial that CDDs are valid conditions is not unusual. This is despite complex dissociative disorders existing as valid diagnoses in the DSM-V and ICD-11 psychiatric manuals and extensive international academic papers that point to the validity of diagnosis and effectiveness of treatment.

There is an urgent need to have CDDs fully recognised among health and social care practitioners and other frontline services as valid complex trauma-related dissociative conditions that are not especially rare.

CDDs are rarely covered in relevant curricula in universities and training establishments. Likewise, once practicing, most healthcare practitioners and other providers of frontline services do not receive training in this field. Therefore, it is common when help is sought for professionals to not recognise either the physical or mental health (MH) symptoms of CDDs. Although a variety of somatic problems often go hand in hand with CDDs, these are currently typically treated or thought about in a segregated way, rather than a holistic one.

Many people with CDDs report being re-traumatised through their search for suitable help within the NHS. This is partly because many healthcare practitioners, despite the current trend towards services becoming ‘trauma-informed’, are not aware of the ways in which they can inadvertently cause psychological harm through not recognising; and therefore invalidating, a person’s dissociative responses. Inappropriate interventions may be offered, or people may need to ‘fail’ in regular MH services before being considered for more suitable support.

In some geographical areas, people with CDDs are labelled too complex for any kind of care, treatment, or support. Even within the same area, people may be treated differently for reasons that are unclear – it seems, most commissioners and senior managers lack expert

insight into how to go about supporting people with CDDs; how to effectively fund treatment; and how to commission and design appropriate services.

There are some examples of services that have been and are being commissioned with positive results. Learnings can be taken from these to inform a more widespread and cohesive effort to bring about change. Examples of these have been written up in published journals and shared at conferences but still there is no coordinated approach to establishing treatment pathways and support.

There are UK therapy centres and networks that have a focus on supporting those with CDDs (for example, The Complex Trauma And Dissociation Clinic, The Pottergate Centre, the Clinic for Dissociative Studies) as well as international bodies, in particular the ESTD and ISSTD. Also, there are a number of private registered practitioners who offer therapy for CDDs.

The need for a new UK Charity

Given the dire picture outlined above and the traumatic origins of CDDs, people living with them are often isolated and their difficulties minimised or misunderstood by those that they could benefit with support from (whether friends and family members, or systems such as healthcare, employment agencies and employers, social services, mental health charities, and the criminal justice system).

The previous UK charity for people with Dissociative Identity Disorder, ‘First Person Plural’ (FPP), closed in 2023. It was recognised in the case for closure, that its dissolution was not an indication that beneficiaries’ needs were not important, but that FPP was no longer the best vehicle to meet those needs. The closure of FPP leaves unmet needs in the community that The DDA working alongside allies hope to serve. We will avoid duplication by seeking to build alliances with those who have shared and/or overlapping goals. By way of examples, there are a number of charities based in the UK or parts of the UK, who support survivors of abuse, such as; The Survivors Trust, MAIRSINN, the National Association for People Abused in Childhood (NAPAC), Rape Crisis England and Wales and Rape Crisis Scotland. However, none of these are solely or specifically for people with CDDs. There are also not for profits and charities operating in this field outside of the UK, some with global reach. For example, ‘The Plural Association’, a volunteer and peer-led nonprofit registered in 2020 in the Netherlands, ‘Multiplied By One Org’, a Canadian registered Charity and An Infinite Mind, a 501(c)3 international non-profit. What is needed for the UK is a charity that also has UK specific knowledge of gaps and deficiencies in this field.

During our establishment as a group of volunteers, to help inform the development of our Strategy and plans for future delivery, we sought views from our community (people with CDDs) via a survey. We intend to continue to involve the community in planning and executing our activities and we will endeavor to adapt to changing needs and priorities.

According to our survey findings, the provision of accurate information and resources was one of the most important areas that the community felt could be addressed by a new charity. Whilst some good information is available, particularly on the internet, there is also a lot of misinformation circulating, particularly within the media and film/television. There are information gaps too in areas such as: the reality of the journey after diagnosis, what to do to help manage symptoms if therapeutic support is not available, people's experiences of therapy, the impact of intersectionality on experiences and access to therapy and much more. There is also a sense that there is a lack of information and transparency about the stark reality of the reasons as to why some individuals have come to develop CDDs - for example, through sexual abuse, neglect, trafficking and, for some, organised and/or ritual abuse.

Some people with CDDs, most of whom have suffered from heinous traumatic experiences, find comfort in knowing there are others in the community who are facing similar challenges. It is not surprising, therefore, that peer-led services and events that provide opportunities to connect are also high on people's wish lists. This identified need is not just amongst survivors but also for families, friends and practitioners working in the field. Once again though, The DDA does not want to duplicate what is already available, we plan to signpost and build upon existing activities where possible. The DDA will also seek to build alliances with those who have established infrastructure and procedures particularly when it comes to ensuring the safety of the community when engaging in on-line/digital initiatives (e.g. Online and In-person Groups, 1:1 Mentoring via email/text chats/WhatsApp).

Our Strategy

Object 1

To achieve **"The advancement of education and provision of accurate, culturally appropriate evidence-based information about trauma, dissociation and CDDs"** we plan to:

a) Provide accessible trauma informed accurate and culturally appropriate information about trauma, dissociation and CDDs, written by and for the community.
b) Work alongside charities and other bodies to ensure that their information about CDDs is accessible, accurate, culturally appropriate and amplifies the voices of a diverse group of people with lived experience.
c) Work alongside those already delivering training about CDDs to make their training more accessible to a broader range of attendees.
d) Encourage training providers to include information and amplify the voices of a diverse group of people with lived experience of CDDs.
e) Become a well-respected charity which the media and other journalists and authors can approach for accurate information about CDDs.
f) Work with allies such as national charities to improve public understanding of CDDs, alongside increasing understanding of types of abuse that can lead to their development.

Object 2

To achieve **"The advancement of supportive and empowering peer led initiatives"** we plan to:

a) Research existing best practice examples of peer support initiatives to inform policies and initiatives.
b) Lead the way in establishing peer support policies of inclusion and good practice supporting minority groups, and responsive to the intersectionality's of people with CDDs. Policies will aim to be sensitive to the needs of internal parts/people of individuals with CDD's.
c) In collaboration with the wider community, develop, set up and facilitate a diverse, safe and inclusive range of peer support initiatives for people with CDDs, practitioners and allies. This may include supportive groups, 1:1 mentoring, creative activities, informative workshops, writing groups, events and advocacy.
d) Establish alliances and where appropriate relevant memberships with charities & others involved in peer led services such as National Survivor User Network and MIND.
e) Build on existing or establish new initiatives that bring people together to discuss how they manage and navigate challenges related to CDDs outside of/in the absence of therapy.

f) Build skills and confidence to empower people with CDDs to share their lived experience and learnings with others.

Object 3

To achieve **"The advancement of awareness, understanding and quality of care among health and social care practitioners and other frontline services",** we plan to:

a) Generate awareness amongst key learning and training establishments of the need for CDDs being part of curricula. The ultimate objective would be mandatory training in fields such as Psychiatry, Mental Health nursing, Clinical Psychology, Counselling and Psychotherapy.
b) Collaborate with allies to understand and help overcome any barriers to the development of NICE treatment guidelines for CDDs.
c) Establish a network of connections with Integrated Care Boards (ICBs) in England (and equivalent bodies such as Boards and Partnerships in Scotland, Wales and Northern Ireland) to initiate improvements in awareness, understanding and treatment of CDDs.
d) Identify any gaps in available training and work to fill them by delivering our own training packages.
e) Establish projects with allies to help us better understand the experiences and needs of people with CDDs who additionally are marginalised in other ways, e.g. by ethnicity, class, gender identity and disability, with the aim of prioritising inclusion and accessibility within services that work with complex dissociative disorders.
f) Explore how our understanding of complex dissociative disorders intersects with the emerging understanding of neurodiversity.

Object 4

To achieve "**The establishment of alliances and relationships with national and international practitioners and organisations", we plan to:**

a) Draw on existing relationships within The Board of Trustees and volunteers and establish new relationships, to build alliances with those who have overlapping goals.
b) Establish relationships with institutions and bodies in the wider system (for example, NHS trusts and teams) in order to deliver our other objects.

c) Contribute to projects of others, for example revisions of treatment guidelines and therapy practice where this will improve the outcome for people living with CDDs.
d) Become a trusted voice of lived experience that organisations with overlapping aims can turn to and draw upon.
e) Involve others as appropriate in projects we are leading on, particularly when the required expertise is not already held within The DDA.
f) Collaborate with other organisations on joint projects, such as awareness raising campaigns and training.

Funding our work

To identify what financial budget and resources are required, our Objectives will need to be prioritised, and draft implementation plans developed. Some of our work will be undertaken by volunteers and we will also need to fundraise. The DDA Trustees will have initial responsibility for identifying possible sources of funding. Our Fundraising policy outlines our approach to safeguard emotional wellbeing and sound ethical principles including the Charity's sources of income. When considering which projects we undertake, any which require ongoing funding should be supported by an appropriate level of reserves.