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School of Social Policy, Sociology and Social Research

Cornwallis North East

University of Kent

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**DETAILED PARTICIPANT INFORMATION SHEET**

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| **Research title** | Trauma, support and identity among late diagnosed autistic women with experience of gender-based violence |
| **Primary researcher** | Katrine Alma Callander |
| **Researcher contact** | Kac45@kent.ac.uk |
| **Research format** | PhD doctoral thesis |
| **Ethics approval number** | 0828 |
| **Supervisors** | Professor Chrissie Rogers and Dr. Damian Milton |

**Study Invitation:**

I would like to invite you to take part in this qualitative research on the trauma experiences of gender-based violence (in various forms) and the impact, identity realignment and unmet support needs among late diagnosed and self-identifying adult autistic women. This research is participatory and co-produced, as I am also a late diagnosed autistic woman with personal experience of gender-based violence including sexual assault. This information sheet explains why the research is being done and what it involves for you. Please read this information carefully and do not hesitate to ask me questions if there is something that is not clear. The research is conducted through SSPSSR-LSSJ, University of Kent, and is related to my doctoral thesis.

**What is the purpose of the research:**

This research will explore life history and narrative expressions of autistic life experiences. It will contribute to an emerging understanding on the consequences of living with trauma resulting from various forms of gender-based violence (GBV) as an autistic woman. The primary aim is to increase visibility of autistic voices and improve understanding of the impacts of GBV trauma for us as a marginalised group and consider this issue beyond the medicalised deficit-based approach to autism. It will consider to what extent perspectives on trauma change following a late autism diagnosis and potential identity re-alignment. Its proposed contribution will be to illustrate the extent of differences between autistic and non-autistic experiences and increase understanding of ways to improve trauma-focused support. Hence, it will provide recommendations for policy changes to address un-met care and support needs.

My personal experiences as an autistic woman will be included in the research and I will consider the impact of this in terms of reflection, positionality and personal bias. Potential areas of conversation may include but are not limited to: life as undiagnosed autistic individual, the impact of trauma experiences, coping strategies, forms of external support or lack of support, autistic identification, the diagnostic process if applicable, identity realignment in relation to autistic identity, potential resurfacing of trauma, feelings about care and support provisions.

**What you will need to do and time commitment:**

If you choose to take part, the preferred method of participation would be a life story interview either via online video calls, pre-recordings or in writing (for safeguarding purposes the video will not be recorded, though the audio will be recorded for transcription purposes) to discuss your personal story in relation to some of the aspects above. While prompts may be given to guide and support the conversation, you will have control over the aspects of your life and experiences that you share about your own story. There is not a set time limit as it depends on what you would like to contribute. To ensure inclusivity, this interview can also be completed in writing, via audio call or other alternative methods. A variety of needs can be accommodated, please ask.

To enable the research to review changing narrative perceptions over time, ideally the participants would be happy to continue the research process through repeated interviews, approx. every other month. This allows for changes over time to be considered in the narrative.

**Eligibility Requirements:**

To take part, you must:

* Be aged 25 years or over
* Have received a diagnosis or self-identify as autistic in adulthood
* Female, or identify and live as a woman
* Have experienced forms of gender-based violence (these could include sexual assault, coercion, domestic abuse, gaslighting or other harmful acts perpetrated against your will)
* Have received some form of trauma support (for safeguarding)

**Do I have to take part?**

Participation in this research study is completely voluntary. If you decide to participate, you will have the opportunity to read the information sheet, ask questions and complete a consent form before any work commences. You will be offered an electronic/paper copy of the information sheet, further information on the research and consent form to keep. In the capacity as primary researcher, I will only be able to access your data once you have given your consent.

You may change your mind about being involved. Even after you agree to participate and begin the study, you are still free to withdraw for any reason during the data collection/participation period and data analysis. After conclusion of data analysis, requests of withdrawal may be limited and reviewed on an individual basis. Withdrawal after publication is not possible. This would not affect your legal rights. If you withdraw, I will no longer collect any information. You will be asked whether you give permission to use information about you that you have already provided.

**What are the possible benefits of taking part?**

Hopefully, sharing your life story and narrative perspective will be a positive experience for you. I cannot promise the research will help you personally but the insights I will gain from you taking part may help improve visibility and understanding of the autistic experience of trauma impacts following gender-based violence and/or sexual assault and provide recommendations for improved support for autistic adults.

**What are the possible disadvantages and risks of taking part?**

There is potential for psychological or emotional risks of re-triggering and re-traumatisation, as difficult life experiences and trauma may be discussed. To mitigate these risks, a detailed distress protocol has been developed for this research. You will not face direct questions on these aspects, and you will be in control of the information you provide as part of your narrative life history. it is deemed ethically important that you have received some form of trauma support in relation to the experiences being discussed. Participants will not be paid for this study.

It is not possible to provide direct counselling in relation to this research but I will provide contact details for support organisations and you are free to pause or leave the research at any time. If you have been affected by anything in the study please contact your GP or providers on the list of support resources that has been sent to you.

**What if there is a problem?**

If you have concerns about any aspect of this research, you should initially speak to myself as the primary researcher, and I will do my best to answer your questions. My contact details are on this information sheet. If you have further queries, please contact the primary PhD supervisor Professor Chrissie Rogers on C.A.Rogers@kent.ac.uk. If you remain unhappy and wish to complain formally, you can do this by contacting the Chair of the Social Research Ethics Committee at *LSSJEthics@kent.ac.uk*. If you prefer to contact the Chair of the Research Committee by post, please use this address: Chair of Research Ethics Committee, School of Social Policy, Sociology and Social Research, Cornwallis North East, University of Kent, Canterbury, Kent, CT2 7NP.

**Will my taking part in the study be kept confidential?**

Any responses you provide will be treated confidentially. Any publication resulting from this work will report only aggregated findings or fully anonymised examples that will not identify you. All data is kept on password-protected encrypted databases in a restricted access computer system and any paper information (such as your consent form and research questionnaires) would be scanned for digital storage and the original copy destroyed. All transcripts will be fully anonymised, and no transcripts will contain personal identifying information about participants. Transcripts will only be accessible by myself and their PhD supervisors. To safeguard your rights, I will use the minimum personally identifiable information possible, and act according to the principles of the General Data Protection Regulation (GDPR) as outlined in the University Privacy Notice (GDPR Privacy Notice), which can be found here:

<https://research.kent.ac.uk/ris-research-policy-support/wp-content/uploads/sites/2326/2021/06/GDPR-Privacy-Notice-Research.pdf>.

**How your information will be used**

The results of the research will be included in the doctoral thesis of my PhD in Social Policy as well as potential future academic publications arising from the approved PhD thesis. In the thesis capacity, the results will be read by the supervisors and examiners, but only in the format of aggregated findings and anonymised examples.

You will be asked if you are interested in providing your email address to receive information about further research opportunities and the results of this study. If you provide your email address, your contact information will be kept by the University of Kent for two years after the end of the study so that I am able to contact you about the results of this study and other related information (unless you advise that you do not wish to be contacted). This information will be kept separately from the research data collected and only the researcher will have access to it. All other data (anonymous research data) will be kept securely for 7 years. After this time your data will be disposed of securely. Your research data may be used by the researcher only.

**Who has reviewed the study, and who is organising and funding the research?**

This study has been reviewed and given ethical approval by the Student Research Ethics Committee of the SSPSSR-LSSJ, University of Kent. This research is completed by University of Kent researchers.

Thank you for taking the time to read this research information sheet and considering whether to take part.

**For further information about the study, please contact:**

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