PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: Parents/Guardians of Children with Autism Spectrum Disorder

Date: June 2019

Full Project Title: The Developmental and Social Benefits of a Classical/Contemporary AllPlay Dance Program for Children with Autism Spectrum Disorder

Principal Researcher: Professor Nicole Rinehart

Student Researcher: Ms Tayla Chellew

Associate Researcher(s): Professor Jane McGillivray, Dr Nicole Papadopoulos, Dr Ebony Lindor, Dr Olivia Millard, Dr Shaun McLeod, Susannah Bellows, A/Prof Jarrad Lum, Dr Jeroen van Boxtel, Jo Lim, Ashlee Barton, Amanda Daniel

Thank you for taking the time to read this Parent/Guardian Plain Language Statement. We would like to invite you and your child to participate in a research project entitled The Developmental and Social Benefits of a Classical/Contemporary AllPlay Dance Program for Children with Autism Spectrum Disorder. The purpose of this document is to explain to you as openly and clearly as possible all the procedures involved in this project so that you can make a fully informed decision whether you are going to participate.

Before you decide to participate, please ensure you read this document carefully. You can contact a member of the research team with any questions you have about the research project. You may also wish to discuss the project with a relative, friend or local health care worker.

1. Purpose and Background

This research project is about the benefits of dance for children with Autism Spectrum Disorder (ASD). We know that dance encourages many positive behaviours such as physical activity, creativity, emotional expression and social interaction, yet children with neurodevelopmental disorders/disabilities often face barriers to participating in dance and have fewer opportunities to take part in recreational programs compared to their typically-developing peers. As a consequence, not many studies have been able to directly assess the benefits of recreational dance for children with ASD. This project aims to fill that gap by offering a classical/contemporary dance program to children with ASD to explore whether these young dancers experience any benefits to social functioning, thinking/cognitive abilities, emotional and behavioural wellbeing, and/or motor skills.

If you have a child aged 7-12 with a diagnosis of ASD without an accompanying intellectual disability, you and your child may be eligible to participate in this project. All children who enrol in the project will have the opportunity to participate in an 8-week dance program during Term 3 or Term 4 of 2019. You and your child will also be asked to complete a range of tasks and questionnaires at two time points (see procedure section for more information).

2. Funding

This project is being funded by philanthropic donations from MECCA and the Grace and Emilio Foundation. Additional funding has also been provided by Jonathan and Simone Wenig, and Deakin University, to support a PhD student on the project.
3. Procedures

General Timeline

If you decide to participate in this research project, we will start by asking you some introductory questions to determine whether the study is suitable for your child. This will involve questions about your child’s age, diagnoses, level of functioning and past dance experience. If your child is eligible for the study, we will ask you to provide confirmation of ASD diagnosis and sign the consent forms. Following this, you will be asked to complete a short online survey and bring your child along to a face-to-face testing session at Deakin University, Burwood Campus. Your child will then be randomly allocated to one of two groups: the intervention group or the wait-list control group. The only difference between the intervention group and the wait-list control group is the time at which the groups complete the dance program.

Children allocated to the intervention group will have the opportunity to engage in the dance program during Term 3. Once the intervention group has completed the dance program, all participants will be asked to repeat the survey and face-to-face measures. When all data has been collected, children allocated to the wait-list control group will have the opportunity to complete the same dance program during Term 4. The reason for this structure is so we can compare any improvements experienced by children who have participated in the dance program (i.e., the intervention group) to children who have not participated in the program (i.e., the wait-list control group). Gathering data from all participants at these two time points will help us assess any potential benefits of the program more accurately.

What Do the Face-to-Face Sessions Involve?

During the face-to-face sessions, children will be asked to complete a range of thinking and movement tasks (e.g., word games, puzzles, coordination and balance games) one on one with a member of the research team. Some of the movement tasks will involve videoing your child as they perform simple actions (e.g., walking, jumping, waving). They will also engage in some computer games while their eye movements are tracked. These games involve following shapes as they appear on screen, working out the location/identity of objects, and interpreting simple human movements and interactions. All face-to-face testing sessions will be held at Deakin University, Burwood Campus and will take around 1.5-2 hours to complete.

What Do the Parent Surveys Involve?

In the initial survey, you will have the option to provide background information about yourself and your child (e.g., your age, education level, employment status, child’s diagnoses and health). The main component of the surveys will then consist of standardised measures of your child’s current level of functioning and strengths and weaknesses; these span a range of domains including social abilities, thinking skills, emotional and behavioural functioning, and movement abilities. As we are also interested in continuing to improve our program, you and your child will also have the opportunity to complete some online feedback questions about your experiences after completing the dance program. All surveys can be completed remotely on any device with access to the internet. Parent surveys will take approximately 30 minutes to complete.

What Happens During the Dance Program?

The dance program will consist of 8 x 1 hour weekly dance sessions, following which your child will be invited to participate in a rehearsal session and short performance for family and friends. The program will have a classical/contemporary focus and sessions will be conducted by dance and disability experts. During each session, children will also be paired with older experienced dancers/buddies who will assist in teaching the syllabus and supporting them through the program. The sessions will be videoed so that the research team can track any improvements in functioning. Between sessions, we will also make available pre-prepared dance videos of the steps and choreography your child will learn in upcoming sessions to further support their learning.
4. **Possible Benefits**

Your child will have the opportunity to learn dance in a safe and inclusive environment designed to cater to their abilities. Your family’s involvement may also help us to gain a better understanding of the social, cognitive, emotional, behavioural and motor benefits of participating in dance.

5. **Possible Risks**

While we do not expect the project to pose any significant risks to you or your child, there is a possibility of physical injury to your child during the dance classes. Other potential risks may include mild discomfort when participating in the classes or assessment process or when answering questions about your child’s challenges. To mitigate any risk of injury or discomfort, all dance classes will be adapted to your child’s needs and conducted by disability and dance experts who hold a first aid certificate and working with children check. Your child will be able to participate in the dance classes with any supports they require including assistance from a carer and/or support worker. Throughout the program, alternative movement variations and participation options will be provided to cater to your child’s strengths. If you or your child finds any part of the research too challenging or anxiety provoking, you are able to take breaks, decline participation in any or all activities, or withdraw from the project. If any of the questions make you feel uncomfortable or you become distressed and you wish to speak to someone about this, please call a member of the research team on the details listed at the end of the Plain Language Statement.

6. **Privacy, Confidentiality and Disclosure of Information**

We respect your privacy and will not disclose your information without your permission. The information we collect will be coded so that all identifiable details are removed and only group-level data or de-identified responses are included in any future publications or presentations. Any information we collect that can identify you will remain confidential and will be stored on a secure Deakin University server in a protected database (REDCap) or password protected computer, or in locked cabinets within the School of Psychology at Deakin University. Data will be kept until the youngest participant in the study turns 25. Only the research team will have access to this information.

7. **Results of Project**

The findings from this project may be published in scientific journals, included in annual reports and/or presented at conferences. This will be done in such a way that you cannot be identified. The findings may also be written up by a student researcher to satisfy the requirements of a PhD thesis. Where consent has been obtained and ethics approval granted, data collected for this research project may also be used in related projects.

If you would like a summary of the overall findings, please select ‘yes’ to this question at the end of the online survey and provide your email address.

8. **Participation is Voluntary**

Participation in any research project is voluntary. You are not obliged to take part; deciding whether to participate is completely your choice. Participation is also independent of and separate from any other involvement with Deakin University, our partners, and/or any clinical care received. If you choose to participate and later change your mind, you are free to withdraw from the project. If you decide to withdraw, please notify the research team. You do not need to tell us the reason why you wanted to stop being in the project. If you leave the project, we will use any information already collected unless you tell us not to do so. Your decision to participate in the project, decline to participate, or withdraw, will not affect your relationship with Deakin University or any research partners.
9. Optional Consents

We would like you to consider the following optional parts of this project. You may agree to none, some or all optional parts. If you choose to not agree, it will not affect your participation in the rest of the project.

Diagnostic and Assessment Records:

We would like to access the results of any assessments related to ASD that your child may have completed in the past, including assessments for diagnosis, IQ, adaptive functioning and/or language. We will use this information to help us understand whether the program is beneficial for children with a range of abilities. If you do not have copies of these reports yourself, with your permission we will request them from health professionals your child has visited.

Video Recording:

During the dance program, we may collect photograph, video and audio footage of you and/or your child to document the program for promotional purposes. The attached consent forms outline where and how this footage may be used in more detail. If you do not wish for you and/or your child’s voice or image to be used in this manner, simply tick “no” to that option on the consent forms.

Using Data in Related Research Projects:

With your consent and ethics approval, we may wish to use the data you and your child provide during this study in other related research projects. As is the case with this project, only group-level data or de-identified responses will be included in any future publications or presentations. Any information we collect that can identify you will remain confidential and will be stored in locked cabinets and password protected computers/servers within the School of Psychology at Deakin University. If you agree to participate in future research related to this study your data may be stored for a longer period of time in accordance with the ethics attached to the future research study. Your data will only be accessible by members of the research team.

Future Research Opportunities:

If you are interested in being contacted about future research opportunities related to this study, please select this option on the consent form. At the end of the final survey we will also invite you to register your details with the Deakin Child Study Centre Research Registry. The Research Registry supports recruitment for child development research and is a helpful way of keeping up to date with any relevant research opportunities that you may be eligible for in the future. The survey will include a link with further information about our Research Registry. You can simply close the browser if you are not interested.

10. Ethical Guidelines

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethics aspects of this research project have been approved by the Human Research Ethics Committee of Deakin University.

11. Complaints

If you have a concern, in the first instance you should speak to one of our researchers on the details listed at the end of this Plain Language Statement. Should you have any further concerns or complaints about any aspect of the project, the way it is being conducted, or any questions about your rights as a research participant, then you may contact:

The Manager, Office of Research Integrity, Deakin University, 221 Burwood Highway, Burwood Victoria 3125,
Please quote project ID: 2019-061

12. Register Your Interest

If you would like to participate in this research project, please begin by registering your interest on our landing page: http://allplaydance.org.au/asd-dancers/. Here, you will be able to provide your contact details and complete some preliminary questions so the research team can assess whether the project is suitable for you and your child. A member of the research team will then be in touch to discuss the suitability of the project, answer any questions you have, and help you complete the enrolment and consent process.

13. Contact Us

For further information, queries or any problems, please contact us on the details listed below:

**Study Phone:** 9244 5712  
**Study Email:** apdancebenefits@deakin.edu.au

**Susannah Bellows, Project Coordinator**  
School of Psychology, Deakin University,  
221 Burwood Highway, Burwood, Victoria, 3125  
E: susannah.bellows@deakin.edu.au  
P: 03 9246 8471

**Professor Nicole Rinehart, Principal Researcher**  
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221 Burwood Highway, Burwood, Victoria, 3125  
E: nicole.rinehart@deakin.edu.au  
P: 03 9244 5469
PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: Parents/Guardians of Children with Autism Spectrum Disorder

Consent Form
This consent form relates to your involvement in the project as a parent/guardian.

Date: June 2019

Full Project Title: The Developmental and Social Benefits of a Classical/Contemporary AllPlay Dance Program for Children with Autism Spectrum Disorder

Reference Number: 2019-061

I have read and I understand the attached Plain Language Statement.

I freely agree to participate in this project according to the conditions in the Plain Language Statement.

I have been given a copy of the Plain Language Statement and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details, including where information about this project is published, or presented in any public form.

Please also consider the following optional parts of this project:

I agree for the data that I provide during this project to be used in future related research conducted by Deakin Child Study Centre. □ Yes □ No

I agree to be contacted about future research opportunities. □ Yes □ No

I agree that my image and voice may be made available by Deakin University as part of the “AllPlay” program, an initiative of Deakin University to make sport, dance and education more inclusive for kids of all abilities. I additionally consent to the use of my image and voice by Deakin University and its partners for advertising; marketing or promotional/commercial materials, teaching and learning and research materials. The images/sounds may be used in websites, social media, publications, presentations, CD-ROMs, DVDs, iTunes U, banners/signage/posters and other digital or print formats. I understand that I will receive no royalty, remuneration or compensation for their use. □ Yes □ No

Parent/Guardian’s Name: ________________________________

Address: ________________________________

Phone: ________________________________

Email: ________________________________

Parent/Guardian’s Signature: ________________________________ Date: ________________
**PLAIN LANGUAGE STATEMENT AND CONSENT FORM**

**TO: Parents/Guardians of Children with Autism Spectrum Disorder**

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<th>Third Party Consent Form</th>
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<td>This consent form relates to your child’s involvement in the study.</td>
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**Date:** June 2019

**Full Project Title:** The Developmental and Social Benefits of a Classical/Contemporary AllPlay Dance Program for Children with Autism Spectrum Disorder

**Reference Number:** 2019-061

I have read, and I understand, the attached Plain Language Statement.

I give my permission for ........................................................................... *(name of child)* to participate in this project according to the conditions in the Plain Language Statement.

I have been given a copy of Plain Language Statement and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details or the identity and personal details of the person for whom I am providing consent, including where information about this project is published, or presented in any public form.

Please also consider the following optional parts of this project:

| I agree for the researchers to access copies of my child’s assessments and medical records related to his/her ASD. | □ Yes | □ No |
| I agree for the data that my child provides during this project to be used in future related research conducted by Deakin Child Study Centre. | □ Yes | □ No |
| I agree that my child’s image and voice may be made available by Deakin University as part of the “AllPlay” program, an initiative of Deakin University to make sport, dance and education more inclusive for kids of all abilities. I additionally consent to the use of my child’s image and voice by Deakin University and its partners for advertising; marketing or promotional/commercial materials, teaching and learning and research materials. The images/sounds may be used in websites, social media, publications, presentations, CD-ROMs, DVDs, iTunes U, banners/signage/posters and other digital or print formats. I understand that my child and I will receive no royalty, remuneration or compensation for their use. | □ Yes | □ No |

**Child’s Name:**

**Name of Parent/Guardian Giving Consent:**

**Relationship to Child:**

**Parent/Guardian’s Signature:** ___________________________  **Date:** __________