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# Information for participants in the multi-domain on risk and resilience of neurodevelopmental diversity

For participants 15 years and older

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## About the project

At Karolinska Institutet, a research project is currently underway on risks and resilience in neurodevelopmental diversity, i.e. in various conditions that have to do with the functioning and maturation of the nervous system. **The study is a cross-sectional study on factors that are important for resilience and that support developmentally diverse people to have successful lives.** *Resilience* is the individual's ability to adapt, recover, and thrive despite negative events and have a positive life despite challenges.

**In this study, you will be interviewed by a member of the research team who will complete a checklist with you. If you are not of age, we might ask a parent or guardian to answer some questions. The checklist interview is expected to take about 60 – 120 minutes.** The questions will focus on you/your child, who you/they are, what you/they do, what things help you/your child have a happy life, and overcome challenges. This information will help us develop better ways to support people with developmental differences to live more successful and happy lives.

The background to the project is that the World Health Organization (WHO) has developed a tool to describe everyday abilities under different conditions. In English, the tool is called the International Classification of Functioning, Disability and Health (ICF). This project aims to develop a specially adapted short version of ICF for resilience in neurodevelopmental diversity. The idea is that this short version of resilience will create opportunities for both better care and better research for neurologically and developmentally different people. For example, healthcare could develop more structured ways to identify and describe the assets that someone has or that could be improved, which could help them have a better everyday life. One step in developing this short version of the ICF is to determine the factors that you think are important for resilience and for having a successful life.

## Why are you being asked?

You are asked to participate because you are an individual or a guardian of an individual who is developmentally different. For example, you or your child have received a diagnosis including autism, ADHD, dyslexia, or cerebral palsy, or were born prematurely, which affects daily life.

## How does the study work?

In this study, you will be interviewed by a researcher who will complete a checklist. The Checklist consists of questions sourced from the International Classification of Functioning, Disability, and Health. The checklist interview is expected to take about 60 – 120 minutes. You will not be required to complete any other tasks.

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## **Does this study involve any burden or risk?**

There are no known or obvious risks or burden associated with participating in this study, other than the time needed to complete your participation.

## **Are you receiving compensation?**

You will receive a gift card of 250 SEK after your participation.

## **Is there any benefit to participating?**

There is no direct benefit to you for participating in this study. However, your participation helps us to gain a better understanding of the things that are important to consider when considering what factors are important to support developmentally diverse people to live happy lives. This information will, in the long term, help us to develop instruments and interventions that can help us better support developmentally diverse people.

## **How do we handle data and privacy?**

The project will collect and record data about you. For this, you need to provide informed consent. You can withdraw your consent at any time. The processing of your personal data takes place in accordance with the EU's General Data Protection Regulation (GDPR).

Karolinska Institutet is responsible for your personal data. Your answers and your results will be processed so that unauthorized persons cannot access them and the data will be stored in accordance with Karolinska Institutet's data security procedures. Sensitive information about health and other personal circumstances is subject to strict confidentiality. All information stored about you will be de-identified, i.e. cannot be traced back to you. The data will only be used for the described purposes of the research project in question, and only information that is necessary for those purposes will be recorded. However, according to Swedish law, de-identified data may be disclosed to other researchers and to statisticians upon special request. We store data for at least 15 years. You have the right to access the personal data that is processed about you once a year, free of charge. If it turns out that there is something incorrect about you, that information must be corrected. After 15 years, the code key will be destroyed, after which it will no longer be possible to give anything out. If you are dissatisfied with how your personal data is processed, you have the right to file a complaint with the Swedish Authority for Privacy Protection (IMY) [imy@imy.se](mailto:imy@imy.se) or 08-657 61 00.

According to the EU's General Data Protection Regulation, you have the right to access the data about you that is processed in the project free of charge, and if necessary, to have any errors corrected. You can also request that data about you be deleted and that the processing of your personal data be restricted. However, the right to erasure and restriction of the processing of personal data does not apply when the data is necessary for the research in question. If you would like to access the information, please contact Sven Bölte, Karolinska Institutet, 171 77 Stockholm, tel. 08-524 800 00, [sven.bolte@ki.se](mailto:sven.bolte@ki.se). Contact information for KI's Data Protection Officer Mats Gustavsson ([mats.gustavsson@ki.se](mailto:mats.gustavsson@ki.se), 08-524 864 73). If you have comments or complaints about how KI processes your personal data, please contact [dataskyddsbud@ki.se](mailto:dataskyddsbud@ki.se).

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## How do I get information about the results of the study?

The results of the study will be published in scientific and popular science journals and can be made available by us upon request.

## How are you insured?

You are insured through patient insurance. In addition, the principal investigator (Department of Women's and Children's Health, Karolinska Institutet) is responsible for the study.

## Participation is voluntary!

Your participation in this study is voluntary. Even if you have accepted, you can discontinue participation in the study at any time and without explanation, without any consequences for your contacts with health care, school, employer or otherwise. If you choose to discontinue your participation in the study, no further information about you will be collected, but we have the right to keep what is collected until then.

## Who can I contact for more information?

If you have any questions about the study that are not answered in this information sheet, you are always welcome to contact us.

Melissa Black, Postdoctoral Fellow

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The project is carried out at the Center of Neurodevelopmental Disorders at Karolinska Institutet (KIND). Department of Women's and Children's Health, Karolinska Institutet. The main person responsible for the project is Sven Bölte, psychologist and professor at Karolinska Institutet.