

Adolescent Information Sheet

(reading/comprehension ages 13-17)

Title: Speech Fluency in Down Syndrome

Study Investigator(s): Dr. Shelly Jo Kraft, CCC-SLP and Emily Lowther, CCC-SLP

What is this about?

This is a research study. Research studies are how scientists find out answers to questions. Only people who choose to take part are included in research studies. You are being asked to take part in this study because you are a person with Down Syndrome. Please take time to make your decision. Talk to your family about it and be sure to ask questions about anything you don't understand.



Key Information about this study.

- This project is being conducted to learn more about the speech characteristics of people with Down Syndrome.
- This study will help us to update what we know about Down Syndrome, and what parts of speech might affect fluency (i.e. flow, or ease of talking) so we can learn how to make speaking a little easier for some.
- It is your choice whether to participate in this research project. This study is completely voluntary and you are free to withdraw at any time.
- This research involves reading through the relevant consent document(s), answering a few case-history questions, and being video-recorded while speaking for 10-20 minutes. It may take up to 30-40 minutes to complete.
- Your privacy is very important to us. The study uses encrypted servers for the videos in addition to safeguards to protect any data provided that could uniquely identify participants to be stored securely and accessed only by the lead investigators.

Why are they doing this study?

This study is being done to find out what parts of your speech affect its fluency. People with Down Syndrome today have very different lives than they had just 50 years ago, so we need to update what we know about lots of different things to do with being a person with Down Syndrome. One of the things we want to know is to do with your speech, and the different parts of your speech that may affect its fluency (i.e. flow, or ease of talking).



What will happen to me?

1. You will talk about this study with your parent/guardian and make sure you understand what is involved. Let them know if you are happy to continue.
2. We will ask you and/or your parent/guardian to complete some online survey questions about you, your speech and your family’s speech. These questions will only take about 5-10 minutes.
3. You will be recorded on video speaking or having a chat with someone for about 10 to 20 minutes.



How long will I be in the study?

You will be in the study for about 40 minutes.

Will the study help me?

You will not directly benefit from being in this study; however, information from this study may help other people with Down Syndrome in the future.

Will anything bad happen to me?

That is very unlikely. Being in this study doesn’t give you a greater risk of bad things happening.

Do my parents or guardians know about this?

This study information has been given to your parents/guardian and they said that you could be in it. You can talk this over with them before you decide.

What about privacy?

Every effort will be made to keep your records and/or your information confidential (i.e. private), however we do have to let some people look at your study records. Access to your videos and the audio part of your videos will be strictly controlled by the researchers and future project collaborators and will not include any information that can personally identify you.

We will keep your personal information private unless we are required by law to share it. The law says we have to tell someone if you might hurt yourself or someone else. The researchers can use the study data as long as you cannot be identified.

Can I change my mind?

Yes, you can change your mind at any time. Just let your parents / guardians know that you don’t want to take part anymore. You do not have to tell anybody why. Nobody will be annoyed if you change your mind.



What if I have any questions?

For questions about the study please call Dr. Shelly Jo Kraft at (313)-577-7587 or Emily Lowther at (313)577-4047. If you have questions or concerns about your rights as a research participant, the Chair of the Institutional Review Board can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call the Wayne State Research Subject Advocate at (313) 577-1628 to discuss problems, obtain information, or offer input.

Do I have to be in the study?

You don't have to be in this study if you don't want to or you can stop being in the study at any time. Please discuss your decision with your parents and researcher. No one will be angry if you decide to stop being in the study.

