

## Information sheet for Parents/Carers of Young Adults with Down Syndrome

*How did the Covid-19 pandemic impact the transition into adulthood for young adults with Down Syndrome? Experiences of parents/carers.*

I would like to invite you to participate in my study. **Please read the information below before deciding whether you would like to participate. Please also read the documents provided for your young adult, and ask them to read these**, supporting them where necessary.

### 1. What is the purpose of the study?

The purpose of this study is to explore how the Covid-19 pandemic may have impacted the transition into adulthood for young adults with Down Syndrome, considering both the period of the pandemic and in the longer-term. This will involve a **one to one interview with myself lasting up to one hour**.

### 2. Why have I been invited?

You have been asked to participate as you are a parent/carer of a young adult with Down Syndrome who was aged 17-25years at the start of the first lockdown (23<sup>rd</sup> March 2020), and so they would be 20-29years now.

### 3. Do I have to take part?

Your participation is completely voluntary and you can withdraw at any time. If you would like to withdraw before the interview, please email me. If you would like to withdraw during the interview, we will stop immediately and the data will be destroyed. If you would like to withdraw your data after the interview, **please email me within one week** of your interview and your responses will be destroyed. After this, the data will be anonymised and it will not be possible to identify your data in order to remove it from the research.

### 4. What will I have to do?

In my email there should be the following attachments for yourself: this **Information Sheet**; the **Consent Form**; and the **Interview Prompt Sheet**. I have also attached an **Information Sheet** and **Consent Form** for your young adult.

If you would like to take part in my study please complete the following steps:

- Read the **Information Sheet**, the **Interview Prompt Sheet**, and the **Consent Form for parents/carers**.
- If you are happy with the terms stated, please complete and sign the **Consent Form**.

- Please ask your young adult to read the **Information Sheet** and **Consent Form for young adults**, supporting them where necessary. I am happy to have a call with you both to offer further explanation; if you would like this, please send me an email.
- If your young adult is happy with the terms stated, please could they complete and sign the **Consent Form**.
- Please send me the signed **Consent Forms (one for yourself and one for your young adult)**.
- We can then arrange an interview time and date.

**Interviews will take place in person at a location convenient to you or online on Microsoft TEAMS.** This will depend on your preference or the distance between us. As this study involves you recollecting experiences across a three-year period, I have provided a Covid-19 timeline as a prompt, and space for notes. Please feel free to write any notes that you think would be helpful for you in the interview. Please note that this is not compulsory, but **I would invite you to familiarise yourself with the prompt sheet before our interview.** I will ask you the questions on the prompt sheet and may ask you to elaborate on your answers or follow-up questions.

You will be able to pass interview questions and you do not need to share an experience if you think it would make you or your young adult feel uncomfortable. You may want to have a conversation with your young adult before your interview about things they would like you to share or not share, but this is not compulsory.

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

Please note that you will be identified by a randomised participant code (and not by name) and any data will be stored confidentially on a password-protected computer. The interview will be audio recorded for transcription. This audio recording will be stored in my password-protected electronic university files and the recording will remain untouched for one week following your interview, to allow you to withdraw your data if you wish. After this I will start transcription and data analysis. The audio recording will be stored for no more than two months after your interview to allow time for transcription. After I have analysed the data, audio recordings will be destroyed, and transcriptions will be anonymised by removing the participant codes. Any names including yours and your young adult's will be changed, and any personal information will be removed. Quotations or themes that are used in the write-up will be completely anonymous.

#### **6. What will happen to the results of the research study?**

The findings will be written up for my thesis, which may be published at a later stage. I plan to share findings with the organisation who advertised my study to you so that they can share them with yourself and others. You can contact me should you wish to discuss the findings or if you have any questions/comments about the study. Your participation in this research will not affect your relationship with the organisation, or any member of it, in any way.

This study will be unique in its orientation on the short-term and long-term impact of the Covid-19 pandemic on the transition into adulthood for young adults with Down Syndrome. Your insights could be helpful to educational psychologists, and wider systems of professionals supporting young adults with Down Syndrome, as well as to young adults with Down Syndrome themselves, and other parents/carers.

## 7. Where could I find advice/support for myself or my young adult following the interview?

If you would like support for yourself or your young adult, please consider getting in touch with the following charities/organisations:

- The Down's Syndrome Association:
  - Website: <https://www.downs-syndrome.org.uk/>
  - Email address: [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)
  - Helpline number: 03331212300 (10am-4pm)
- Mencap:
  - Website: <https://www.mencap.org.uk/advice-and-support/our-services/learning-disability-helpline>
  - Helpline numbers: 08088000300 (Wales); 08088081111 (England) – Monday - Friday
- Mind:
  - Website: <https://www.mind.org.uk/>
  - Email address: [info@mind.org.uk](mailto:info@mind.org.uk)
  - Helpline number: 03001233393 (9am-6pm; Monday to Friday, except bank holidays).
- If you need urgent advice:
  - Crisis coping tools: <https://www.mind.org.uk/need-urgent-help/>  
Contact NHS 111 if you live in England or NHS 111 Wales if you live in Wales.  
<https://www.mind.org.uk/information-support/guides-to-support-and-services/crisis-services/getting-help-in-a-crisis/>

## 8. What if there is a problem?

If you have any questions relating to the research, please contact me on the email address below. I have also provided contact details for my research supervisor, Dr Dale Bartle.

### Contact Details:

- Eleri Davies, Researcher & Trainee Educational Psychologist:  
[daviesen1@cardiff.ac.uk](mailto:daviesen1@cardiff.ac.uk)
- Dr Dale Bartle, Research Supervisor, Course Tutor & Educational Psychologist:  
[bartled@cardiff.ac.uk](mailto:bartled@cardiff.ac.uk)

**Any complaints may be made to:**

Secretary of the Ethics Committee  
School of Psychology  
Cardiff University  
Tower Building  
Park Place  
Cardiff  
CF10 3AT  
Tel: 029 2087 0707  
Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk)

*Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. The University has a Data Protection Officer who can be contacted at [inforequest@cardiff.ac.uk](mailto:inforequest@cardiff.ac.uk). Further information about Data Protection, including your rights and details about how to contact the Information Commissioner's Office should you wish to complain, can be found at the following: <https://intranet.cardiff.ac.uk/staff/supporting-your-work/manage-use-and-protect-data/data-protection>*