

## Understanding Research

### What is Autism Spectrum Disorder Research?

Autism Spectrum Disorder (ASD) research studies help to provide information about the nature and potential causes of ASDs, how to minimise the impact of ASD on individuals and their families, and how to best assist and support people with an ASD and their families.

There are lots of ways that researchers study ASDs, including looking at genes or how the brain functions; investigating how social skills, communication and behaviour develop compared with other children; and developing better educational and behavioural interventions for individuals on the spectrum.

#### Biological Research

Researchers want to find out the biological markers for ASD. Some investigate what genes might be involved in increasing the risk of developing an ASDs; others try to find out what brain chemicals or brain pathways are involved in ASDs. By understanding the neurobiology of ASDs we may be able to prevent ASDs in some cases and that we will be able to find medical treatments for people with an ASD.

#### Psychological and Language Research

Some researchers try to discover how the development of children with an ASD differs from other children. They are trying to understand why children have trouble with social skills like sharing interests, making friends or learning to communicate with others. Others are interested in why certain kinds of behaviours like special interests, repetitive behaviours or difficult behaviours occur and what this might tell us about ASDs. Understanding the behavioural development of children with an ASD helps us understand what parts of the brain might be functioning differently and what kinds of educational and intervention programs need to be developed to assist them.

#### Educational and Intervention Research

Many researchers are interested in developing educational programs that will help people with an ASD learn better, or in the case of young children, minimise the impact of an ASD on their development. Others are interested in developing specific interventions to address particular behaviours associated with ASDs, for example developing and testing social skills programs or a program for helping with difficult behaviour or sleep disturbances.

#### Family Research

Researchers also work with the families of people with an ASD for many reasons. First this can help to understand about the genetics of autism because we might see milder behaviours in some family members; second, by studying families we can better understand the positive and negative impacts of ASD on families and develop better ways to assist parents and brothers and sisters.

## What could you or your child be asked to do in a research study?

### **Biological Research Studies**

In these kinds of studies blood or saliva samples might be collected so that researchers can look at genes or various kinds of biochemicals, for example neurotransmitters or hormones. In other studies participants might be asked to wear a cap with wires that connect to electronic equipment to measure brain waves, or they might be asked to lie in a scanner that will take pictures of their brain. Often participants will be asked to do a simple activity while wearing the cap or lying in the scanner so that the researchers can see how the brain changes as they engage in the activity.

### **Surveys and questionnaires**

In many studies (including biological studies) participants are asked to complete surveys or questionnaires. These can give researchers information about types and patterns of strengths and difficulties that people with an ASD or their families face. This information can be used to assist in developing very specific studies about factors that might be important to improving our understanding of ASDs or for developing educational and intervention programs that better target the needs of people with ASDs and their families.

### **Epidemiological Studies**

These kinds of studies are not common, as they are hard to conduct. They survey large populations to find out how common ASDs are in a population, or how common particular kinds of problems or difficulties are for people with an ASD or their families. This kind of information is important for making sure that the right services are available and that there are enough services to meet the needs of those affected.

### **Observations**

Often researchers can learn a lot about ASDs by observing and recording behaviour in different kinds of situations and settings. These observations may take place in a laboratory at a university or in a school playground, depending on what the focus of the study. Behaviour observations can tell us more about the kinds of difficulties people with an ASD have, for example in social settings; or what they are good at. This information can inform both our understanding of ASDs and the development of interventions to assist people with ASDs.

### **Longitudinal Studies**

These kinds of studies try to follow people over a long period of time, for example if we follow a large group of infants for several years we can find out more about how ASDs develop, what they may look like in very young children and how they change over the course of development. Thus studies where people participate several times over a longer period of time can help inform the detection of ASDs, and treatment and intervention studies.

## **Intervention Studies or Randomised Trials**

These kinds of studies are conducted to try and find out which medical, educational or behavioural interventions work best for those with an ASD and their families. The best evidence comes from randomised controlled trials where participants are randomly assigned to a particular treatment group. Where possible it is also best if the participants don't know what kind of treatment they are getting but this is usually only possible for drug treatments.

## **What happens if I decide I am interested in participating in research?**

You can register your interest in participating in ASD research at the Olga Tennison Autism Research Centre. Your contact information remains confidential.

When a new research project is starting we will contact you with information about the study. At this point you can tell us if you are or are not interested or you can tell us that you want to find out more.

All studies that you are contacted about will have appropriate ethics approval. That is they have been seen and approved by the La Trobe University Human Research Ethics Committee (and sometimes an external ethics committee too). Ethics committees consist of members of the university and the community and their job is to look at the research and decide that there is minimal risk to participants and that the study is potentially beneficial.

You will be given written information about the study that explains what is involved. You are encouraged to ask any questions if there is something you don't understand. If you are still willing to participate, you (and sometimes your child if s/he is old enough), will be asked to sign that you understand about the study and are willing to participate. This is called giving informed consent.

## **What are the benefits to me, my child or family?**

Sometimes participating in research will have direct benefits to you and sometimes the benefits are indirect.

Direct benefits may occur for example if you participate in an educational or intervention study. However for most other kinds of studies benefits are indirect as you are helping researchers learn more about ASDs which may lead to benefits in the future for people with ASD or their families. If you are participating in a research project being conducted by an Honours or post-graduate student you are also helping train those who will work in the ASD field in the future.