



Assent

Social Story

Adolescent Version

For NeuroDev South Africa
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RESEARCH

Research is an organized way of collecting information to answer hard questions. We are doing research to: find out about **causes of diseases** and to **help prevent them and treat them.**



WHY?

We are questioning why some children and teenagers have difficulties making friends and have difficulties learning.



ASSENT

Before we start the research process, we need to make sure that you understand and agree to take part. This process is called **“assent”**.



WHO?

This study is being carried out by the University of Cape Town and scientists in the United States at Harvard University.



HARVARD
UNIVERSITY



WHO?

Some children and teenagers in our study have difficulties with their thinking and making friends and others do not. We are going to have **thousands** of children, teenagers and adults from different countries in our research.



WHAT?

We want to find out if there is something in our **DNA** that causes these problems.



DNA

DNA are in all the cells that make up our body. We get our DNA from both of our parents. That's why people might say you look like your mom or dad.



GENETICS

Our DNA are the **instructions** that tell cells to do different things in our body. The science of DNA is called **genetics**.



We can get DNA from **blood** and from **saliva**.



PARTICIPATION

To take part in this research we will get you to:

- Give us a blood and saliva sample
- Answer some questions
- Do some problem solving activities and games
- Have a photo

You **do not have to** take part in the study. You can decide if you want to take part or not, this is called **voluntary participation**. You can also decide later that you do not want to be part of the research.

Voluntary

RISKS

When we take your blood, it might cause a little pain – like a pin prick, there might also be a bruise and you might feel a bit dizzy.



RISKS

The information we collect about you will be stored on “the Cloud”, which is a group of computers that people access via the internet where documents are stored.



PROTECTION

The information we collected is protected with special passwords. The way your information is stored is coded (or changed) by using a barcode so no-one will know that it is you.

Your name will also not be stored anywhere.



RISKS

It probably won't happen, but there is a small chance that someone can hack into the Cloud and access your information. You may also be recognized by your photo, even though your name will not be on it.



BENEFITS

If you take part in our study you might help other children, teenagers and adults in the future by helping us learn and understand more.



STORAGE

Your blood and saliva will be sent to our **laboratories** in the United States and in South Africa where it will be stored and the scientists will have a look at it.



ACCESS

Some of the results the scientists get will be made available on databases that anyone can access. But, **none of the information will have your name on it.** It will only say if you are male or female, where you are from and what ethnic group you belong to.



CONSENT

If you agree to take part, we will ask you to fill-in a short form and sign it. This form says that you **understand** what we have told you and that you agree to take part. Your parents will also be asked to fill in a form.



Any questions?

