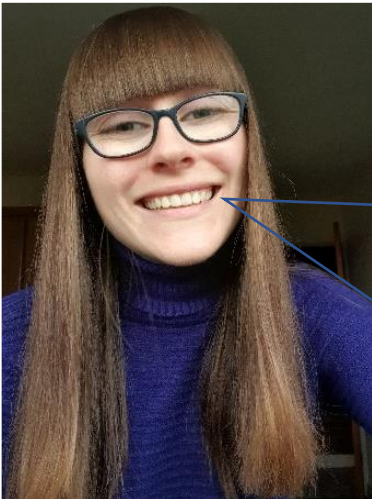


Information sheet for Young Adults with Down Syndrome

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



- My name is Eleri.
- I want to invite your parent/carer to take part in my research.
- I'm exploring how Covid-19 may have affected you and your parent/carer, as you became an adult.
- **Please read the information below if you want your parent/carer to take part.**



To help you understand this information you could:

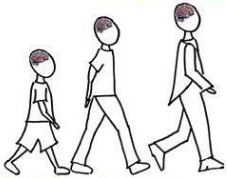
- Ask your parent/carer or another person you trust to go through it with you.
- Watch my video - [Research Video.mp4](#)
- Arrange a phone call or video call with me and your parent/carer.

1. What is the study?

I want to explore how the Covid-19 pandemic may have affected you and your parent/carer, as you became an adult.

I would like to interview your parent/carer.

2. Why has my parent/carer been invited?



You became an adult during the Covid-19 pandemic.

You were between **17-25 years old at the start of the first lockdown (23rd March 2020)**.

So you are between **20-29 years old now**.

3. Does my parent/carer have to take part?

No. They will only take part **if they want to** and you want them to.

They can only take part if you consent (agree) to this. You do not need to consent, it's completely **your choice**.

They can stop taking part before or during their interview and they don't need to say why.

They can take away their information from the study **up to one week after their interview**.



4. What will my parent/carer do?

They will take part in a **one-to-one interview with myself lasting up to one hour.**

This can be **in-person or online** depending on their choice and the distance between us, and at a date and time chosen by them.

Please see the **Interview Prompt Sheet** which shows the questions I plan to ask your parent/carer, and I may ask other questions to find out more about what they say.



Interview Prompt Sheet for Parents/Carers of Young Adults with Down Syndrome

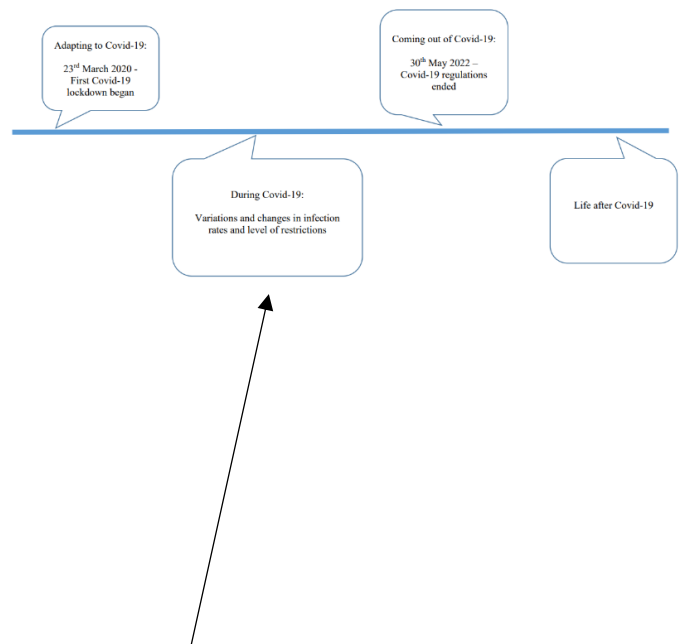
How did the Covid-19 pandemic impact your young adult's transition into adulthood?

Questions

1. Could you tell me a little about your young adult?
 - We could discuss:
 - Their age.
 - Their living arrangements.
 - How often you see them.
2. What was the Covid-19 pandemic period like for you and your young adult generally?
What has life been like since the pandemic?
3. How did Covid-19 and related restrictions impact your young adult's behaviour, at the time of the pandemic and in the longer-term?
 - We could discuss:
 - Their daily activities.
 - Their interests.
 - Interactions with yourself/others.



Covid-19 Pandemic Timeline (Memory Prompt)



The **Interview Prompt Sheet** also has a **Covid-19 timeline** to help your parent/carer remember your experiences.



Your parent/carer does not have to answer questions if they think this would make you or them feel uncomfortable.

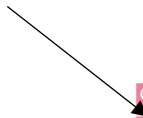
You could have a conversation with your parent/carer before their interview about things you would like them to share or not share, but **you do not have to do this**.

The interview will be **voice recorded** so that I can remember what they say.



5. What will I do?

If you are happy for your parent/carer to take part, please read, fill in and sign the **Consent Form for Young Adults with Down Syndrome**.



Consent Form for Young Adults with Down Syndrome

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

Thank you for your interest.

If you would like your parent/carer to take part, please:

- Read the **Information Sheet for Young Adults**.
- Read this form.
- Tick the boxes if you agree.
- Write or type your signature at the bottom.



- I have read and understood the **information sheet** and this **consent form** and I agree to my parent/carer taking part.
- I understand that **my parent/carer does not have to take part**. They can stop before or during their interview and don't need to say why. They also **don't have to answer questions** that would make them or me feel uncomfortable.



You can ask your parent/carer to help you with this.

You both could also get in touch with me if you have any questions.

6. Will our information be kept confidential (private)?

Yes.

Information will be stored securely on my **password-protected** computer.



Only me and my supervisor can see it.

The voice recording of your parent/carer's interview will be stored for **no more than two months** after their interview.



After I have made sense of the interview, **the recording will be destroyed.**

The **transcription** (a written version of the interview) will be **anonymised.**

This means **no one will know the interview was about you or your parent/carer.**

7. What will happen to the results of the research?

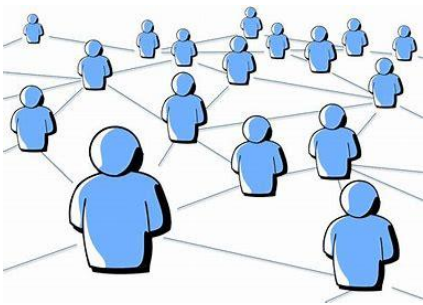
The findings will be written up for my thesis, which is a large research project that might be published (so more people can see it) at a later stage.

I plan to share findings with the organisation who advertised my study to your parent/carer so that they can share them with yourself and others.



You and your parent/carer can contact me if you want to talk about the findings or have any questions.

Your parent/carer taking part in this research will not affect your relationship with the organisation, or any member of it, in any way.



What your parent/carer shares with me could be helpful to you both, other young adults with Down Syndrome, and other parents/carers.

The findings could also be helpful to educational psychologists, and other people supporting young adults with Down Syndrome.

8. Where could I find advice/support for myself or my parent/carer?



If you would like support for yourself or your parent/carer, please speak to your parent/carer and consider contacting the following charities/organisations:

- **The Down's Syndrome Association:**
 - Website: <https://www.downs-syndrome.org.uk/>
 - Email address: 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
 - 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/>



9. What if there is a problem?

If you or your parent/carer have any questions, please contact me on the **email address below**.

There is also the email address for **my supervisor, Dr Dale Bartle** (the person who guides me with this research).

Contact Details:

- Eleri Davies, Researcher & Trainee Educational Psychologist:
daviesen1@cardiff.ac.uk
- Dr Dale Bartle, Research Supervisor, Course Tutor & Educational Psychologist: 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

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