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**Participant Information Leaflet for Parents/Guardians**

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| **Study Title:** | The Intersectional Effects of Disability and Social Class on Becoming NEET |
| **Investigator(s):** | Dr Stella Chatzitheochari and Dr Angharad Butler-Rees |

**Introduction**

We are inviting you to take part in a research study. Before you decide whether or not to consent to this, it is important that you understand why the research is being done and what it would involve for yourself. Please take the time to read the following information carefully. You can also find more information about the project by visiting our website https://warwick.ac.uk/fac/soc/sociology/research/projects/isc/becoming-neet/.

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to give your consent.

**Who is organising and funding the study?**

The study is led by Dr Stella Chatzitheochari (Reader in Sociology, University of Warwick) and it is funded by The British Academy/Leverhulme Trust.

**What is the study about?**

The study focuses on disabled young people who are not currently in employment, education, or training (also known as NEET). We are interested in better understanding the role that disability and social disadvantage have on young people’s educational and employment experiences. In order to achieve this, we will interview approximately 20 physically and/or sensory disabled young people (aged 18-30) from across England, who are from socially disadvantaged backgrounds and are not currently in employment, education, or training. This project’s overarching aim is to produce evidence that can be used to understand and address educational and occupational inequalities faced by disabled young people.

**What would taking part involve?**

We will invite you to take part in a biographical interview. Taking part in this interview is entirely voluntary. The interview will be 1-to-1 and conducted face-to-face, online or over the phone. You will be interviewed once and the interview will take approximately one hour. Within this interview we will discuss educational and/or employment experiences that you may have had to date. We will also discuss the impact that you think your disability and your family background may have had on your current employment situation, along with your hopes and expectations for your future. We will send you a list of possible questions in advance of the interview. The interview will be audio recorded, and pseudonymized (removing any identifiable details). You will be given the opportunity to view your transcript.

**Do I have to take part?**

No. Participation in this study is entirely voluntary and choosing not to take part will not affect your rights in any way. You can choose to withdraw your participation and/or your consent at any time (without providing a reason) by contacting a member of our research team. Further details about withdrawing from the study are provided later on in this document.

**What are the possible benefits of taking part in this study?**

There are no direct benefits from participation. Participating in research can be an enjoyable experience, as it is an opportunity for people to share their own opinions and experiences. By taking part you will be involved in research which will helps to understand educational and occupational disadvantage frequently faced by disabled young people in England. It is hoped that the findings might lead to a greater awareness of the barriers and challenges disabled young people face in education and the labour market.

**What are the possible disadvantages, side effects or risks, of taking part in this study?**

No foreseen disadvantages or risks will be brought about through taking part in this research. The interviewer has previous experience of interviewing and working with disabled young people and will ensure that the interview is adapted to cater for your specific needs. It is possible, however, that you feel some discomfort when sharing your personal experiences of disability, employment, education and/or childhood. We will always do our best to put you at ease and remind you that you do not have to share any experiences that make you feel unsafe or uncomfortable. You will also be given a list of support organisations and helplines which you can contact if the interview has made you feel upset, anxious or if you feel like you require any further support.

**Expenses and payments**

Any travel costs will be reimbursed, and you will be given a £20 ‘Love to Shop’ voucher to thank you for your time and participation.

**Will my taking part be kept confidential?**

Your participation in this study and your data will be kept strictly confidential. Data will be collected about yourself in two ways, a) through a screening questionnaire which will be administered with you over the phone and b) through a biographical interview with the researcher. Only data necessary for the research purposes will be collected and processed. All electronic data will be stored on an encrypted, password protected and restricted access server at the University of Warwick. Data will only be accessed on university computers and not transferred onto any personal devices. Similarly, all paper documentation involving personal data will be stored in a locked filing cabinet within a locked office at the University of Warwick. No personal data will leave the University of Warwick. Only members of our research team, that is, Dr Stella Chatzitheochari, Dr Angharad Butler-Rees and a research assistant (yet to be appointed) will have access to the data. It may however be necessary to share data with the relevant authorities if there is a safeguarding concern e.g., if a young person were to disclose that they, and/or others, may be at risk of harm. The researchers have a duty of care to report this to the relevant authorities. Beyond this, no personal data will be transferred or shared with any other organisation outside the University of Warwick.

Your data will be pseudonymized. You will be given a study number to protect your identity. The key which links you to this study number, will be stored separately to the research data. Six months after your interview this study key will be deleted, at which point your data will become fully anonymised – with no possible way of connecting you to the data. Your name, the name of family members, schools attended, employers and/or any other organisations which you may have personal involvement with, will be pseudonymised. No data will be included in the research report or publications that could make you personally identifiable.

At the end of the study, we will ask for your consent to archive your data, through an exit consent form. The reason for wanting to archive data is to enable future research, both by the University of Warwick and potentially others. Archiving will mean that your interview data will be available to researchers for an indefinite amount of time. It is not mandatory that you consent to this. If you do not consent to the archiving of data, all data will be destroyed 10 years after the end of the study. The reason for storing your data for 10 years is to provide evidence for research findings and publications, and so that we can show that we have presented your voice and experiences correctly.

**What will happen to the data collected?**

As a publicly funded organisation, the University of Warwick has a responsibility to ensure that all personal data is used carefully and only for specified research purposes. This means that, when you consent to take part in a research study such as this one, data will only be used to achieve the research aims.

We will be using information from you in order to undertake this study and will act as the data controller for this study. We are committed to protecting the rights of individuals in line with data protection legislation. The University of Warwick will keep identifiable information about you for 10 years after the study has finished.

Research data will be **pseudonymised** as quickly as possible after data collection. This means all direct and indirect identifiers will be removed from the research data and will be replaced with a participant number. The key to identification will be stored securely and separately to the research data to safeguard your identity. You will be able to withdraw your data up to 1 month following your interview date and you will not be required to give a reason for doing so. Simply inform the researcher Dr Angharad Butler-Rees in person, by telephone - +44(0)24 765 22034 or email angharad.butler-rees@warwick.ac.uk that you want to personally withdraw from the study and do not want to be contacted again. Once you withdraw yourself from the study the data collected up to this point will be destroyed.

**Data Sharing**

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. The University of Warwick has in place policies and procedures to keep your data safe.

This data may also be used for future research, including the sharing of findings to the general public and policymakers, following review and approval by an independent Research Ethics Committee and subject to your consent at the outset of this research project.

For further information, please refer to the University of Warwick Research Privacy Notice which is available here: <https://warwick.ac.uk/services/idc/dataprotection/privacynotices/researchprivacynotice>or by contacting the Legal and Compliance Team at GDPR@warwick.ac.uk.

**What will happen if I don’t want to carry on being part of the study?**

Participation in this study is entirely voluntary. You are able to withdraw from the study without giving any reason for doing so and without your legal or statutory rights being affected. If you no longer want to take part in the study, you should contact Dr Angharad Butler-Rees via phone on +44(0)24 765 22034 or by emailing angharad.butler-rees@warwick.ac.uk.

If you decide to personally withdraw from the study, it will only be possible to withdraw your data up until 6 months following your interview date. After this point, all data will be fully anonymised. It will therefore no longer be possible to connect you with your data. To safeguard your rights, we will use the minimum personally identifiable information possible and keep the data secure in line with the University’s Information and Data Compliance policies*.*

**What will happen to the results of the study?**

The results of this study will be published in academic journals. We will also use the findings for posts for popular blogs (e.g., The Conversation) and share them with local and national Disabled People’s Organisations. In addition to this, we will also be sharing and discussing the research findings at a series of academic conferences.

Results from the study will also be shared with you through a participant newsletter, approximately 9 months after your interview. You will be able to choose what format you would like to receive the newsletter in. You will also be sent a copy of all other research outputs.

**Who has reviewed the study?**

This study has been reviewed and given favourable opinion by the University of Warwick’s Humanities and Social Science Research Ethics Committee (HSSREC): HSSREC 58/22-23.

**Who should I contact if I want further information?**

Please contact Dr Angharad Butler-Rees via telephone on +44(0)24 765 22034 or email angharad.butler-rees@warwick.ac.uk.

**Who should I contact if I wish to make a complaint?**

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the Head of Research Governance, who is a senior University of Warwick official entirely independent of this study:

**Head of Research Governance**

Research & Impact Services

University House

University of Warwick

Coventry

CV4 8UW

Email: researchgovernance@warwick.ac.uk

Tel: 02476 575733

If you wish to raise a complaint on how we have handled personal data, you can contact our Data Protection Officer who will investigate the matter: DPO@warwick.ac.uk.

If you are not satisfied with our response or believe we are processing personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

**Thank you for taking the time to read this Parental Participant Information Leaflet.**