**PARTICIPANT INFORMATION STATEMENT (PARENT OR GUARDIAN)**

**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.

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

**ABOUT THE RESEARCH STUDY:**

Your adolescent or young adult is 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. Your adolescent or young adult is being asked to take part because they are aged 13-30 years and have a disability.

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

**TESTS:**

Your adolescent or young adult 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 will need to transport your adolescent or young adult 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 your adolescent or young adult that money on the day of the test.

Your adolescent or young adult will be asked to answer nine questionnaires. You may be asked to assist your adolescent or young adult with answering these questionnaires. These are:

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

We will also measure the following:

1. Physical Activity: your adolescent or young adult will be asked to wear a small monitor for 8 days around their waist to measure the amount of movement and walking that they do.
2. Walking capacity (6 minute walk test): we will ask your adolescent or young adult to walk for **6-minutes** and measure how far they can walk in that time. If your adolescent or young adult cannot walk, then they will not have to do this test.

Your adolescent or young adult will be asked to do the following after they finish the 12 week exercise program:

1. Self-reported Experiences of Activity Settings. This asks 22 questions about their 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 your adolescent or young adult liked and did not like about doing the exercise program. We also invite you (the parent) to take part in a short interview to get your perspectives about the exercise program. These interviews will be recorded, so that we can listen to the 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 your adolescent or young adult and your family such as where they work or go to school, how much money they earn, what help do they need from other people, what they like to do in their spare time, how much it costs for them to do the program and how often they had to see a health professional such as their GP, physiotherapist or occupational therapist.

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

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

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

If your adolescent or young adult decides to take part in this research study they may get fitter; for example, their arm and leg muscles might get stronger, and they 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 adolescent or young adult’s 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 data collected as part of this research study will be confidential. If your adolescent or young adult takes part in the research study they will be given a code number, which will be used when entering data on computer files. Paper data will be stored in a filing cabinet in the locked office of Professor Nora Shields at La Trobe University. Data will be put on an electronic file on a computer that is password protected. Although the researchers will know who your adolescent or young adult is during the research study, their name will not be included as part of the results of this research study. Their identity will remain confidential. During and after the research study, computer records and written forms will be kept in a filing cabinet in the locked office of Professor Nora Shields at La Trobe University. No one apart from the researchers will have access to data. At the end of the research study a summary of the results will be kept as a computer file at La Trobe University. Data will be kept for 15 years after publication of the results of the research study and then it will be destroyed.

**RESULTS OF THE RESEARCH STUDY:**

When the research study is finished, the researchers will send a written report about the results to everyone who took part. If your adolescent or young adult wants a copy of their results they will be given these. The results of this study may appear in journal publications and in presentations at conferences but participants will not be named.

**WITHDRAWING FROM THE RESEARCH STUDY:**

Your adolescent or young adult has the right to stop taking part in the research study at any time. If they change their mind, you can request for them to be withdrawn from the study, provided you tell the principal researcher (Professor Nora Shields) within 4 weeks of having finished taking part. Once we receive your request, we will destroy all data we have related to your adolescent or young adult. To make this request, you will need to complete and sign a Revocation of Consent Form and send it to Professor Nora Shields at La Trobe University, Bundoora, VIC 3086. You may only make this request if they change your mind within 4 weeks of finishing the research study.

Taking part is purely voluntary and there are no disadvantages, penalties or adverse consequences for not taking part in or from stopping taking part in the research early.

**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)