

Part A - General Information

Organisation/Individual Name

Emotion Dysregulation in Autism

Organisation Type/Structure

Charitable Incorporated Organisation (CIO)

Theme/Nature of Project

Mental Health

Charity Registration Number (if applicable)

1201408

Company/CIC Registration Number (if applicable)

Emotion Dysregulation Autism

Project Name (if same as Organisation Name, please leave this blank)

EDA Peer Support Programme

Name of Lead Contact

ZeZe Sohawon

Email

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Phone / Mobile

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Website

<https://emotiondysregautism.org/>

Social Media Handles (Twitter, Facebook, LinkedIn, Instagram etc):

Twitter: @EDysregAutism

Facebook: Emotion Dysregulation in Autism

LinkedIn: Emotion Dysregulation in Autism

Instagram: @emotiondysregautism

Part B - Project Proposal

Project Mission: A snapshot of the project's intention (50 words max)

Our aim is to provide mental health support skills to autistic young people in Birmingham to prevent self-harm and suicidality. Our soon-to-be-peer support workers to empower young people, enabling them to build a life worth living. We aim to transform their lives and the systems that support them.

Situation (250 words)

Misunderstood. Excluded. Deliberated." EDA was born from lived experience. ZeZe, our founder, was once included in the 32% of Children and Young People (CYP) represented in the total population of those who reside in inpatient psychiatric units. (RCPSCH, 2020).

Since the COVID-19 pandemic, there has been a rising tide of mental health crises, with rates of referrals overwhelming local NHS mental health services.

Across all ages, 57% of those admitted in recent years have had autism/ASD. (NHS, 2021). Despite this, there are no specific provisions or interventions for autistic people. We believe that this is further demonstrated by shocking statistics such as how the average length of stay for autistic people in psychiatric inpatient wards is 5.5 years, or how 90% of autistic people in such wards were sectioned.

This is particularly concerning given that social gradients are heavily implicated in the development of mental

illness.

Our Charity Ambassador, Lindsey Bridges, claims her daughter Lauren died of suicide as a result of neglect, having been 'failed by the system'. Having tragically lost her daughter, Lindsey is using her lived experience as a force for change to prevent future systemic failures. On TikTok, Lindsey has amassed a large following with over 118k followers and 1.2 million likes.

Meanwhile, recent documentaries such as 'Locked Away: Autism Scandal' further highlight the consistent failures in the system to protect the lives of vulnerable autistic young people.

We need to help them. We need empowerment. We need change

Complication (250 words)

Whilst there has been a £300 million investment in transformation of current NHS mental health services, charities are vitally needed to bridge the gap now and achieve early preventative approaches to suicide in autistic young people.

Recent reform in the Mental Health act stipulates that autistic people should not be sectioned purely for their autism, as it does not constitute a mental illness. However, this does not address the core issue of the disproportionate number of autistic people facing acute mental health crisis as a result of comorbid mental health conditions and associated trauma.

As of March 2023, NHS mental health services still do not have a structured provision for autistic young people. This is because autism is not a mental health condition but a neurodevelopmental disorder, despite autistics being at a higher risk for mental illness. Instead, we are facing a social issue, which EDA hopes to solve by providing effective and consistent solutions to the persistent distress experienced by young people who fall through the gaps in mental health services.

From previous scoping work where we interviewed several young people, we understand how important it is to have a peer support charity tackling this issue, to ensure that other young people do not have the same poor experiences as in the NHS. More so, we now know how beneficial it would be to young people who are struggling to have someone who understands.

Solution (250 words)

We will deliver peer support to autistic young people in emotional distress using a psychological model; this model is based on Dialectical Behavioural Therapy and has been adapted for autism. It is used for suicidality providing practical skills on distress tolerance and emotion regulation.

We will begin to deliver peer support in 2023, initially running as a pilot to test the success of providing a 6-month intervention in the local community. We will establish a self-referral access point online through a secure server.

We will measure outcomes through the CHIME theory of change; this stands for Connection, Hope, Identity, Meaning, Empowerment. We will measure these aspects of recovery in young people using the recovery INSPIRE-O standardised survey.

We take safeguarding seriously and believe it is everyone's responsibility; we have 2 named safeguarding leads as well as relevant policies in place to protect young people from harm.

Skills Building

We will deliver this as an emotional support group held virtually on Zoom. We will run each session for 1.5 hours, including a 1-hour session of delivering skills and an optional 30-minute drop in and catch up. These meetings will be held twice a week.

The full curriculum course of DBT will run for 4 weeks and rotate every 4 weeks to accommodate new members.

Here is how the 4 weeks will run:

Week 1- Stabilisation

Week 2- Distress Tolerance

Week 3- Emotion Regulation

Week 4- Interpersonal Effectiveness

Part C - Wider Support

How would the Stephen Lloyd Award network of partners' support be beneficial to your project? (250 words max)

If we were to be successful, we would jump at the chance to maximise our benefit from the award. This includes more than financial benefit alone, as it is about growth and awareness of the charity so that we are able to achieve our goals.

We know that the Stephen Lloyd Awards as an arm of the Bates Wells Foundation is well-connected and well-established. We would greatly benefit from the support that you offer, this includes:

- ELE Global and Helen Squared could help with marketing and communications support.

- Amanda Wells Psychotraumatology could help with training our peer support workers in mental health first aid.
- Patrick Crawford CB could help as a CEO mentor to the founder of the charity, as would Michael Norton. David Saints Action Planning would be incredibly beneficial for us to grow the charity through careful organisational strategy.
- Paul Hamlyn foundation could provide financial investment. We are a new charity so would not normally be subject to their eligibility criteria but with this award, hopefully it would give EDA the credibility and power to be able to be considered.
- Tudor Trust could also prove beneficial for core cost funding for the year whilst we are setting up the peer support programme.
- Haymacintyre would be very helpful with their chartered accountancy services towards the end of our financial year to prepare our annual accounts.
- Finally, having links with NVCO would be great for our charity to have access to additional funding announcements in our region

Part D - Financial Justification

In general terms, please explain how the winning funds would be used to carry out your project. (50 words max)

If we won £25,000:

12792.96 for peer support worker salaries

12,200 for training for the peer support workers(DBT training, sensory training)

If we won £2500:

For the peer support workers, 4x laptops, £400 each =£1600

4x mobile phones, £150 each= £600

Credit for the phones=£300

Part E - Supporting Information

Governing Documents: Where relevant, please upload any recent charity accounts and governing documents as attachments.

- [CIO-Emotion-Dysregulation-in-Autism-Final_Const-with-address.docx](#)

Team: We would like to learn a little more about the individual or team invested into the project. What are your individual credentials? Is there a story behind how you or your team all came together to support the project? (75 words max)

ZeZe, our founder, has helped 9 young people avoid psychiatric inpatient admission, when 57% of them were autistic. She has given a TEDx talk and is an author. She has lived experience of being sectioned for 4 years from her autism.

She is supported by 7 trustees, of whom 40% are clinicians and the 85% have lived experience of autism. Some are NHS psychiatric hospital directors, mental health clinicians, policy specialists and finance managers

YouTube Video

https://www.ted.com/talks/zaynab_zeze_zaynab_sohawon_my_triumph_over_my_mental_health_struggles

Additional References: You are welcome to provide a list of up to 5 links with any relevant supporting material or visuals, as further reference

https://www.canva.com/design/DAFeBY1_w9M/Kq_--gH1Toi8sVfNQHVI0A/view?utm_content=DAFeBY1_w9M&utm_campaign=designshare&utm_medium=link&utm_source=homepage_design_menu