**PARTICIPANT INFORMATION STATEMENT (YOUNG ADULT)**

**RESEARCH STUDY TITLE:**

*FitSkills*: A community-university partnership to increase exercise participation among youth with disability

**INVESTIGATORS:**

Professor Nora Shields is Professor of Clinical and Community Practice at La Trobe University and Northern Health.

Professor Nicholas Taylor is Professor of Allied Health at La Trobe University and Eastern Health.

Professor Christine Imms is Professor of Occupational Therapy at Australian Catholic University.

Associate Professor Jennifer Watts is Associate Professor in Health Economics at Deakin University and is responsible for the economic evaluation aspect of this project.

Dr Luke Prendergast is Head of Department of Mathematics and Statistics at La Trobe University.

**ABOUT THE RESEARCH STUDY:**

You are invited to take part in our research study. We want to find out if an exercise program we have developed for youth with disability called *FitSkills* is feasible, effective and socially and economically useful. The program matches a young person with disability with a mentor from their community and they exercise together at their local gym, for an hour, twice a week for 12 weeks. You are being asked to take part because you are aged 13-30 years and have disability.

All participants in this research study will participate in the *FitSkills* program at some point. If you agree to take part, we will match you with a mentor from your local community and you will exercise with your mentor for 12 weeks at your local gym. The timing of when the program starts at your local gym will be decided at random but will start within the next 12 months. We will also ask you to do some tests 8 times over 2 years so that you will do some tests before and after doing the exercise program at your local gym.

**TESTS:**

You will be asked to do some tests, 8 different times over 2 years. The tests will be done either at La Trobe University (Melbourne campus at Bundoora), at your local community gym or at your home (if there is enough space at your home to do the test of walking capacity). Each testing session will take about 90 minutes. You and your family will need to travel to the place where the tests are done by yourself. The researchers will pay $20 towards the cost of travelling to do the tests, and will give you that money on the day of the test.

You will be asked to answer nine questionnaires. These are:

1. *Physical Activity Recall questionnaire*. This asks questions about what organised and non-organised sports, games and other physical activities you do at school, before and after school and on weekends, how many times each week you usually do them and how long you spend doing them.
2. *Sedentary Activity questionnaire*. This asks questions about 12 sedentary activities you might do and how often you do them during the school week and at the weekends.
3. *Children’s Assessment of Participation and Enjoyment questionnaire*. This asks questions about 16 physical activities you might do and how often you do them, who you do them with, where you do them, how much you enjoy them and your preference for doing these activities.
4. *Participation and Environment Measure-Children and Youth (community section)*. This asks questions about 10 community-based activities you might do and how involved you are in those activities. It also asks questions about your community environment, such as what makes it easier or harder for you to participate in your community.
5. *Child Health Utility instrument*. This asks 9 questions about your quality of life.
6. *Life Satisfaction Scale*. This asks 20 questions about your well-being.
7. *Exercise Outcome Expectations Scale*. This asks 9 questions about your attitude to exercise.
8. *Exercise Barriers Scale*. This asks 18 questions about things that might make it harder for you to exercise.
9. *Self-Efficacy Measure*. This asks 5 questions about how confident you are doing exercise.

We will also measure the following:

1. Physical Activity: you will be asked to wear a small monitor for 8 days around your waist to measure the amount of movement and walking that you do.
2. Walking capacity (6 minute walk test): we will ask you to walk for **6-minutes** and measure how far you can walk in that time.

You will be asked to do the following after you finish the 12 week exercise program:

1. Self-reported Experiences of Activity Settings. This asks 22 questions about your experience of the exercise program.
2. Measure of Environmental Qualities of Activity Settings questionnaires. This asks 66 questions about the setting of the exercise program (e.g. atmosphere, physical set-up).
3. A short interview to talk about what you liked and did not like about doing the exercise program. This interview will be recorded, so that we can listen to your answers later.

We also want to find out if the program is value for money. To do this we will need to collect information about you and your family such as where you work, how much money you earn, what help you need from other people, what you like to do in your spare time, how much it cost you to do the program and how often you had to see a health professional such as your GP, physiotherapist or occupational therapist.

**EXERCISE PROGRAM (*FITSKILLS*):**

You will be asked to take part in an exercise program called *FitSkills*. This program is specially designed for young people with disability. You will be buddied up with a student mentor who you will meet at a gym close to where you live and who you will exercise with. Your mentor will help you do the exercises in your program and they will exercise too.

* You will exercise two times a week for 12 weeks.
* You will need to travel to the gym by yourself or with your family.
* The researchers will pay the cost of you going to the gym.
* The researchers and you will plan and decide what exercises you will do at the gym. This will happen during an extra visit to the gym, just before your 12 week exercise program starts. During this visit, you will meet one of the researchers who will show you around the gym, introduce you to the equipment you may be using, and complete some exercises that will help us make an exercise program that is best for you.
* Your 12 week program might include exercise to make your muscles stronger (weight training exercises) or exercise to make your heart and lungs work better (aerobic exercise such as walking, running or cycling). As you get fitter, you will be asked to lift more weight with each exercise or run or cycle for a longer amount of time. It will take you about 60 minutes to do all your exercises during each session. You should tell your mentor straight away if you feel unwell or uncomfortable while doing your exercises.

If you decide to take part in this research study you may get fitter; for example, your arm and leg muscles might get stronger after doing the exercise program, and you might get better at doing some activities like going up and down stairs. Sometimes when people start exercising their muscles get sore but after a day or two their muscles are not sore anymore. This might happen at the start of your exercise program.

This research study has been approved by the University Human Ethics Committee at La Trobe University (HEC17-012) and Australian Catholic University. It has been given a grant from the National Health and Medical Research Council ($857,941.20) and we have also received cash ($190,000) and in kind contributions from our seven partner organisations (Victoria Department of Health and Human Services; Disability Sport & Recreation; YMCA Victoria; Cerebral Palsy Support Network; Down Syndrome Victoria; Joanne Tubb Foundation; City of Boroondara).

**DATA STORAGE:**

All the information we collect about you will be kept private. If you take part, we will not put your name on any files associated with the research study and no one apart from the people doing the study can see the files. The forms you fill out will be kept in a filing cabinet in the locked office of Professor Nora Shields at La Trobe University. At the end of the research study a summary of the results will be kept on a computer at La Trobe University. All this information we collect will be kept for 15 years after the end of the research study and then it will be destroyed.

**RESULTS OF THE RESEARCH STUDY:**

When the research study is finished, we will send you a summary of the results. Information about the research study may be written in journal articles or in presentations at conferences and seminars but your name will not be included in these reports.

**WITHDRAWING FROM THE RESEARCH STUDY:**

You may choose to stop being a part of this research study at any time. You may ask us to destroy any forms you have completed as part of the research study, provided that you tell us this within 4 weeks of having finished taking part. You do not have to take part in this research study and nothing bad will happen if you do not take part.

**QUESTIONS OR COMPLAINTS?**

If you have any questions about this research study you can telephone Professor Nora Shields at La Trobe University on (03) 9479 5852. If you have any complaints or questions that the researchers have been unable to answer, you may ask the Secretary of the University Human Ethics Committee, La Trobe University, Victoria 3086 by telephone 03 9479 1443 or by e-mail [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au)