



Date

## PRIVACY NOTICE

You are participating in scientific research. This privacy notice informs you about the processing of your child's personal data as part of the research. You have a legal right to receive this information under the European Union and Finnish legislation.

### **Data Controller(s) in a study "The experience of parenthood in families with children with neurodevelopmental disorders (NDDs) living in Finland."**

The Data Controller is responsible for the lawful processing of personal data in this research.

The researcher (the Data Controller and implementer of the research) is Clara Vázquez. Contact information: 044 977 8482, [vazqmavz@jyu.fi](mailto:vazqmavz@jyu.fi).

Supervisor(s) name, position and contact information:

Aarno Laitila, Senior Lecturer at the Unit of the Faculty of Education and Psychology, [aarno.a.laitila@jyu.fi](mailto:aarno.a.laitila@jyu.fi), +358 40 805 3464  
(<https://www.jyu.fi/en/people/aarno-laitila>).

Tuija Aro, Associate Professor at the Unit of the Faculty of Education and Psychology, [tuija.i.aro@jyu.fi](mailto:tuija.i.aro@jyu.fi), +358 40 805 3732  
(<https://www.jyu.fi/en/people/tuija-aro>).

### **Team members who process personal data in this research:**

The Data Controller, the implementer of the research, and the supervisor are named above.

Katri Savolainen (Senior Lecturer, [katri.s.savolainen@jyu.fi](mailto:katri.s.savolainen@jyu.fi), +358 40 805 4854) will have access to the data in the supervision group.  
<https://www.jyu.fi/en/people/katri-savolainen>

#### **1. Processor(s) of personal data**

Processor of personal data refers to somebody processing personal data on behalf of the Data Controller and according to the Data Controller's instructions. In this research, there is no additional processors of personal data.

#### **2. Other disclosure of personal data during research**

Your data will be handled confidentially and without disclosing them to any outsiders.

#### **3. Personal data to be processed in "The experience of parenthood in families with children with neurodevelopmental disorders (NDDs) living in Finland."**

Your personal data will be processed for the research purpose described in the information letter.

In this research, we will collect the following personal data on you [e.g. age, email address, phone number, interview notes or videos). Data collection is based on the research plan.

This research involves the processing of personal data of the following special categories or offenses and criminal records:

- Race or ethnic origin.
- Health.

This privacy notice is delivered to the participants of this research via email and home address.

All data subjects are adults.

#### **4. The lawful basis for processing personal data in scientific research.**

- Scientific research serving a public interest (GDPR, Article 6.1e, special personal data categories 9.2j)
- Data subject's consent (GDPR, Article 6.1a, special personal data categories 9.2a)

#### **5. Transfer of personal data outside the EU/EEA area**

In this research, your personal data will not be transferred outside the EU/EEA area.

#### **6. Protection for personal data**

Processing of personal data in this research is based on an appropriate research plan and the study has a designated person in charge. The personal data collected and saved for this research will include only such data that is necessary for the research purpose.

##### **Preventing identification.**

- The data set is anonymised at the compilation stage (all identification data are fully removed so that there will be no return to the identifiable data and no new data can be connected to the data set).
- As a protective measure, any direct identification data are removed upon the compilation of the data set (pseudonymised data allowing restored identification using codes or equivalent information, and also new data connected to the data set).

#### **7. PROCESSING OF PERSONAL DATA AFTER THE RESEARCH HAS ENDED.**

The research register will be anonymised after the study has ended, approximately by 6 months. This means that all identification data are fully removed so that there will be no return to the identifiable personal data, nor any new data can be connected to this data set.

#### **8. Rights of the data subject**

##### Right to access your personal data (GDPR, Article 15)

You have the right to get to know whether and which personal data of yours are processed. If you wish, you can also request a copy of your personal data to be processed.

##### Right to rectification (GDPR, Article 16)

If there are any inaccuracies or errors in your personal data to be processed, you are entitled to request that these be rectified or supplemented.

##### Right to erasure (GDPR, Article 17)

You have the right to demand in some cases that your personal data be erased. However, the right of erasure is not applicable if the erasure would prevent or greatly hinder reaching the goal of processing in scientific research.

#### Right to restriction of processing (GDPR, Article 18)

You have the right to restrict the processing of your personal data in some cases, like when you challenge the correctness of your personal data.

#### Deviating from the rights

In some individual cases, it is possible to deviate from the described rights on the grounds stipulated in the GDPR and the Data Protection Act insofar as the rights would prevent or greatly hinder reaching the goals of scientific or historical research or statistical purposes. The need for deviating from the rights is always assessed case-specifically. It is also possible to deviate from the rights if the data subject cannot, or cannot any longer, be identified.

#### Profiling and automatised decision-making

In this research, your personal data will not be used for any automatic decision-making. In this research, the purpose of the processing of personal data is not to assess your personal qualities, i.e. profiling, but personal data and qualities are considered from the perspective of broader scientific research.

#### Reporting an actual or suspected information security breach to JYU

<https://help.jyu.fi/jp>

You have to lodge a complaint with a supervisory authority, especially with a locally relevant one in terms of your permanent place of residence or work if you regard that the processing of personal data violates the EU General Data Protection Regulation (EU) 2016/679. In Finland, the supervisory authority is the Data Protection Ombudsman.

Updated contact information of the Office of Data Protection Ombudsman: <https://tietosuoja.fi/etusivu>