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**A survey of the educational experiences of children with Down syndrome currently in UK schools (Reception-Year 11)**

**Participant Information Sheet (PIS)**

You are being invited to take part in a survey looking at the educational experiences of children with Down syndrome currently attending school in the UK (Reception-Year 11). Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

**About the research**

* **Who will conduct the research?**

This research is being conducted by researchers at The University of Manchester (Dr Kelly Burgoyne and Stephanie Hargreaves, Division of Human Communication, Development and Hearing) and LETS Go!, a specialist support service for children with Down syndrome.

* **What is the purpose of the research?**

The purpose of this research is to examine parents and educators’ views of the educational experiences of children with Down syndrome who are currently attending school in the UK.

We are looking for **parents and educators (including teachers, teaching assistants, SENCos) who have or are currently working with a child with Down syndrome attending a UK school** **(Reception-Year 11)** to take part in this survey. Your responses will inform several important questions about educational provision for children with Down syndrome and the factors which might support successful school experiences.

* **Will the outcomes of the research be published?**

We will prepare a written report of the study for publication, as well as a lay summary of the findings to be distributed via contact lists, websites and social media sites. We will also give at least one oral presentation of the study at a Down syndrome conference/event.

* **Who has reviewed the research project?**

The project has been reviewed by The University of Manchester Proportionate Research Ethics Committee.

**What would my involvement be?**

* **What would I be asked to do if I took part?**

You will be invited to complete an online survey about the educational experiences of children with Down syndrome, which includes questions about you and the child/children you are working with; the child’s participation in the curriculum and in extra-curricular activities; and educational resources and support. **You will not be asked to provide any personal information in the survey: all responses will be anonymous**.

The survey should take around 15 minutes to complete. We ask that you answer the questions as accurately as possible and complete the survey in 1 session as it is not possible to save and return to complete later.

* **Will I be compensated for taking part?**

You will not be compensated for taking part.

* **What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part. You have the right to withdraw at any time before the end of the survey, by simply not completing the survey. By virtue of completing and submitting your survey responses, you will be giving implied consent. If you decide to take part you are still free to withdraw without giving a reason and without detriment to yourself by not submitting your survey responses. Please note that it will not be possible to remove your data from the project after submitting your responses, because we are not collecting any identifiable information. This does not affect your data protection rights. If you decide not to take part you do not need to do anything further.

**Data Protection and Confidentiality**

* **What information will you collect about me?**

We will not collect any personal information that could identify you or the child/children you are working with. Some questions will have free-text response boxes - **please do not include names or any other information that could possibly link you/the child to your data.**

**What if I have a complaint?**

If you have a complaint that you wish to direct to members of the research team, please contact: **DR KELLY BURGOYNE –** [**KELLY.BURGOYNE@MANCHESTER.AC.UK**](mailto:KELLY.BURGOYNE@MANCHESTER.AC.UK) **/ 0161 275 7208 STEPHANIE HARGREAVES –** [**STEPHANIE.HARGREAVES@MANCHESTER.AC.UK**](mailto:STEPHANIE.HARGREAVES@MANCHESTER.AC.UK) **/ 0161 275 7208**

**If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact:**

TheResearch Governance and Integrity Officer, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: [research.complaints@manchester.ac.uk](mailto:research.complaints@manchester.ac.uk)  or by telephoning 0161 275 2674.

If you wish to contact us about your data protection rights, please email [dataprotection@manchester.ac.uk](mailto:dataprotection@manchester.ac.uk) or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner’s Office](https://ico.org.uk/concerns) about complaints relating to your personal identifiable information: 0303 123 1113.

**Contact Details**

If you have any queries about the study or if you are interested in taking part then please contact the researcher(s)**: DR KELLY BURGOYNE –** [**KELLY.BURGOYNE@MANCHESTER.AC.UK**](mailto:KELLY.BURGOYNE@MANCHESTER.AC.UK) **/ 0161 275 7208; STEPHANIE HARGREAVES –** [**STEPHANIE.HARGREAVES@MANCHESTER.AC.UK**](mailto:STEPHANIE.HARGREAVES@MANCHESTER.AC.UK) **/ 0161 275 7208.**