

**Participant Information Leaflet for Parents/Guardians**

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| **Study Title:** | Educational Pathways and Work Outcomes of Disabled Young People in England |
| **Investigator(s):** | Dr Stella Chatzitheochari and Dr Angharad Butler-Rees |

**Introduction**

We are inviting a young person in your care 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 the young person. 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/currentresearch/educationalpathways/.](https://warwick.ac.uk/fac/soc/sociology/research/currentresearch/educationalpathways/)

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 (Associate Professor of Sociology, University of Warwick) and it is funded by The Leverhulme Trust.

**What is the study about?**

The study explores why disabled young people lag behind their non-disabled peers in educational and occupational outcomes in adulthood. We seek to better understand the social processes that contribute to these inequalities. Our study will interview 60 disabled young people aged 15-16 years old in secondary mainstream schools across the West Midlands prior to their GCSE examinations (or equivalent) and approximately one year later. Participants will be sought from three long-standing condition groups: a) autism, b) dyslexia and c) cerebral palsy. We will focus on post-16 transitions, and we will examine the varying barriers and challenges faced by disabled young people across these three groups. We are particularly interested in how parental socioeconomic background interacts with adolescent disability to affect occupational and educational attainment. Our study is unique in giving voice to disabled young people, who have been typically excluded from earlier research on the topic.

**What would taking part involve?**

Part 1 - We will ask the young person to take part in two biographical interviews, approximately one year apart. Each interview will take around an hour. The interview will take place either via an online platform (e.g., Microsoft Teams or Skype) or face-to-face (if coronavirus restrictions allow and you feel comfortable with us doing so). When conducting the interview face-to-face we will allow the young person to choose a location in which they feel comfortable. We imagine that most interviews will take place in participants’ homes, but this is entirely up to the young person. During the interviews, the young person will be asked to talk about their own experiences of disability, school/education and any plans they may have for after completing their GCSEs. In the second interview which will be around a year after they’ve completed their GCSEs, we will ask them about their experience of this transition and the choices that they have made. We will send them a participant pack before each interview with a list of possible questions that they may be asked so that they know what to expect. All interviews will be audio recorded, transcribed, and pseudonymised (removing any identifiable details). The young person will have the opportunity to view their transcript.

Part 2 – We will also invite yourself as the parent of a young person with autism/dyslexia/mobility difficulties to take part in an interview. Taking part in this interview is completely voluntary. You do not need to agree to this for your child to take part in the study. The interview will be 1-to-1 and conducted online or over the phone. The interview will take approximately 45 minutes. Within this interview we will discuss your reaction to your child’s diagnosis, your experience of parenting, access to support/resources along with your hopes and expectations for the young person’s 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/they have to take part?**

No. Participation in this study is completely voluntary and choosing not to take part will not affect you or your child’s rights nor their education or grades in any way. You and/or your child 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?**

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 and the young person will be involved in research which will help to understand differences in the education and work outcomes of disabled young people. It is hoped that the findings might lead to a greater awareness of the barriers and challenges facing disabled young people in education and the workplace.

**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 researcher has previous experience of interviewing and working with disabled young people and will ensure that the interview is adapted to cater for the young person’s specific needs. The young person may however feel some discomfort when sharing their personal experiences of disability, education and/or childhood. Similarly, you may experience some discomfort in sharing your experiences around parenting and responding to your child’s diagnosis. We will always do our best to put both you and the young person at ease and will remind you both that you do not have to share any experiences that make you feel unsafe or uncomfortable. You will also both 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 the young person will be given a £20 ‘Love to Shop’ voucher after each interview to thank them for their time and participation.

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

Both your participation in this study and your data will be kept strictly confidential. Data will be collected about young people in two ways, a) through a screening questionnaire which will be administered with you over the phone and b) through two biographical interviews with the researcher. Data will also be collected about yourself if you decide to take part in an interview around your experience of parenting the young person. 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, except from the parental interview recordings which will be uploaded onto Otter.ai for automated/electronic transcription. Otter.ai abide strictly by GDPR and have comprehensive data security procedures in place. Transcripts will be both downloaded and deleted from Otter.ai as soon as they are made available by the software. Only Dr Stella Chatzitheochari, Dr Angharad Butler-Rees and Melissa Chapple 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.

Both yours and the young person’s data will be pseudonymized. You will both 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 the young person’s second interview this study key will be deleted, at which point your and their data will become fully anonymised – with no possible way of connecting either of you to the data. Your names, the name of family members, the young person’s school and/or any other organisations which they/you may have personal involvement with, will be pseudonymised. No data will be included in the research report or publications that could make them or you personally identifiable.

At the end of the study, we will ask for your consent to archive your and their data, through an exit consent form. It is not mandatory that you consent to this. However, this is likely to be of value to future research in this area. If you do not consent to the archiving of data, all data will be destroyed 10 years after the end of the study.

**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 for a young person to take part in a research study such as this one, data will only be used to achieve the research aims. This principle will similarly be applied to your own data.

We will be using information from both you and the young person 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 and the young person 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 the young person’s identity. The young person and/or yourself will be able to withdraw yours and their data up to 1 month following your interviews and 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 disabled.transitions@warwick.ac.uk that you want to personally withdraw and/or withdraw the young person from the study and do not want to be contacted again. Once you withdraw yourself and/or the young person from the study the data collected up to this point will be destroyed.

The audio recording of parent/guardian interviews, which may contain personal data if you have shared this during your interview, may be shared with Otter.ai - a commercially available, confidential transcription service for the purpose of transcribing the information you share during your interview (<https://blog.otter.ai/privacy-policy/>). Occasionally, Otter.ai may transfer your data out of the EEA, however your data will remain protected by the appropriate privacy policies and would be protected by the Privacy Shield Framework used by Otter.ai. After processing, your data will be immediately deleted from Otter.ai, making your data irrecoverable by the service. We will not be uploading interview data from the young people involved in the study to Otter.ai. Should you wish for a member of the research team to manually transcribe your interview instead, you will be given the opportunity to opt out of your data being uploaded to Otter.ai through the consent procedure prior to your interview.

**Data Sharing**

Your rights to access, change or move yours and the young person’s information are limited, as we need to manage their 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 the young person’s 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 the young person and/or myself to carry on being part of the study?**

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

If you decide to personally withdraw or withdraw the young person from the study, it will only be possible to withdraw both yours and their data up until 6 months following your interview dates. After this point, all data will be fully anonymised. It will therefore no longer be possible to connect your or them with your data. To safeguard both yours and the young person’s 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 and as a research monograph. We will also write the findings into posts for popular blogs (e.g., Teacher’s Toolkit, 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 first wave of the study will also be shared with you and the young person through a participant newsletter, approximately 6 months after their first interview. Both you and the young person will be able to choose what format they would like to receive the newsletter in. You and the young person will also be sent the second wave of findings in November 2023 along with 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 65/20-21.

**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 disabled.transitions@warwick.ac.uk.

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

Any complaint about the way you or the young person have been dealt with during the study or any possible harm you/they 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.**