



CAWRI

Creativity and Wellbeing Hallmark Research Initiative

This is me: Exploring how shared musical expression with peers can support psychological wellbeing in autistic young adults.

Final report

2 September 2022

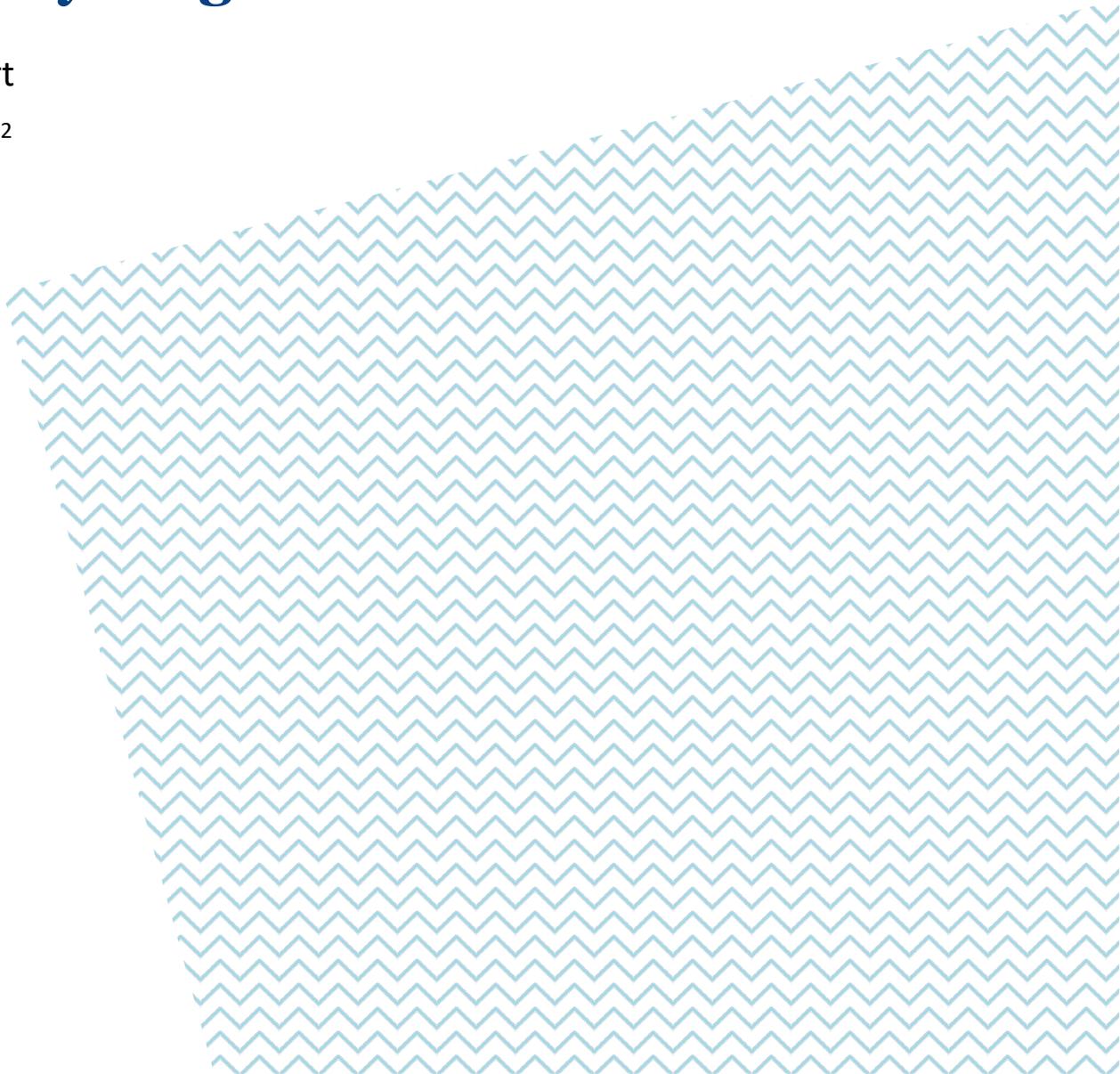


Table of Contents

- Project summary 2**
- Research team 2**
- Partners 2**
- Acknowledgements..... 2**
- Background..... 3**
 - Research context.....3
 - Project aims.....3
 - Methodology.....4
- Key findings 5**
 - Project outcomes6
- Discussion, implications and future directions 7**
- References 8**
- More information 9**

Project summary

Social isolation amongst autistic young adults are recognized as significant risk factors for poor mental health. Reducing isolation and increasing meaningful social networks appear to be protective factors for wellbeing in this population. While research shows that participating in community music making can foster a sense of belonging and connection between group members, this potential has not been researched in the Australian autistic community. Engaging in expressive music creation that does not rely on verbal communication (a common barrier for autistic people) was expected to provide participants with a distinct opportunity to build peer social networks. This feasibility project therefore aimed to better understand whether music-making workshops could foster social connectedness and improve wellbeing for autistic young adults. Taking the quantitative and qualitative findings together, participation in the workshops was found to enhance social connection and promote a sense of inclusion. The outcomes for wellbeing were unclear given the small sample size and the data collection period taking place during the COVID-19 pandemic.

This project ran from September 2019 to May 2022

Research team

Grace Thompson	University of Melbourne Faculty of Fine Arts and Music
Melissa Raine	University of Melbourne Faculty of Arts
Susan Hayward	University of Melbourne School of Social and Political Sciences

Partners

Elena Ashley	Manager, Information & Services, AMAZE
--------------	--

Acknowledgements

This project was funded by the Creativity and Wellbeing Hallmark Research Initiative of the University of Melbourne.

In Kind support was also received from the Faculty of Fine Arts and Music.

We acknowledge and appreciate the support of the Different Journeys community group for their help with recruitment. Thank you to Zoë Kalenderidis, Registered Music Therapist, and Freya Hombergen, Bachelor of Music student, for their contributions as workshop facilitators.

Background

Research context

Social activities in the community that are accessible to a diverse range of people are scarce (Shiloh & LaGasse, 2014). The number of autistic people in Australia is estimated to be somewhere between one in 70 people (Autism Spectrum Australia, 2018) and one in 150 (Australian Institute of Health and Welfare, 2017). Autism is hallmarked by challenges with social interaction, and often sensory sensitivities (American Psychiatric Association, 2013). The autistic community in Australia is substantial, yet a recent survey by a peak body for autistic people reported that the majority of the general public in Australia (84%) perceive that discrimination against autistic people occurs (Jones et al, 2018). Perhaps unsurprisingly, 70% of the autistic participants surveyed in the same report felt socially isolated, while others indicated they had lost friends and jobs as a result of their condition and worried about how others would behave towards them. These relational concerns seem to spill over into their participation in Australian cultural life, with 54% of autistic people reporting their main reason for avoiding going out to venues was because they had nobody to go with (Jones et al., 2018). A study of 220 Australian autistic adults reported that the combination of environmental factors, such as noise levels, and social interaction challenges often create substantial anxiety and exhaustion leading to avoidance and isolation (Ee et al., 2019).

The mental health of people living with disability is increasingly being recognized and reported, particularly within the Australian autistic adult population (Uljarević et al., 2020). Compared with the general population, as many as 60% of autistic people in Australia experience anxiety, and up to 49% experience depression (Uljarević et al., 2020). Loneliness is frequently reported amongst autistic adults (Ee et al., 2019) and adolescents (Lasgaard, Nielsen, Eriksen, & Goossens, 2010). The majority (63%) of autistic Australians aged under 21 years report experiencing difficulty fitting in socially (Australian Institute of Health and Welfare, 2017). Some autistic people camouflage their autistic traits in social settings in an attempt to “fit in” (Hull et al., 2017). Camouflaging can lead to feelings of shame and internalized stigma (Cage & Troxell-Whitman, 2019), and the effort and energy required to hide autistic traits can be detrimental to wellbeing (Hull et al., 2017). Therefore, finding ways to build inclusive social support networks appears to be fundamental to addressing mental wellbeing in an autistic population.

Project aims

This project aimed to:

1. Determine whether inclusive community-based music making workshops could strengthen the social networks of autistic young adults and thus contribute to increased subjective wellbeing and quality of life;
2. Identify the elements of community music making that successfully foster a sense of social connection and wellbeing among autistic young adults.

Methodology

This project involved two phases as follows:

Phase 1 – Co-Design Survey with Follow-Up Interviews

Our academic team included autistic, disabled and non-autistic researchers with backgrounds in Psychology, Music Therapy, and Arts. We also invited young autistic adults to join an advisory group, since this age group would ultimately be invited to participate in the music workshops. The academic team created a first draft of the online survey questions to meet the research aims and then engaged with our three autistic advisors aged 18 to 24 years who reviewed the content, language, and formatting of survey questions. In addition, we took advice from the information manager of the autism peak body in Victoria, Australia, and a program coordinator of a community group for autistic young people. The wording and order of several survey questions were modified in an iterative way following this consultation period, with some questions removed and others added. Survey respondents were also invited to participate in a follow-up interview.

Phase 2 – feasibility study evaluating wellbeing outcomes for participants

Building on the findings from phase 1, we next designed and piloted a program of inclusive music making workshops for autistic young adults over a period of five weeks. We re-advertised for participants, and also sent information to people who filled in the survey and indicated that they wanted to receive information about future studies. To measure the impact of participation in the program on psychological wellbeing, mixed data was collected as follows:

Social connectedness. To measure social connectedness, the Friendship Questionnaire (FQ) (Baron-Cohen & Wheelwright, 2003) was used pre and post the music workshops. The FQ asks participants to select the statement about friendship that “most applies” to them. For example, participants select between three options for item 1: a) I have one or two particular best friends; b) I have several friends who I would call best friends; or c) I don’t have anybody who I would call a best friend. Other items require participants to complete a rating scale. For example, item 16 asks “How easy do you find discussing your feelings with your friends?” and participants complete a 5-point likert scale from “very easy” to “very difficult” (Baron-Cohen & Wheelwright, 2003, p. 515).

Wellbeing. The Personal Wellbeing Index-Adult (PWI-A) measured the subjective wellbeing of participants pre and post the music workshops (International Wellbeing Group, 2013). Each question is related to a “quality of life domain”, including “standard of living, health, achieving in life, relationships, safety, community-connectedness, and future security.” (International Wellbeing Group, 2013, p. 9). Therefore, the questions ask participants to rate how satisfied they are with each of these domains on a scale of one to ten, with ten being “completely satisfied”, and one being “no satisfaction at all”.

Group Inclusion. Group inclusion was measured by two subscales from the Perceived Group Inclusion Scale (PGIS) (Jansen et al., 2014). These subscales were “group membership” and the two subscales that together measure “authenticity”. Each item is scored on a five-point Likert scale where, 1=strongly disagree and 5=strongly agree. Items related to “Group membership” measure feelings of belonging to a group. For example, question 1 asks participants to rate the statement: “The music workshops gave me the feeling that I belong”. Items related to

“Authenticity” consider the extent to which individuals feel they can be themselves; it encompasses the subscales of “room for authenticity” and “value in authenticity”. For example, question 12 asks participants to rate the statement: “The music workshops allowed me to be myself the way I am”. Since the PGIS requires participants to evaluate their subjective experience of a particular group, this was used as a post-measure only.

Feasibility evaluation. Nine questions were devised by the research team to determine the participants’ experience of the workshops, as well as their perceptions of the assessment measures. These questions were scored on a three- or five-point Likert scale and included in the post-workshop series questionnaire.

Semi-Structured Interviews. Participants were invited to participate in an interview with a member of the research team, who was not the workshop facilitator, at the end of the five-week workshop series. Within the context of a feasibility study, the interview was designed to offer the opportunity for broader discussion around the themes covered by the quantitative self-report measures. Seven interview questions inquired about themes such as: most and least preferred activities; social experiences with group members and workshop leaders, and an open question that provided the opportunity for any further feedback.

Key findings

Phase-1 survey and interviews

There were 30 responses to the online survey questions which collected demographic information, opinions about group music-based activities, and views about ways to best support access and participation in the local community. In addition, five structured interviews were conducted with survey participants who volunteered to provide in-depth follow-up responses. Participants described being motivated to join music-making workshops offered in the community and proposed various ways to improve accessibility. The qualitative themes from the survey free text and interviews suggest that both environmental and social factors work together to create a sense of safety and inclusion. In particular, a welcoming atmosphere and acceptance of diversity were expected from the workshop facilitator and group members. These findings have important implications for the co-production of future music-making workshops for the wellbeing of autistic people.

Phase-2 music-workshops feasibility study

Data was collected from 12 participants. Overall, there was a positive change in social connectedness as measured by the Friendship Questionnaire (FQ), with an average increase of 11.44 points. Prior to analysing the scores for wellbeing, as measured by the PWI-A, we first inspected the quality-of-life screening question. There were no extreme responses to the screening question, and congruence with the participants’ overall ratings, and therefore proceeded with the analysis. The average score on the PWI-A declined by 10.31 points. Both the pre-study mean (67.86) and the post-study mean (57.55) was notably below the Australian normative range of 73.4 – 76.4 points (International Wellbeing Group, 2013). Group inclusion, as measured by the PGIS, was rated by participants at the end of the five-week workshop program.

Seven participants who completed the PGIS on average indicated that they felt like a member of a group ($M=3.82$, $SD=1.27$) and they could be their authentic selves ($M=4.02$, $SD=1.29$).

There were six participants for whom data could be matched pre and post workshops. The mean difference for these participants increased on the FQ (9.33 points), however mean difference on the PWI-A showed a decrease (-12.86 points). As this is a feasibility study, we focused on a preliminary analysis of the magnitude of any effect. The small numbers mean that the study is underpowered and therefore the reporting of statistical significance is preliminary. Indeed, the Wilcoxin signed-rank test revealed no significant difference on pre and post scores on the FQ or the PWI-A for this small sample.

Seven participants participated in an interview at the end of the five-week workshop program. The category “experience of being part of the group” included most themes and codes across the qualitative responses. Participants described the important role that “friendly people” and “sharing interests together” played in creating a sense of belonging. Some participants described how the music workshops “filled a social need”, while others expressed a sense of “comfort to be themselves”. Within the category “most enjoyable activities”, there was a range of perspectives. Some participants enjoyed engaging with music activities that were related to their pre-existing personal interests, while others highlighted that they enjoyed trying something new. Some people particularly enjoyed music activities that involved the whole group.

Taking the quantitative and qualitative findings together, participation in the workshops enhanced social connection but may not improve wellbeing. The workshops were perceived as inclusive and accessible.

Project outcomes

Publications: Phase 1 data

Thompson, G. A., Raine, M., Hayward, S. M., & Kilpatrick, H. (2020). Gathering community perspectives to inform the design of autism-friendly music-making workshops for wellbeing. *International Journal of Wellbeing*, 10(5), 117-143. <https://doi.org/10.5502/ijw.v10i5.1497>

Conference presentations: Phase 1 data

8th Nov 2020, National Australian Music Therapy Association Conference, paper titled: “Collaboratively designing autism-friendly music making workshops to support social connection.” Thompson.

Publications: Phase 2 data

Thompson, G., Raine, M., & Hayward, S. (in press). Feasibility study exploring wellbeing outcomes of music-making workshops for autistic young adults. *Australian Journal of Music Therapy*.

Other outcomes: Phase 2 data

Townsend, E. (Host). (2022, May). *Episode 6: 'This is Me' music workshops for young autistic adults* [Audio podcast]. CAWRI Creativity Talks Podcast. <https://www.cawri.com.au/posts/this-is-me>

Discussion, implications and future directions

This feasibility project aimed to better understand whether music-making workshops could foster social connectedness and improve wellbeing for autistic young adults. Taking the quantitative and qualitative findings together, participation in the workshops was found to enhance social connection and promote a sense of inclusion. The outcomes for wellbeing were unclear given the small sample size and the data collection period taking place during the COVID-19 pandemic. With growing reports of social isolation and loneliness amongst autistic adults (Ee et al., 2019; Jones et al., 2018), and the potential flow-on effects for mental illness and poor quality of life (Hull et al., 2017; Uljarević et al., 2020), autism-friendly community groups may provide a preventative or even therapeutic experience (Hillier et al., 2012; Young, 2020).

This feasibility study highlighted various challenges with collecting data from young autistic adults. We found that participants were enthusiastic to participate in the music workshops, but less enthusiastic about completing the wellbeing and inclusion measures to help determine feasibility of the workshops. Those who only attended once or twice did not respond to our invitation to provide feedback. Future research should consider how to better explain the research aims, the process for data collection (including for those who leave the study), and design processes to support completion of the measures. Employing an autistic research assistant and workshop leader, as suggested by one participant, may be one way to improve engagement in the research. While the study team included two academics with lived experience of autism, and one who has a physical disability, this information was not disclosed to the research participants.

The sudden and unexpected short lockdowns that occurred during our data collection period required us to adapt at short notice to these unpredictable disruptions. We started collecting data in May during a time where the city of Melbourne had few restrictions on movement. However, within three weeks of commencing data collection, the situation had significantly changed. Once we embarked on data collection, we felt a moral obligation to our participants to provide the opportunity we had promised to them and made the decision to see the project through. Future research would benefit from having a clear “plan B” that is explained to participants at the recruitment stage to provide a supportive framework for their expectations.

Lastly, qualitative data collection needs careful planning to accommodate participants’ varied forms of communication. We provided opportunities for both spoken and written responses, and participants could choose to have a support person with them during the interviews. While these methods improved accessibility for most participants, more creative options might be needed for others. For example, using visual ranking scales, providing paper and coloured pens/markers, and allowing more time for the interview may have helped improve the quality of data collection.

Autistic advocates have questioned the research community’s focus on interventions versus addressing issues related to understanding, acceptance and inclusion of autistic individuals within society (Garcia, 2021). A better appreciation of how to improve accessibility and to design autism-friendly social opportunities is greatly needed (Lai et al., 2020). Autistic adults, like all adults, have diverse needs, hopes and dreams. Researchers in this preventative and therapeutic space will ideally embrace the opportunity to identify inclusive modes of access, available to all, to determine the potential benefits of different programs and approaches for a variety of people.

References

- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders - DSM-5* (5th ed.). American Psychiatric Publishing.
- Australian Institute of Health and Welfare. (2017). *Autism in Australia*.
<https://www.aihw.gov.au/reports/disability/autism-in-australia>
- Autism Spectrum Australia. (2018). *Autism prevalence rate up by an estimated 40% to 1 in 70 people* [Press release].
<https://www.autismspectrum.org.au/news/autism-prevalence-rate-up-by-an-estimated-40-to-1-in-70-people-11-07-2018>
- Baron-Cohen, S., & Wheelwright, S. (2003). The Friendship Questionnaire: An investigation of adults with Asperger syndrome or high-functioning autism, and normal sex differences. *Journal of Autism & Developmental Disorders*, 33(5), 509-517. <https://doi.org/https://doi.org/10.1023/A:1025879411971>
- Cage, E., & Troxell-Whitman, Z. (2019). Understanding the reasons, contexts and costs of camouflaging for autistic adults. *Journal of Autism and Developmental Disorders*, 49(5), 1899-1911. <https://doi.org/10.1007/s10803-018-03878-x>
- Ee, D., Hwang, Y. I., Reppermund, S., Srasuebkul, P., Trollor, J. N., Foley, K.-R., & Arnold, S. R. (2019). Loneliness in adults on the autism spectrum. *Autism in Adulthood*, 1(3), 182-193. <https://doi.org/10.1089/aut.2018.0038>
- Garcia, E. (2021). We don't need a cure for autism. We need to make living with it easier. *Time*. 27 August 2021.
https://time.com/6092407/autism-making-life-easier/?fbclid=IwAR3Hj8VdTeMvguu5kY0_P_1eHEhHJMxT_zVYkxQPzfs4aruuc7sXPZ_wdY
- Hillier, A., Greher, G., Poto, N., & Dougherty, M. (2012). Positive outcomes following participation in a music intervention for adolescents and young adults on the autism spectrum. *Psychology of Music*, 40(2), 201-215.
<https://doi.org/10.1177/0305735610386837>
- Hull, L., Petrides, K., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.-C., & Mandy, W. (2017). "Putting on my best normal": social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders*, 47(8), 2519-2534. <https://doi.org/10.1007/s10803-017-3166-5>
- International Wellbeing Group. (2013). *Personal Wellbeing Index: 5th Edition*. Centre on Quality of Life, Deakin University. <http://www.acqol.com.au/instruments#measures>
- Jansen, W. S., Otten, S., van der Zee, K. I., & Jans, L. (2014). Inclusion: Conceptualization and measurement. *European Journal of Social Psychology*, 44(4), 370-385. <https://doi.org/https://doi.org/10.1002/ejsp.2011>
- Jones, S., Akram, M., Murphy, N., Myers, P., & Vickers, N. (2018). Community attitudes & behaviours towards autism; and experiences of autistic people and their families: General awareness, knowledge and understanding of autism and social isolation. *AMAZE*. <http://www.onethingforautism.com.au/wp-content/uploads/2018/05/Autism-research-report-General-awareness-knowledge-and-understanding-of-autism-and-social-isolation-1.pdf>
- Lai, M.-C., Anagnostou, E., Wiznitzer, M., Allison, C., & Baron-Cohen, S. (2020). Evidence-based support for autistic people across the lifespan: Maximising potential, minimising barriers, and optimising the person–environment fit. *The Lancet Neurology*, 19(5), 434-451. [https://doi.org/https://doi.org/10.1016/S1474-4422\(20\)30034-X](https://doi.org/https://doi.org/10.1016/S1474-4422(20)30034-X)
- Lasgaard, M., Nielsen, A., Eriksen, M. E., & Goossens, L. (2010). Loneliness and social support in adolescent boys with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 40(2), 218-226.
<https://doi.org/10.1007/s10803-009-0851-z>
- Shiloh, C., & LaGasse, A. B. (2014). Sensory friendly concerts: A community music therapy initiative to promote neurodiversity. *International Journal of Community Music*, 7(1), 113-128.
https://doi.org/10.1386/ijcm.7.1.113_1
- Uljarević, M., Hedley, D., Rose-Foley, K., Magiati, I., Cai, R. Y., Dissanayake, C., Richdale, A., & Trollor, J. (2020). Anxiety and depression from adolescence to old age in autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 50(9), 3155-3165. <https://doi.org/10.1007/s10803-019-04084-z>
- Young, L. (2020). Finding our voices, singing our truths: Examining how quality of life domains manifested in a singing group for autistic adults. *Voices: A World Forum for Music Therapy*, 20(2). Retrieved from
<https://voices.no/index.php/voices/article/view/2554>



More information

For more information about this project, contact A/Prof Grace Thompson at graceat@unimelb.edu.au

For more information about CAWRI, visit <https://research.unimelb.edu.au/creativityandwellbeing>