1. ADMINISTRATION DETAILS

ETHICS ID: 1441672.1
TITLE: Parent perception of the benefits of music therapy for their children with autism spectrum disorder.
APPLICATION TYPE: Minimal Risk
RESPONSIBLE RESEARCHER: THOMPSON, DR GRACE ANNE
RESPONSIBLE HEAG: Music
HESC: Humanities and Applied Sciences
ADMINISTERING DEPARTMENT: 7420 - Melbourne Conservatorium Of Music
ADMINISTERING CENTRE: (if applicable)

2. MINIMAL RISK CHECKLIST REVIEW

The responses to the Minimal Risk Checklist are summarised below.

<table>
<thead>
<tr>
<th>Risk Assessment Topics</th>
<th>None identified</th>
</tr>
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<tbody>
<tr>
<td>Risk Assessment Procedures</td>
<td>None identified</td>
</tr>
<tr>
<td>Risks to Researchers</td>
<td>None identified</td>
</tr>
<tr>
<td>Vulnerability Assessment</td>
<td>None identified</td>
</tr>
<tr>
<td>Overseas Research</td>
<td>None identified</td>
</tr>
</tbody>
</table>

3. PROJECT DETAILS

PROJECT TYPE: Staff Research Project
RESEARCH INVOLVES: Locations other than/in addition to Uni of Melbourne
BRIEF DESCRIPTION: This project will invite parents who participated in a family-centred music therapy research project in 2010 to complete a follow up survey about their use of music in the home, and participate in an interview exploring what they now perceive to be the most valuable aspects of music therapy for their child and family, if any, as they reflect back over the past 4 years.

PROPOSED DURATION OF WHOLE RESEARCH PROJECT:
From: SEP-2014 To: FEB-2016

PROPOSED DATE TO COMMENCE DATA COLLECTION: 01-Sep-2014

4. PERSON DETAILS

Responsible Researcher

<table>
<thead>
<tr>
<th>Name</th>
<th>Thompson, Dr Grace</th>
<th>Department</th>
<th>7420 - Melbourne Conservatorium Of Music</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person Type</td>
<td>Staff</td>
<td>Centre</td>
<td></td>
</tr>
<tr>
<td>Phone Number</td>
<td>03 9035 8978/Alt:9035 8978</td>
<td>Email Address</td>
<td><a href="mailto:graceat@unimelb.edu.au">graceat@unimelb.edu.au</a></td>
</tr>
</tbody>
</table>
Qualifications
- Bachelors Degree, University of Melbourne
- PhD, University of Melbourne

Experience & Skills Relevant to the Project
Previous experience with interview analysis in PhD research.

Additional Training Required

Ethics Training Already Undertaken
Current member of the local HEAG

5. ADDITIONAL QUESTIONS

5.1 Location of Research

Location Where Research Will Be Carried Out: External sites within Australia
Category of External Location: Private Venues

5.2 Other Approvals Required (other than ethics clearances)

Approvals Required: Not required

5.3 Other Ethics Clearances/Details of Multicentre Research

Other Clearances Required: Not required
Responsible HREC:
Comments:

6. ATTACHMENTS

PLEASE ENSURE YOU ATTACH A PAPER COPY OF EACH OF THE FOLLOWING ATTACHMENTS:

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>Attached Via Themis</th>
<th>Hard Copy Only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Application</td>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Consent Form</td>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Interview</td>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Plain Language</td>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Statement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Questionnaire/Survey</td>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
Enter the Ethics ID number assigned by Themis Research to this ethics application.

1441672.1

Parent perception of the benefits of music therapy for their children with autism spectrum disorder (ASD).

Enter the title of the Project as recorded in Themis Research

Parent perception of the benefits of music therapy for their children with autism spectrum disorder (ASD).

Enter the name of the Responsible Researcher as recorded in Themis Research

Dr Grace Thompson

PROJECT REFERENCE DETAILS

1. PROJECT DETAILS

1.1 EXECUTIVE SUMMARY IN PLAIN ENGLISH: Provide a brief summary of the project outlining the broad aims, background, key questions, research design/approach, the participants in the study and what they will be asked to do, and the importance or relevance of the project. [This description must be in everyday language, free from jargon, technical terms or discipline-specific phrases. (No more than 300 words).]

Background: Preschool aged children with ASD now routinely participate in family-centred intervention programs, where parents and professionals collaborate together to support the child’s development and social inclusion (ECIA, 2011). While past studies have sought to investigate how music therapy assists children with ASD with core impairments, such as social interaction and communication (Reschke-Hernandez, 2011), these domains are also targeted by many other early childhood professionals and programs (Kaale, Smith, & Sponheim, 2012). Understanding why parents of children with ASD seek to engage in music therapy will help to shape future research by highlighting developmental domains or family needs that may be especially addressed by music therapy and therefore warrant further investigation.

Aim & Key questions: To explore parents' perspectives on the value and use of music and music therapy for their child with ASD, focussing on two aspects:

1. What has been the impact of the families’ use of music in the home following participation in a music therapy program?
2. What do parents perceive are the most valuable outcomes of music therapy when reflecting on their child's and family’s participation?

Design: Question 1 will collect survey data, comprising a combination of numeric data, sort and long answer text. Question 2 will involve conducting semi-structured interviews with participants, which will be analysed using Interpretative Phenomenological Analysis (IPA).

Participants: Twenty-three families participated in an earlier family-centred music therapy research project in 2010 (Thompson, 2012). It is hoped that at least 12 parents will be available to answer survey-style questions over the phone or online, and at least 6 of these parents will be available for an in depth interview.

Data (what participants will be asked to do): Complete a survey over the phone or online taking approximately 15 minutes, and then if interested, to participate in a face-to-face interview for approximately 45 minutes. Participants can choose to complete both or either components.

Importance/relevance: This study provides an opportunity to collect longitudinal data about if and how families have continued to use music in the home with their child, as well as their longitudinal perspective on how music therapy was valuable to their child and family. To the researcher's knowledge, this will be the first study of its
kind to investigate parents’ reflections on the impacts of a past program which will likely provide important insight into areas for future research.

1.2 AIMS OF AND JUSTIFICATION FOR THE RESEARCH: State the aims and significance of the project. Where relevant, state the specific hypothesis to be tested. Also provide a brief description of current research/literature review, a justification as to why this research should proceed and an explanation of any expected benefits to the community. [No more than 500 words]

Background: Preschool aged children with ASD now routinely participate in family-centred intervention programs, where parents and professionals collaborate together to support the child’s development and social inclusion (ECIA, 2011). Early child development theory identifies that strong parent-child relationships are a significant factor in the child’s social and emotional growth, which is considered foundational in promoting developmental gains (Greenspan, 2001). Early childhood professionals strive to work alongside parents and collaboratively identify goals that are meaningful to both the child’s developmental stage and the family’s priorities (Dunst & Trivette, 2009).

While past studies have sought to investigate how music therapy assists children with ASD with core impairments, such as social interaction and communication (Kim, Wigram, & Gold, 2008; Reschke-Hernandez, 2011; Thompson, McFerran, & Gold, 2013), these domains are also targeted by many other early childhood professionals and programs (Kaale, Smith, & Sponheim, 2012; Vivanti, Dissanayake, Zierhut, & Rogers, 2012). Understanding why parents of children with ASD seek to engage in music therapy will help to shape future research by highlighting developmental domains or family needs that may be especially addressed by music therapy and therefore warrant further investigation.

In addition, family-centred approaches aim to build the capacity of parents to support their child’s development immediately and into the future, and therefore offer parents a variety of resources. One indication of whether these resources have been relevant and useful to the family is to consider how well they have been incorporated into everyday life (Thompson, 2014). Understanding how participating in music therapy programs has impacted the way families use music in their daily routines will further assist music therapists to develop relevant and meaningful programs for children with ASD.

Aim: This project will explore parents’ perspectives on the value and use of music and music therapy for their child with ASD, focussing on two aspects and asking the following research questions:

1. "What has been the impact of the families’ use of music in the home following participation in a music therapy program?"

This project will firstly follow up with parents who previously participated alongside their children in an intensive family-centred music therapy program in 2010 (Thompson, 2012). This study provides an opportunity to collect longitudinal data about if and how families have continued to use music in the home with their child, and would be the first study of its kind to the researcher’s knowledge.

2. "What do parents perceive are the most valuable outcomes of music therapy when reflecting on their child's and family’s participation?"

This project will therefore also explore parents’ reflections on the benefits of music therapy for their child with ASD now that 4 years have passed since their participation. Interviews will be conducted with parents who previously participated alongside their children in an intensive family-centred music therapy program in 2010 (Thompson, 2012), providing the opportunity for parents to provide a longitudinal perspective on change.

Benefits to the community: To the researcher’s knowledge, this would be the first study of its kind to investigate reflections on the impact of music so long after the child’s participation. While definitive developmental data will not be collected, parent perspective on the value of participating in music therapy will likely provide important insight into areas for future research. It is therefore anticipated that this study will form the first stage of a larger sequential study, with the design of subsequent stages based on these findings.

1.3 METHOD
(a) What data collection technique(s) will be used? [Tick as many as apply]
- Questionnaire (attach a copy)
- Interviews (attach a copy)
- Observation of participants without their knowledge
- Covert observation
- Audio- or video-taping interviewees or events (with consent)
- Other (Please give details. Use no more than 50 words): 

(b) What tasks will participants be asked to do? What is the estimated time commitment involved? How will data be analysed?

Participants will be invited to complete a survey over the phone or online taking approximately 15 minutes, and then if interested, to participate in a face-to-face interview for approximately 45 minutes. Participants can choose
to complete both or either components. Families will also have the opportunity to read the analysis summary of their interview for approval and editing, taking approximately 30 minutes.

The survey data will comprise a combination of numeric data, sort answer and long answer. Data in the form of text will be analysed using a content analysis approach (Hsieh & Shannon, 2005), while numeric data will be descriptively reported and presented.

The interview will follow a qualitative research approach through conducting semi-structured interviews with participants, which will be analysed using Interpretative Phenomenological Analysis (IPA). IPA is an approach to qualitative, experiential and psychological research that is concerned with the detailed examination of personal lived experience, the meaning of experience to participants and how participants make sense of that experience. In IPA, data collection events are designed to elicit detailed stories, thoughts and feelings from the participants, with semi-structured, one-to-one interviews being the preferred method for collecting such data (Smith, Flowers, & Larkin, 2009). Families will also have the opportunity to read the analysis summary of their interview for verification. This qualitative inquiry using semi-structured interviews will allow the researcher to deeply examine and better understand parent’s subjective experiences of music therapy with their child.

### 1.4 USE OF INDEPENDENT CONTRACTORS

*Will parts of this project be carried out by independent contractors? (e.g. interviewing, questionnaire design and analysis, sample testing, etc)*

<table>
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<th>☒ YES</th>
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*If YES, confirm that the independent contractor will be engaged on the basis of relevant qualifications and experience and will receive from the first named Principal Researcher, a copy of the approved ethics protocol and be made aware of their responsibilities arising from it. [The responsibility for effective oversight and proper conduct of the project remains with the Principal Researcher(s)]*

An experienced research assistant will conduct the interviews with the families. The principal researcher will then transcribe and analyse the interviews.

The principal researcher will set up the online survey, and conduct the survey with those where parents who wish to complete it over the phone. As the survey does not ask families to evaluate the music therapy program, there is no risk of bias.

### 1.5 MONITORING

(a) *How will researchers monitor the conduct of the project to ensure that it complies with the protocols set out in this application, the University’s human ethics guidelines and the National Statement on Ethical Conduct in Human Research? [Address, in particular, cases where several people are involved in recruiting, interviewing or administering procedures, or when the research is being carried out at some distance from the Principal Researcher (i.e. interstate or overseas)]*

The principal researcher will train and supervise the research assistant at the time of the interviews. All recruitment will be carried out by the Principal Researcher in accordance with the National Statement. The Principal Researcher is a member of the local HEAG committee, and so has considerable experience with human ethics guidelines.

(b) *For student research projects how will the student be supervised to ensure they comply with the protocols? If the student is working overseas, provide additional details of any local supervision arrangements.*

N/A

### 2. PARTICIPANT DETAILS

#### 2.1 TARGET PARTICIPANT GROUP

*Please indicate the targeted participant group by ticking all boxes that apply. Expand any responses necessary in the space provided at “Other”.*

| Students or staff of this University | ☐ | Adults (over 18 years old and competent to give consent) | ☒ |
| Children/legal minors (under 18 years old) (with parental consent) | ☐ | Other (Please give details. Use no more than 50 words): | ☐ |

| People from non-English speaking backgrounds | ☐ |

#### 2.2 NUMBER, AGE RANGE AND SOURCE OF PARTICIPANTS
Provide number, age range and source of participants.

Participants will be parents of children with ASD, and so expected to be in the age range of 25-45 years old. Participants will be sourced from the pool of twenty-three families who participated in the earlier family-centred music therapy research project in 2010 (Thompson, 2012). It is hoped that at least 12 parents will be available to answer survey-style questions over the phone or online, and at least 6 of these parents will be available for an in-depth interview.

2.3 JUSTIFICATION OF PARTICIPANT NUMBERS [The quality and validity of research is an essential condition of its ethical acceptability (refer National Statement)]. Where applicable, provide a justification of sample size (including details of statistical power of the sample, where appropriate), explaining how this sample size will allow the aims of the study to be achieved.

As the aim of this study is to explore parents’ perspectives on the value and use of music and music therapy for their child with ASD, small numbers are adequate to inform the design of a planned subsequent study. There are two components to the data collection, both with different considerations for justification of participant numbers.

The survey data: It is difficult to know how many of the 23 original participants from the 2010 music therapy program will respond to this call for recruitment. As this study aims to provide exploratory and preliminary data for a subsequent study, any data collected will be useful, however ideally the researchers aim to recruit a minimum of 6 families, and hope to recruit at least 12 families. Numeric data analysis will only be descriptive, so there is no threshold for power for statistical significance. If less than 6 families respond to the invitation to participate, this data can still inform the planned subsequent study, but results will likely not be meaningful enough to publish.

The interview data: IPA approaches advocate for at least 6 participants to conduct a meaningful study (Smith, Flowers, & Larkin, 2009). It is anticipated that these in-depth interviews will provide meaningful results in order to inform the design of the planned subsequent study. For example, if parents identify that family-centred music therapy sessions were very helpful in building parent-child relationships, and not so helpful in progressing communication skills, then the next study will seek to include relevant assessment measures to further explore these assumptions.

2.4 PARTICIPANT RECRUITMENT

(a) Please indicate the method of recruitment by ticking the appropriate boxes. Tick all that apply.

<table>
<thead>
<tr>
<th>Mail out - see below</th>
<th>Email - see below</th>
<th>Telephone</th>
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<tbody>
<tr>
<td>□</td>
<td>□</td>
<td>□</td>
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</table>

<table>
<thead>
<tr>
<th>Advertisement - see below</th>
<th>Recruitment carried out by third party (eg. employer, doctor) - see below</th>
<th>Recruitment carried out by researcher/s Personal contacts</th>
</tr>
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<tbody>
<tr>
<td>□</td>
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<td>□</td>
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<table>
<thead>
<tr>
<th>Contact details obtained from public documents (eg. phone book)</th>
<th>Contact details obtained from private sources (eg. employee list, membership database) - see below</th>
<th>Snowball (participants suggest other potential participants)</th>
<th>Other (Please explain in no more than 50 words):</th>
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<tr>
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<td>□</td>
<td>□</td>
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</table>

- If using a mail out or email who will be distributing it?

The principal researcher will distribute the Plain Language Statement to families via mail/email according to the contact details provided by families from the 2010 study.

- If using an advertisement:
  - explain where will it be placed?[e.g. on waiting room wall, in newspaper, in newsletter]
  - have you attached a copy?
    Yes □ No □ NA □ If “No” please explain (no more than 50 words):

- If recruitment is to be conducted by a third party, (eg employer, doctor) have you attached an approval letter?
  - requesting their assistance?[yes, no or not applicable]
    Yes □ No □ NA □ If “No” please explain (no more than 50 words):

  - confirming their willingness to assist?
    Yes □ No □ NA □ If “No” please explain (no more than 50 words):

  - that has been drafted for the third party to send to potential participants?
    Yes □ No □ NA □ If “No” please explain (no more than 50 words):

- If contact details are to be obtained from private sources, have you attached an approval letter?
(b) Describe how, by whom, where potential participants are to be identified or selected for this research.

Families from the 2010 study (also conducted by the Principal Researcher) will be selected for this research project due to the fact that they have participated in a family-centred music therapy program and are able to provide relevant perspectives determined by the research questions.

(c) Describe how, by whom, where potential participants are to be approached or invited to take part in this research.

The principal researcher will distribute the Plain Language Statement to families via mail/email according to the contact details provided by families from the 2010 study.

2.5 DEPENDENT RELATIONSHIPS

[The issue of research involving persons in dependent or unequal relationships (e.g. teacher/student, doctor/patient, student/lecturer, client/counsellor, warder/prisoner, and employer/employee) is discussed in Sections 2 and 4.3 of the National Statement. Such a relationship may compromise a participant’s ability to give consent which is free from any form of pressure (real or implied).] Are any of the participants in a dependent relationship with any of the researchers, particularly those involved in recruiting for or conducting the project?

☐ YES ☐ NO

(If YES, explain the dependent relationship and the steps to be taken by the researchers to ensure that participation is purely voluntary and not influenced by the relationship in any way)

2.6 PAYMENT OR INCENTIVES OFFERED TO PARTICIPANTS

Do you propose to pay, reimburse or reward participants?

☐ YES ☐ NO

(If YES, how, how much and for what purpose? Please justify the approach)

3. INFORMATION FOR PARTICIPANTS AND INFORMED CONSENT

Before research is undertaken, the informed and voluntary consent of participants (and other properly interested parties) is generally required (refer Section 2 of the National Statement for more details). Information needs to be provided to participants at their level of comprehension about the purpose, methods, demands, risks, inconveniences, discomforts and possible outcomes of the research. Such information is often provided in a written Plain Language Statement. Each participant’s consent needs to be clearly established (e.g. by using a signed Consent Form, returning an anonymous survey or recording an agreement for interview).

3.1 PROVIDING INFORMATION FOR PARTICIPANTS

(a) Will you be providing participants with information in a written Plain Language Statement?

☐ YES ☐ NO

(If NO, provide details of the protocol you will use to explain the research project to participants and invite their participation?)

(b) Will arrangements be made to ensure that participants who have difficulty understanding English can comprehend the information provided about the research project?

☐ YES ☐ NO

(If YES, what arrangements have been made? If NO, give reasons. All families who participated in the 2010 study had adequate English skills, and no further families are planned to be included in this study. Therefore, the principal researcher already knows that no further arrangements are required.)

3.2 PLAIN LANGUAGE STATEMENT (IF APPLICABLE)

CONFIRM THAT THE PLAIN LANGUAGE STATEMENT WILL:

YES NOT APPLICABLE

1. be printed on University of Melbourne letterhead ☒
2. include clear identification of the University, the Department(s) involved, the project title, the Principal and Other Researchers ☒
(including contact details), and the study level if it is a student research project.

3. provide details of the purpose of the research project

4. provide details of what involvement in the project will require (e.g., involvement in interviews, completion of questionnaire, audio/video-taping of events), and estimated time commitment

5. provide details of any risks involved and the procedures in place to minimise these.

6. advise that the project has received clearance by the HREC

7. (if the sample size is small), confirm that this may have implications for protecting the identity of the participants

8. include a clear statement that if participants are in a dependent relationship with any of the researchers that involvement in the project will not affect ongoing assessment/grades/management or treatment of health (if relevant)

9. state that involvement in the project is voluntary and that participants are free to withdraw consent at any time, and to withdraw any unprocessed data previously supplied

10. provide advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations (see ** below)

11. provide advice as to whether or not data is to be destroyed after a minimum period (if relevant)

12. provide in the footer, the project HREC number, date and version of the PLS

13. provide advice that if participants have any concerns about the conduct of this research project that they can contact the Executive Officer, Human Research Ethics, The University of Melbourne, ph: 8344 2073; fax 9347 6739

[**Re 10 – it is possible for data to be subject to subpoena, freedom of information request or mandated reporting by some professions. Depending on the research proposal you may need to specifically state these limitations]

PLEASE ATTACH A COPY OF THE PLAIN LANGUAGE STATEMENT TO YOUR APPLICATION

3.3 OBTAINING CONSENT

(a) How will each participant’s consent be established?

By signing and returning a Consent Form – see 3.4 below

By returning an anonymous survey

Via a verbal agreement

Via a person with lawful authority to consent (e.g. parent, doctor) – see 3.3(b) below

Via a recorded agreement for interview

Other (Please describe in no more than 50 words):

(b) If participants are unable to give informed consent, explain who will consent on their behalf and how such consent will be obtained.

N/A

3.4 CONSENT FORM (IF APPLICABLE)

Please note: For parents that choose to complete the survey online, the consent items will be built in to the first screen of the survey and contain the same information as the paper consent form related to the items below.

CONFIRM THAT THE CONSENT FORM WILL:

YES NOT APPLICABLE

1. be printed on University of Melbourne letterhead

2. include the title of the project and names of researchers

3. state that the project is for research purposes

4. state that involvement in the project is voluntary and that participants are free to withdraw at any time, and free to withdraw any unprocessed identifiable data previously supplied

5. outline particular requirements of participants including, for example, whether interviews are to be audio and/or video-taped

6. include arrangements to protect the confidentiality of data

7. include advice that there are legal limitations to data
confidentiality (see below)**

8. (if the sample size is small) confirm that this may have ☒ ☐ implications for protecting the identity of the participants

9. (once signed and returned) be retained by the researcher ☒

[**Re 7 – it is possible for data to be subject to subpoena, freedom of information request or mandated reporting by some professions. Depending on the research proposal you may need to specifically state and explain these limitations]

PLEASE ATTACH A COPY OF THE CONSENT FORM TO YOUR APPLICATION

4. PRIVACY AND CONFIDENTIALITY

Privacy can be described as “...a complex concept that stems from a core idea that individuals have a sphere of life from which they should be able to exclude any intrusion.” A major application of the concept of privacy is information privacy: the interest of a person in controlling access to and use of any information personal to that person. ‘Confidentiality’, a narrower more specific term than ‘privacy’ refers to the legal and ethical obligation that arises from a relationship in which a person receives information from or about another.

At the Commonwealth level, the collection, storage, use and disclosure of personal information by Commonwealth agencies is regulated by the Privacy Act 1988. Sections 95 and 95A of the Act are of particular relevance to researchers. There is regulation at State and Territory level in the form of legislation related to privacy generally or the administration of agencies, or administrative codes of practice. In Victoria, the Health Records Act 2001 regulates health information handled by the Victorian public sector and private sector, while the Information Privacy Act 2000 regulates the collection and handling of non-health-related personal information. The National Statement states that an HREC must be satisfied that a research proposal conforms to all relevant Commonwealth, State or Territory privacy legislation or codes of practice.

4.1 ACCESSING PERSONAL INFORMATION

[Personal Information’ includes names, addresses, or information/opinion about an individual whose identity is apparent, or can reasonably be ascertained, from the information/opinion. It also includes Health Information (e.g. health opinions, organ donation or genetic information) and Sensitive Information (e.g. political views, sexual preferences, criminal records)]

Is there a requirement for the researchers to obtain Personal Information (either identifiable or potentially identifiable) about individuals without their consent? YES ☒ NO ☐

a) from Commonwealth departments or agencies?

b) from State departments or agencies?

c) from Other Third Parties, such as non-government organisations?

If you answered YES to (a), (b) or (c), you will need to complete Module P and attach it to this application

4.2 REPORTING PROJECT OUTCOMES

(a) Will the project outcomes be made public at the end of the project?

☒ YES ☐ NO (If YES, give details of how the results will be made public (eg in journal articles book, conference paper, the media, working paper or other). If NO, explain why not. Either or both journal articles and professional conference papers.

(b) Will a report of the project outcomes be made available to participants at the end of the project?

☒ YES ☐ NO (If Yes, give details of the type of report and how it will be made available. If No, explain why not. Families will be provided with a summary of the findings if they have indicated that they would like to.)
4.3 WILL THE RESEARCH INVOLVE:

- complete anonymity of participants (i.e., researchers will not know the identity of participants as participants are part of a random sample and are required to return responses with no form of personal identification)? ☒ NO
- de-identified samples or data (i.e., an irreversible process whereby identifiers are removed from data and replaced by a code, with no record retained of how the code relates to the identifiers. It is then impossible to identify the individual to whom the sample of information relates)? ☒ NO

*This will be the case if any families complete the online survey only
- potentially identifiable samples or data (i.e., a reversible process in which the identifiers are removed and replaced by a code. Those handling the data subsequently do so using the code. If necessary, it is possible to link the code to the original identifiers and identify the individual to whom the sample or information relates)? ☒ NO
- participants having the option of being identified in any publication arising from the research? ☒ NO
- participants being referred to by pseudonym in any publication arising from the research? ☒ NO
- any other method of protecting the privacy of participants? Please describe:

Note that where the sample size is very small, it may be impossible to guarantee anonymity/confidentiality of participant identity. Participants involved in such projects need to be clearly advised of this limitation in the Plain Language Statement.

5 DATA STORAGE, SECURITY AND DISPOSAL

5.1 DATA STORAGE


☒ YES ☐ NO (If NO, please explain.)

5.2 DATA SECURITY

(a) Will the Principal Researcher be responsible for security of data collected?

☒ YES ☐ NO (If NO, please provide further details. You may also use this space to explain any differences between arrangements in the field, and on return to campus.)

(b) Will data be kept in locked facilities in the Department through which the project is being conducted?

☒ YES ☐ NO (If NO, please explain how and where data will be held, including any arrangements for data security during fieldwork.)

(c) Which of the following methods will be used to ensure confidentiality of data? (select all options that are relevant)

- data and codes and all identifying information to be kept in separate locked filing cabinets ☒
- access to computer files to be available by password only ☒
- access by named researcher(s) only ☒
- other (please describe) ☒

(d) Will others besides the named researchers have access to the raw data?

☒ YES ☐ NO (If YES, please explain who and for what purpose? What is their connection to the project?)

5.3 DATA RETENTION AND DISPOSAL

[Research data and records should be maintained for as long as they are of continuing value to the researcher and as long as recordkeeping requirements such as patent requirements, legislative and other regulatory requirements exist. The minimum]
retention period for research data and records is five years after publication, or public release, of the work of the research as stated in the University of Melbourne Code of Conduct for Research. If the project involves clinical trial(s), the data should be kept for a minimum of 15 years (refer to Section 3.3 of the National Statement for further details). [1]

Specify how long materials (e.g. files, audiotapes, questionnaires, videotapes, photographs) collected during the study will be retained after the study and how they will ultimately be disposed of.

Materials from this study will be retained after the study for a minimum of 7 years, and after that time paper materials will be shredded and electronic materials appropriated deleted/wiped from hard drives.

6. POTENTIAL CONFLICT OF INTEREST

6.1 POTENTIAL CONFLICT OF INTEREST

Is there any affiliation or financial interest for researchers in this research or its outcomes or any circumstances which might represent a perceived, potential or actual conflict of interest?

☐ YES ☒ NO (If YES, give brief details?)

[If you have declared a potential conflict of interest, you should include an appropriate comment on the Plain Language Statement and Consent Form]

6.2 COMPLIANCE WITH THE CODE OF CONDUCT FOR RESEARCH

[University researchers must disclose and manage Conflict of Interest in accord with the provisions of the University’s Code of Conduct for Research. See http://www.unimelb.edu.au/ExecServ/Statutes/r171r8.html]

Is the Conflict of Interest noted above in section 6.1 being managed in accordance with the Code of Conduct?

☒ YES ☐ NO ☐ Not Applicable

7. DECLARATION BY RESEARCHERS

The information contained herein is, to the best of our knowledge and belief, accurate.

We have read the University’s current human ethics guidelines, and accept responsibility for the conduct of the procedures set out in the attached application in accordance with the guidelines, the University’s Code of Conduct for Research and any other condition laid down by the University of Melbourne’s Human Research Ethics Committee or its Sub-Committees. We have attempted to identify all risks related to the research that may arise in conducting this research and acknowledge our obligations and the rights of the participants. We have the appropriate qualifications, experience and facilities to conduct the research set out in the attached application and to deal with any emergencies and contingencies related to the research that may arise.

If approval is granted, the project will be undertaken in strict accordance with the approved protocol and relevant laws, regulations and guidelines.

We, the researcher(s) agree:

• To only start this research project after obtaining final approval from the Human Research Ethics Committee (HREC);
• To only carry out this research project where adequate funding is available to enable the project to be carried out according to good research practice and in an ethical manner;
• To provide additional information as requested by the HREC;
• To provide progress reports to the HREC as requested, including annual and final reports;
• To maintain the confidentiality of all data collected from or about project participants, and maintain security procedures for the protection of privacy;
• To notify the HREC in writing immediately if any change to the project is proposed and await approval before proceeding with the proposed change;
• To notify the HREC in writing immediately if any adverse event occurs after the approval of the HREC has been obtained;
• To agree to an audit if requested by the HREC;
• To only use data and any tissue samples collected for the study for which approval has been given;

We have read the National Statement on Ethical Conduct in Human Research and agree to comply with its provisions.
All researchers associated with this project must sign

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<tr>
<th>Researchers’ Name (please PRINT)</th>
<th>Signature</th>
<th>Date</th>
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<tbody>
<tr>
<td>Grace Thompson</td>
<td></td>
<td>5/06/2014</td>
</tr>
</tbody>
</table>

8. DECLARATION BY DEPARTMENTAL HUMAN ETHICS ADVISORY GROUP (HEAG)

DATE APPLICATION RECEIVED: / / HEAG NO:

☐ TECHNICAL REVIEW COMPLETED ☐ ETHICAL REVIEW COMPLETED

The HEAG has reviewed this project and considers the methodological/technical and ethical aspects of the proposal to be appropriate to the tasks proposed and recommends approval of the project. The HEAG considers that the researcher(s) has/have the necessary qualifications, experience and facilities to conduct the research set out in the attached application, and to deal with any emergencies and contingencies that may arise. [Note: If the HEAG Chair is also a principal researcher for this project, the declaration should be signed by another authorised member of the HEAG]

Comments/Provisos:

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<th>Name of HEAG Chair (in BLOCK LETTERS)</th>
<th>Signature</th>
<th>Date</th>
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</table>

9. DECLARATION BY HEAD OF DEPARTMENT

DATE APPLICATION RECEIVED: / / HEAG NO:

☐ TECHNICAL REVIEW COMPLETED ☐ ETHICAL REVIEW COMPLETED

I have reviewed this project and consider the methodological, technical and ethical aspects of the proposal to be appropriate to the tasks proposed and recommend approval of the project. I consider that the researcher(s) has/have the necessary qualifications, experience and facilities to conduct the research set out in the attached application, and to deal with any emergencies and contingencies that may arise. [If the Head of Department is also a principal researcher for this project, the declaration should be signed by another authorised member of the Department]

This project has the approval and support of this Department/School/Centre.

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<th>Name of Head (in BLOCK LETTERS)</th>
<th>Signature</th>
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10 WHEN COMPLETE

When this form has been completed and finalised it should be attached to the coversheet section of the application completed in Themis Research and then submitted to the nominated Human Ethics Advisory Group for review.
References:


Plain Language Statement

Parent perception of the benefits of music therapy for their children with autism spectrum disorder (ASD)

Researcher details:
Name: Dr Grace Thompson, Melbourne Conservatorium of Music – Responsible Researcher
Email: grace@unimelb.edu.au and University phone number: +61 3 9035 8978

Project details:
You are invited to participate in this project, which is being conducted by Dr Grace Thompson of the Faculty of the VCA & MCM at The University of Melbourne. This project has been approved by the Human Research Ethics Committee.

The aim of this study is to enhance our understanding of what parents’ value about music therapy programs involving parents and children, and how parents have used music in their home life as a result of participating in music therapy.

You are receiving this invitation because you have already participated in a music therapy program with Grace in 2010, where Grace visited your home to provide sessions for your child with ASD. Therefore, your reflections on the benefits of music therapy are particularly interesting to the researcher in order to understand more about your experience of music therapy now that some time has passed.

What will I be asked to do?
Should you agree to participate, you would be asked to contribute in the following ways:

There are two parts to this research, and you can choose to be involved in either parts or both. Your participation is completely voluntary.

Part 1: A survey about how you are using music in your home life. Even if you are not using a lot of music, this information is important for music therapist to know and understand. You can either complete the survey online (the link is provided at the end of this document), or by phone. The survey should take no more than 15 minutes.

And/or:

Part 2: An interview asking you to describe if and how participating in family-centred music therapy sessions was valuable or helpful to your child and family. The interview should take no more than 45 minutes. With your permission, the interview would be tape-recorded so that we can ensure that we make an accurate record of what you say. You will also be given the opportunity to read the summary of your interview, and make any changes you wish.

Your involvement in the project is completely voluntary and you are free to withdraw from this study at any point. Further, you are free to withdraw any of your contributions to the project at any time until the data has been collated and it is no longer possible to separate your contribution to the overall data.

How long is my contribution expected to take?
We estimate that the time commitment required of you would be approximately 15 minutes for the survey component, and 45 minutes for the interview.
How will any potential risks be minimised?
The risks involved in this project are envisaged to be minimal, as you will not be asked to do anything other than talk about your experiences of participating in music therapy with your child. You are free to ask to skip a question if you do not wish to answer it.

Will I be able to be identified as a participant in this project?
We will protect your anonymity to the fullest possible extent within the limits of the law and any records of your contribution will be kept on the Principal Researcher’s password protected computer. If you participate in the interview, you can choose a pseudonym (made up name) to protect your identity. You should note, however, that since the number of potential participants is small, it might still be possible for someone to identify you.

What about confidentiality?
Your survey answers and interview recordings/transcripts, and all identifying information is to be kept in locked filing cabinets or access to computer files will only be available via password. Only the Principal Research will have access to the data. Please note that there are legal limits to data confidentiality. It is possible for data to be subject to subpoena, freedom of information request or mandated reporting by some professions.

What happens to my contributions after the project has finished?
Materials collected during this study will be retained for a minimum of seven years after publication of the research in academic journals.

What if I have concerns?
If you have any questions or concerns, or would like further information about the research project, please contact the researcher. Contact details are listed at the start of this Plain Language Statement.

If you are concerned about the conduct of the project, please contact the Executive Officer, Human Research Ethics, The University of Melbourne, ph: 8344 2073.

What happens next?
Thank you for considering this invitation to participate in our research project.

If you wish to participate in the Survey online, please go to the following link at your convenience:

www. The name of the link

If you wish to participate in the interview or need to complete the survey via the phone, please indicate that you have read and understood this information by signing the accompanying consent form and return it to Dr Grace Thompson via post or email. Grace will then contact you to make a time for the interview/phone survey.

Whether or not you decide to participate, this Plain Language Statement is yours to keep.
Consent Form

Parent perception of the benefits of music therapy for their children with autism spectrum disorder (ASD)

Researcher’s names: Dr Grace Thompson, Melbourne Conservatorium of Music
Email: grace@unimelb.edu.au and University phone number: +61 3 9035 8978

I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written plain language statement to keep;

1. I agree that the researchers may use my contributions as described in the plain language statement;

2. I understand that after I sign and return this consent form it will be retained by the researcher;

3. I understand that my participation in this research project will involve:
   a. Completing a survey about using music in my home life with my child
   And/or
   b. Being interviewed about whether music therapy sessions I participated in with my child in 2010 was helpful to my child and family

I acknowledge that I have been informed that:

4. This project is for the purposes of research and the possible effects of participating in the research project have been explained to my satisfaction;

5. I am free to withdraw from this study at any point. Further, I am free to withdraw any of my contributions to the project at any time until the data has been collated and it is no longer possible to separate my contribution to the overall data;

6. While every precaution will be taken to protect my identity if I choose to remain anonymous or be referred to by a pseudonym, the small numbers in this project may mean that I could be identified;

7. The confidentiality of any personal information I provide will be safeguarded subject to any legal requirements;

8. Outcomes of this research may be published in journal articles or conference papers and my contributions will be acknowledged appropriately;

Please tick:
I consent to my interview being audio-taped □ yes □ no
I wish to receive a summary of the results □ yes □ no

Please provide contact details so that we can book in an interview or send you the summary of results:

Email: _____________________________________________________________________________________

Phone numbers (you can provide more than one contact number if needed): ____________________________________

Name of participant: ___________________________________________________________________________

Participant signature: _____________________________________________ Date: _______________________
In depth interview – interpretive phenomenological analysis

Proposed Questions:

1. Why did you volunteer for the music therapy research sessions with your child back in 2010?
   a. Probe: What were your expectations for the music therapy sessions?

2. Looking back on your involvement, what do you think your child gained from participating in music therapy?

3. What do you think you/your family gained from participating in music therapy?

4. How would you describe the benefits of music therapy to other families of children with ASD?

5. Did music therapy offer something special to your child and/or family that other therapies did not? If yes, please describe.

6. Was there anything about your involvement in music therapy that was not helpful for you or your child?
Survey questions – content analysis

The survey will be developed via an online platform, such as Survey Monkey. As some parents may have limited access to computers or internet, they will be offered the option of completing the survey over the phone.

Intro: Back when you participated in the 16 week music therapy program with your child, I also asked you to keep a record of what you did with music in the home in between sessions.

Brief demographic details:
- Age
- Sex
- Marital Status
- Cultural heritage
- Highest level of education
- Local Government Area (which will then provide indirect average income data via the ABS)

Questions:
1. Do you still use music activities at home with your child now? Why or why not?
(if yes)
2. What is your favourite music activity to use with your child?
3. Why is this activity your favourite?
4. In the past week, how often have you engaged in this favourite music activity?
   - Every day of the week
   - Almost every day of the week
   - A couple of the days of the week
   - One day of the week
   - Not at all

5. What other music activities do you engage your child in at home?
6. In the past week, how often have you engaged in these music activities (one for each):
   - Every day of the week
   - Almost every day of the week
   - A couple of the days of the week
   - One day of the week
   - Not at all

7. Do you think your child enjoys engaging with you in music activities? Why/why not?
8. Do you enjoy engaging with your child in music activities? Why/why not?
9. Do you use music for any of the following purposes?
   - Not at all
   - Sometimes
   - Often
   - Calm down
   - At meal time
   - At bed time
   - Understand daily routine
   - Have fun and experience enjoyment
   - Exercise
   - Transition smoothly between activities
   - Learn new things
   - Travel calmly in the car, bus, etc.

10. Are there any other uses of music you would add to this list?
11. Are you happy to participate in a further interview about your reflections on the value of the music therapy program for your child and family? Please provide contact details: