

# INFOSHEET



## Participant Recruitment Advertisement

# Westmead Feelings Program pilot study for adolescents with a co-diagnosis of autism and mild intellectual disability

### What is this research study about?

The Westmead Feelings Program is a therapy program designed to improve the mental health and well-being of children on the autism spectrum who also have an intellectual disability. To date, the Program has been run for younger children. This study will pilot a version of the Westmead Feelings Program that has been adapted for adolescents aged 12 to 16 years. It will also investigate how this adapted version of the Westmead Feelings Program impacts on the emotions skills and well-being of these adolescents.

### Why should I take part?

Adolescents with a co-diagnosis of autism and mild intellectual disability are vulnerable to developing mental health problems like anxiety and depression. The results of this study will contribute to understanding how to best support the mental health and well-being of these adolescents. The adolescents and parent that take part in the clinical pilot will also directly benefit from being a part of the program as they will learn more about their own emotions and strategies that can support their emotional regulation. All adolescent participants in the focus group and clinical pilot will also receive a copy of their assessment reports.

### Who can take part?

The study is seeking participation from:

- *Adolescents* (aged 12 to 16 years) who have a co-diagnosis of autism and mild intellectual disability, and who can speak English in a minimum of short phrases and follow simple short instructions
  - together with *their parent/carer*
  - and *their school teacher*.
- *Educators or other professionals* who have at least three years' experience working with adolescents on the autism spectrum, and/or with a mild intellectual disability.

All participants will need to speak and understand English.

### Who is conducting this study?

This study is funded by Sydney Children's Hospitals Network, The Children's Hospital Westmead.

The study is being conducted by a research team from The Children's Hospital Westmead, Department of Psychological Medicine. The researchers are Anita Gardner, Dr Michelle Wong, Dr David Dossetor, Dr Belinda Ratcliffe, Jodie Caruana and Kim Eisler.

### What does the study involve?

#### Focus groups

The first part of the study involves focus groups. The purpose of the focus groups is to explore whether the version of Westmead Feelings Program that has been adapted for adolescents with a co-diagnosis of autism

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and mild intellectual disability meets the needs of these adolescents.

Separate focus groups will be held for adolescents; for their parents/carers, and for educators/other professionals.

### **Clinical pilot**

In the second part of the study, the adolescents, their parents/carers and their school teacher will be invited to take part in a clinical pilot of the adolescent version of the Westmead Feelings Program.

### **Eligibility assessment**

Prior to the focus groups and the clinical trial, adolescents whose families are interested in taking part in the study will first be assessed, to confirm their eligibility for the study. The families of those adolescents who are assessed as being eligible to take part in the study can then choose to participate in the focus groups, or the clinical pilot, or both.

## **What will adolescents be asked to do?**

### **Eligibility assessment**

Adolescents will be assessed at the Children's Hospital at Westmead to confirm their eligibility for the study. This assessment will be conducted by a psychologist and will include an autism assessment (Autism Diagnostic Observation Schedule - ADOS-2) and a cognitive assessment (Wechsler Intelligence Scale for Children - WISC-5). This assessment will take place in one appointment of approximately three hours; alternatively, it can be conducted in two appointments if this is helpful for the young person. Families will receive a report of these assessments. Adolescents who are assessed to be eligible to take part in the study will then be invited to participate in the focus group and/or the clinical trial, together with their parents/carers, and their school teacher.

### **Focus group**

Adolescents will attend one, 90-minute focus group. Focus groups will be run by members of the research team who are psychologists and a social worker.

There will be a maximum of five adolescents in each focus group. However, some adolescents may not feel comfortable communicating in a small group setting, or may have additional support needs that would not be suitable in a small group. To enable these adolescents to take part in this part of the study, the research team can hold an individual (one-on-one) session for each of these participants. This will be discussed in consultation with the adolescent's parent/carer, during the eligibility assessment.

During the focus group, children will be asked whether they like Westmead Feelings Program materials (for

example, "Which of these pictures do you like best?"); how important they think different skills are that are taught in the Westmead Feelings Program (for example, "Is it important for kids to be able to do something to help them to feel good when they feel upset?"); and about some of the social and emotional challenges that they currently face (for example, "What can make it hard to make friends?").

The focus group session will be video recorded so that it can be later transcribed.

The adolescents will also complete questionnaires relating to their learning, social skills, friendships and well-being. The questionnaires will take approximately 20 minutes to complete.

### **Clinical pilot**

In the clinical pilot, adolescents will attend 15 group sessions of the Westmead Feelings Program, plus one booster session (to be held six months after the completion of the program). Each session will run for 90 minutes, and will be conducted by members of the research team who are psychologists and a social worker. In the sessions, the adolescents will be taught skills in understanding their own emotions and the emotions of others, structured problem solving, and the management of emotions.

In addition, on four occasions the adolescents will complete paper and computer-based questionnaires that will ask for their opinion on how beneficial and suitable the Westmead Feelings Program has been in supporting their learning, social skills, friendships and well-being. On each occasion, the questionnaires will take approximately 30 minutes to complete.

## **What will parents/carers be asked to do?**

### **Eligibility assessment**

Prior to the focus groups and clinical pilot, parents/carers will be asked to assist in the completion of the assessments for the study. This will include bringing their child to The Children's Hospital Westmead for assessment. While their child is completing the assessment, parents/carers will complete questionnaires about their child's behaviours, social skills, strengths, interests and support needs. These questionnaires will take approximately 70 minutes to complete.

During the assessment, the research team will consult with parents/carers to consider if an individual session rather than a small group session will be more appropriate for their child.

### **Focus group**

Parents/carers who agree for their child to participate in the focus group stage will be invited to attend one parent/carer focus group. This focus group session will be

for two hours. In the focus group session, parents/carers will be asked about their understanding of their child's social and emotional strengths and weaknesses and some of the social and emotional challenges that their children currently face; and to provide feedback on the age appropriateness of a variety of resources and videos used in the Westmead Feelings Program. The focus group session will be video recorded so that it can be later transcribed.

### **Clinical pilot**

In the clinical pilot, parents/carers will attend three information sessions. Each information session will be one hour.

Parents/carers will also receive three handouts that summarise what their child has learnt throughout the program. Parents/carers will be asked to support their child's skills development in the periods between the clinic sessions by assisting their child with their Westmead Feelings Program take-home tasks and providing opportunities to practice the new skills at home.

Parent/carers sessions will be held at a time and place agreed by parents/carers and researchers.

As part of the clinical pilot, parents/carers will complete questionnaires to collect data on the Westmead Feeling Program, their child and their well-being. Questionnaires will take approximately 50 minutes to complete on three occasions.

### **What will teachers in the clinical pilot be asked to do?**

#### **Clinical pilot**

Each adolescent's school teacher will be asked to take part in the clinical pilot, by completing questionnaires and supporting the adolescent's emotional and social skills when they are at school.

Teachers will be asked to complete questionnaires on three occasions. The questionnaires will collect data on the Westmead Feeling Program and the adolescent's social and emotional skills at school. Each set of questionnaires will take approximately 40 minutes to complete.

Handouts on the Westmead Feelings Program will be sent home with the adolescents to be given to their teachers, so that teachers can help support their student's emotional and social skills when they are at school.

### **What will educators and other professionals in the focus group be asked to do?**

### **Focus group**

Educators and other professionals will attend one focus group. The focus group session will be for two hours and will be conducted by members of the research team. Participants will be asked about their understanding of adolescents' social and emotional strengths and weaknesses in the community and school settings, for feedback on the age appropriateness of a variety of resources and videos used in the adapted Westmead Feelings Program, and how feasible the program might be if conducted as part of the school curriculum or in a clinical setting. The session will be video recorded so that it can be transcribed later.

### **When and where?**

The eligibility assessment for adolescents will be held in Term 1, 2018 at Westmead.

All focus groups for adolescents, parents/carers and educators/professionals will be held in Term 1, 2018.

The clinical pilot for adolescents will be held across Term 2, Term 3 and Term 4 in 2018, with one booster session in Term 2, 2019.

For the clinical pilot, parents will attend a total of three information sessions, one in Term 2, 2018 one in Term 4, 2018 and one in Term 2, 2019.

All focus group and clinical pilot sessions will be held at Parramatta or Westmead at a time that is mutually agreeable for participants and researchers.

### **Ethics**

This study has been approved by Sydney Children's Hospitals Network Human Research Ethics Committee.

If you have any concerns about the conduct of this study, please contact the Executive Officer of the Ethics Committee (02 9845 3066) and quote approval number HREC/17/SCHN/386.

### **To find out more about the study and register to participate:**

To register to participate in the study, or if you would like further information about this study, please contact.

Anita Gardner, Research Psychologist, The Children's Hospital at Westmead

**telephone** 9845 2005

**email** Anita.Gardner@health.nsw.gov.au

*Please feel free to forward this information to others who might also be interested in participating.*