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THE ROLES OF MUSIC IN THE WELL-BEING OF AUTISTIC ADULTS

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THE ROLES OF MUSIC IN THE WELL-BEING OF AUTISTIC ADULTS

Thesis for Doctoral Degree (Ph.D.)

By

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The thesis will be defended in public at the Royal College of Music in Stockholm, on the 15th of November 2024, at 9:30

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To my parents, who took their time for every question.

Popular science summary of the thesis

Music is often used as a form of support for autistic people, but surprisingly, there are only a few scientific studies about how they actually experience it. This thesis dives into the musical experiences of autistic adults and explores how music affects their well-being, both positively and negatively. Using a psychological framework called Self-Determination Theory (SDT), which highlights the importance of autonomy, relatedness, and competence, the research helps us better understand how music can help—or sometimes harm—individuals, depending on the context.

The thesis includes three studies. In the first two studies, we asked 13 autistic adults about how they use and experience music in their daily lives. We then analysed the interviews in two different ways: firstly, to learn more about the different ways in which they use and experience music, and secondly, to investigate whether SDT could help us connect the findings from different studies that investigated the musical experiences of autistic adults. In the third study, we developed a new questionnaire that measures how people use music to support their well-being. Sixty-three autistic adults completed the survey and gave us feedback on how clear the questions were and how well they captured their musical experiences.

Based on the three studies, we found that autistic adults use and experience music in a variety of ways, much like non-autistic adults. For some, music was a source of comfort, connection, and self-expression. However, in some contexts, music was also stressful and overwhelming. The common thread was that the positive or negative effects of music depended on whether people could engage with music on their own terms. This means having control over what kind of music they engage with, when, and how.

This thesis highlights how important it is to consider a diverse range of subjective experiences when it comes to music-related policies or support services. It also addresses the current knowledge gap in our understanding of how music might also be harmful. Ultimately, this research calls for more pluralistic approaches to understanding how music impacts well-being. By valuing different ways of engaging with music and being mindful of potential harms, we can create supportive environments that help all individuals, including autistic adults, to thrive.

Abstract

While music-based support services have been widely implemented for autistic people, their subjective experiences with music remain underexplored. This thesis investigates the roles of music in the lives of autistic adults, emphasising its impact on well-being. Drawing on Self-Determination Theory (SDT), particularly the basic psychological needs for autonomy, relatedness, and competence, it aims to provide a framework for understanding both the positive and negative effects of music, thereby advancing research and informing future interventions.

The thesis consists of three empirical studies. The first two studies aimed to explore autistic people's musical experiences and establish a framework that could provide a theoretical common ground for the existing exploratory studies. Studies I and II involved in-depth interviews with 13 autistic adults (aged 24–69). In the first study, a bottom-up thematic analysis identified emergent themes, while the second study applied a top-down approach using predefined categories derived from SDT. The aim of the third study was to develop and test a questionnaire assessing how people engage with music to support their well-being. Using a mixed-methods design, we analysed the answers of 63 autistic adults who filled out our questionnaire, as well as gave qualitative feedback on how clear the items were and how well the items reflected their experiences of music and well-being.

Findings show that autistic adults experience musicking as both beneficial and detrimental, depending on the context. SDT seems to be a promising theory for investigating the mentioned context, given how important a sense of self-determination is in music engagement. Furthermore, the thesis provides an example of how we can extend and adapt models and theories developed on the general population to its sub-populations and use them to create assessment tools. By integrating autistic perspectives into existing theories and models, such as SDT, this work calls for a more pluralistic approach to understanding music engagement, one that respects the heterogeneity of people and agency of individuals and actively considers the potential for harms and negative experiences.

List of scientific papers

- I. **Korošec, K.**, Osika, W., & Bojner Horwitz, E. (2022). "It is more important than food sometimes"; Meanings and functions of music in the lives of autistic adults through a hermeneutic-phenomenological lens. *Journal of Autism and Developmental Disorders*, 54(1), 366–378. <https://doi.org/10.1007/s10803-022-05799-2>
- II. **Korošec, K.**, Backman Bister, A. & Bojner Horwitz, E. (in press). "A space to be myself": Music and self-determination in the lives of autistic adults. *Psychology of Music*.
- III. **Korošec, K.**, Lundqvist, L.-O., Perkins, R., Détári, A., Osika, W., Bojner Horwitz, E. (in review). Development of the Participatory Music Engagement for Mental Well-being questionnaire (PaMEW): A pilot study with autistic adults. *Psychology of Music*.

Scientific papers not included in the thesis

- I. Lundqvist, L.-O. & **Korošec, K.** (2021): Use of music for mood regulation in adolescents with intellectual disabilities: a case control study. *International Journal of Developmental Disabilities*, 69(5), 675–682. <https://doi.org/10.1080/20473869.2021.2001728>
- II. Bojner Horwitz, E., **Korošec, K.**, Theorell, T. (2022) Can dance and music make the transition to a sustainable society more feasible? *Behavioural Sciences*, 12, Article 11. <https://doi.org/10.3390/bs12010011>
- III. **Korošec, K.**, Bačlija Sušić, B., & Habe, K. (2022). Improvisation as the foundation of flow in music education: Connections to attitudes, gender, and genre. *Journal of Elementary Education*, 15(3), 339–356. <https://doi.org/10.18690/rei.15.3.339-356.2022>

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List of abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
APA	American Psychological Association
ARC	Autonomy, Relatedness, and Competence
B-MMR	Brief Music in Mood Regulation
BPN	Basic Psychological Needs
DSM	Diagnostic and Statistical Manual of Mental Disorders
ERI	Emotion Regulation Inventory
MHC-SF	Mental Health Scale – Short Form
MUSEBAQ	Music Use and Background Questionnaire
NSFS	Need Satisfaction and Frustration Scale
RCT	Randomised Controlled Trial
PaMEW	Participatory Music Engagement and Mental Well-being Questionnaire
SDT	Self-determination Theory
WHO	World Health Organisation

Introduction

Music has been linked to the history of autism since one of the earliest articles on autism (Kanner, 1943), which referenced music in relation to the behaviors of autistic children. Despite this early reference, the role of music in the lives of autistic people has been largely overlooked in research for decades. While there has been a growing academic and clinical interest in music and autism over the last 80 years, the subjective experiences of autistic adults engaging with music have only recently begun to be explored in depth. For much of this period, the focus has been on using music as a therapeutic tool, often neglecting the lived experiences of autistic individuals. Additionally, the potential negative effects or harms of music engagement have been rarely acknowledged, leaving a significant gap in our understanding of the full spectrum of its impact.

The aim of this thesis is to investigate the roles of music in the lives of autistic adults, with a particular emphasis on how these experiences relate to their well-being. By exploring both positive and negative aspects of musical engagement, this research seeks to shed light on the nuanced and varied ways autistic adults use music to navigate their personal and social worlds. In addition to contributing new knowledge to the field, the aim is also to integrate existing research, ultimately working toward the development of a common framework and assessment tools that can be used in future studies.

Through multiple studies, this thesis addresses several key research questions: What roles does music play in the lives of autistic adults? Under what circumstances does it become a source of stress or discomfort? How can music satisfy the basic psychological needs of autonomy, competence, and relatedness? Additionally, the thesis explores the gaps in current models and theories, particularly regarding the experiences of autistic individuals, and works toward creating tools that accurately assess the role of music in supporting well-being.

By focusing on the subjective experiences of autistic adults, this research emphasizes the importance of understanding how people engage with music on their own terms. It highlights the active roles of autistic adults as creators and participants in the music-making process. Finally, this thesis underscores the importance of a pluralistic and inclusive approach, considering the diverse ways people experience music and the potential harms that might be overlooked in current theories and practices.

1 Literature review

1.1 Autism

The term “autism” was coined in the first half of the 20th century (Bleuler, 1950 [1911]; Kanner, 1943) and was strongly influenced by psychoanalysis and phenomenology. With the rise of behaviourism, the focus shifted in the 1960s towards precise and repeatable observations of behaviour, which meant that autistic¹ people’s subjective experiences were excluded from the way autism was conceptualised (for a historical account see Evans, 2013, Verhoeff, 2013 and Heaton, 2024). Autism became a distinct diagnosis in the end of the 1970s (American Psychiatric Association, 1980; World Health Organization, 1977) and while most mental health nosologies nowadays integrate subjective experience of a condition with observable behaviour, autism remains one of the few which are defined solely by the latter (Milton & Green, 2024).

1.1.1 Biomedical paradigm

According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) (American Psychiatric Association, 2022) which is currently in use in Sweden, autism (or “autism spectrum disorder”) is a “neurodevelopmental disorder” defined by two categories of behaviours: “persistent deficits in social communication and social interaction²” and “restricted, repetitive patterns of behaviour, interests, or activities³” (Section II, Neurodevelopmental Disorders, Autism Spectrum Disorder). To fulfil the criteria for the diagnosis, the listed characteristics have to be present since early childhood, cause “clinically significant” impairment in different areas of life (e.g.,

¹ In this thesis, I use the term autism (not autism spectrum disorder) and identity-first language (autistic person) instead of person-first language (person with autism) to avoid ableist language (Bottema-Beutel, Kapp, et al., 2021). However, in conversations with our participants, we used whichever term they preferred.

² These consist of a) deficits in social-emotional reciprocity (e.g., reduced sharing of interests or emotions, failure to initiate or respond to social interactions); b) deficits in nonverbal communicative behaviours used for social interaction (e.g., poorly integrated verbal and nonverbal communication, abnormalities in eye contact and body language); and c) deficits in developing, maintaining, and understanding relationships (e.g., difficulties adjusting behaviour to suit various social contexts) (American Psychiatric Association, 2022).

³ These consist of a) stereotyped or repetitive motor movements, use of objects, or speech; b) insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal or nonverbal behaviour; c) highly restricted, fixated interests that are abnormal in intensity or focus; d) hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (American Psychiatric Association, 2022).

at home, school, or work), and cannot be better explained by intellectual disability or global developmental delay (American Psychiatric Association, 2022).

Globally, around 0,4–1% of people have received an autism diagnosis, with women being four times less likely to have the diagnosis than men (Salari et al., 2022; Talantseva et al., 2023; Zeidan et al., 2022). Over the past few decades, researchers have increasingly recognised that autism envelops a highly heterogeneous group of people (both in terms of phenotypic presentations as well as measured by biomarkers) (Dwyer, 2022a). This could be in part connected to the fact that the definition and characteristics of autism have expanded, while the diagnostic threshold for autism seems to have lowered over time, bringing more individuals under the umbrella of the autism spectrum (Arvidsson et al., 2018; Avlund et al., 2021). Another contributor to the heterogeneity is diagnostic substitution, where individuals previously diagnosed with other conditions such as learning disabilities now receive a diagnosis of autism (King & Bearman, 2009). Clustering of different subtypes is being increasingly discussed as a way to provide more targeted and tailored support, but this approach comes with its own set of challenges (see Dwyer, 2022a, for more details). This heterogeneity presents challenges for autism research, as defining subgroups of autism can reshape how the condition is understood, influencing both its ontology and political implications (Dwyer, 2022a).

The traditional medical understanding of autism follows a biomedical paradigm built on the premise that disabilities stem from pathological conditions of the body and mind, and that the correct response is to transform disabled people into able-bodied people. The biomedical definition of autism is based predominantly on what autism *looks* like to a (non-autistic) observer, excluding experiential aspects, and focusing on what autistic individuals cannot do or struggle with compared to non-autistic norms (Dwyer, 2022b). Many interventions have thus been built around the implied premise that the challenges an autistic person's experiences stem solely from their personal "deficits", and that making the person more like non-autistic people will solve the challenges they face (for a detailed ethical consideration of this topic, see Bovell, 2020).

However, a lot of the suffering that autistic people experience stems from stigma, societal exclusion, discrimination, and marginalisation (Botha & Frost,

2020; Chapman, 2020b; Han et al., 2023), and hiding autistic traits does not seem to help for most individuals. Autistic people who camouflage or “mask” their autistic traits (e.g., monitoring facial expressions and eye contact, suppressing stimulatory behaviour) experience poorer mental health and well-being (Cage & Troxell-Whitman, 2019; Cook et al., 2021, 2022; Hull et al., 2019) and are at higher risk for suicidal behaviour (Cassidy et al., 2018, 2020).

As the biomedical perspective and diagnostic criteria alone fail to provide a full picture of autistic people’s strengths, challenges, and environmental factors that contribute to them, we are seeing the emergence of a “new era of autism research” (Pellicano et al., 2018, p. 83). This shift is seen both in what the research focuses on (with more efforts being directed towards improving quality of life and support services across lifespan) as well as how we understand autism.

1.1.2 Neurodiversity paradigm

In response to the biomedical paradigm, we are seeing shifts in conceptualisations of autism as well as disability in general. The term “neurodiversity” was collectively coined by autistic scholars and activists across several online communities in the mid-1990s (Botha et al., 2024). Neurodiversity in its broadest sense simply refers to the fact that all body-minds are different (similar to the biodiversity of an environment) (Walker, 2021). The theoretical perspectives stemming from it are interchangeably called “neurodiversity paradigm(s)”, “neurodiversity framework(s)” or “neurodiversity approach(es)” and are built on a premise that what the biomedical paradigm calls “neurodevelopmental disorders”⁴ are not a result of pathology but of normal variability in how human nervous systems develop (Chapman, 2020a; Dwyer, 2022b; Walker, 2021). Autism is therefore described, for example, as a “developmental disability” (The Autism Self-advocacy Network, 2009), or “a genetically-based human neurological variant” (Walker, 2021). These approaches challenge the idea of normativity, upon which the biomedical paradigm is built, and prove it to be difficult to define and far from objective (Chapman, 2020b). This denial of “abnormality” can be perceived by some as denying people’s suffering and struggles, which is far from the goals of the neurodiversity

⁴ In many approaches, the premise extends beyond only “neurodevelopmental disorders” (Chapman, 2020a).

movement. A possible reconciliation between pathologising differences and denying hardships is the value-neutral model of disability, proposed by Barnes (2009). The model describes disability as partially socially constructed and partially determined by the physical properties of a body. It is called 'value-neutral' because it does not define disabilities as inherently good or bad for one's 'global well-being'. Instead, it shifts the focus to 'local well-being' meaning the well-being of a specific person in a specific time and context, to give a more nuanced understanding of the variables affecting their well-being (for autism as an example see Chapman, 2020b).

The DSM-5-TR (American Psychiatric Association, 2022) classification of autism as a disorder has reinforced a deficit-focused perspective in research and practice. However, there is growing support for conceptualising autism not as a disorder but as a natural variation in brain development, reflecting human diversity. How autism is understood carries significant implications for research, practice, and policy, influencing whether it is approached as something to be treated, accommodated, or embraced as part of human diversity.

The importance of including autistic voices in research and considering their disabilities as part of a broader context, is increasingly being recognised in medical contexts and mainstream academic discourse (Pellicano et al., 2018). By excluding autistic people's perspectives, scientists risk missing crucial questions or misinterpreting their data (see, for example, the 'double empathy problem' coined by Milton, 2012; 2022). We therefore see a shift not only in *what* research is being conducted, but also *how* (Pellicano et al., 2018).

1.1.3 Refocusing autism research

While the majority of funding in autism research goes towards biomedical studies (Cervantes et al., 2021; Harris et al., 2021), the priorities of the stakeholders lie elsewhere and are receiving more consideration in the recent years (Benevides et al., 2020; Chown et al., 2023; Pellicano et al., 2014; Pukki et al., 2022; Roche et al., 2021).

Roche et al. (2021) have conducted a literature review of studies investigating the research priorities of stakeholders and condensed them into the following list: 1) skills development and training from childhood into adulthood and employment; 2) physical health, wellbeing, and mental health; 3) expertise, coordination, availability, and accessibility of services across the lifespan; 4) accurate identification, screening, and understanding of autism across the

lifespan; 5) developmental profile and cognitive, thinking, and learning skills of individuals on the autism spectrum; and 6) transitions and support for transitions (p. 341). This demonstrates a clear desire for research that directly improves the quality of life for autistic people across the lifespan in practical, immediate ways.

In addition to the shift in *what* is being researched, there is also a shift in *how* research is being conducted. Participatory research, for example, is becoming more prominent (den Houting et al., 2021; Fletcher-Watson et al., 2019; Keating, 2021; Pellicano et al., 2022; Pickard et al., 2022). The field increasingly focuses on including autistic individuals and their allies in decision-making processes related to research topics, methods, and implementation. This approach strives to connect the current research with the needs identified by the stakeholders. Despite growing interest, participatory research in autism is still relatively underdeveloped, and researchers face challenges such as navigating communication barriers and working in academic environments that often lack the time, funding, and support for this approach (Pickard et al., 2022).

In short, we are witnessing a slow yet considerable shift towards research that prioritises human rights, ethics, and social policies, focusing on the well-being of autistic people.

1.2 Well-being

Broadly speaking, there are two traditions when it comes to conceptualising well-being (Lamers et al., 2011). The hedonic tradition focuses on subjective experiences such as happiness and the pursuit of pleasure, emphasising the importance of maximising positive emotions and minimising negative ones. It is closely associated with emotional well-being, which includes both the balance of pleasant versus unpleasant emotions and overall life satisfaction. A well-known example is work on subjective well-being by Diener et al. (1985). In contrast, the eudaimonic tradition emphasises optimal functioning and personal growth. It is concerned with realising one's potential and living a life that is meaningful and fulfilling. This approach is measured through psychological well-being, which includes dimensions like self-acceptance, autonomy, and purpose in life, as well as social well-being, which evaluates how individuals feel integrated and valued within their communities. A well-known example is Ryff's (1989) model of psychological well-being.

There are also approaches that combine the hedonic and eudaimonic understandings of well-being. Keyes' (2005) model, for example, links emotional, psychological, and social well-being and combines them into a broader *mental well-being*.⁵ According to this model, mental well-being is assessed through variables such as subjective experiences of positive emotions, as well as self-acceptance, positive relations with others, personal growth, purpose in life, environmental mastery, autonomy, social acceptance, social actualisation, social contribution, social coherence, and social integration (Keyes et al., 2008). While Keyes' (2005) model outlines various aspects that make up well-being, it does not explain the mechanisms that influence it, such as the impact of psychosocial environments.

1.2.1 Self-determination theory (SDT)

SDT is a meta-theory of human motivation and well-being⁶ and, among other things, aims to explain what people need from their psychosocial environments in order to experience well-being. It stems from an organismic approach to understanding life, seeing "healthy human functioning as becoming increasingly complex yet more integrated and coordinated over time, expressing inherent capacities to grow, quest, connect, and ultimately flourish." (Ryan & Vansteenkiste, 2023, p. 8).

The evolution of SDT can be traced back to Deci's (1975) work on intrinsic and extrinsic motivation. They represent two key types of motivational processes that are essential for understanding human behaviour and well-being. Intrinsic motivation refers to engaging in activities for their inherent satisfaction, interest, or enjoyment, such as curiosity-driven exploration or learning "for its own sake" (Deci & Ryan, 2000). In contrast, extrinsic motivation involves performing tasks to achieve outcomes separate from the activity itself, such as acquiring rewards or avoiding punishment. Being intrinsically motivated for an activity is often connected with positive outcomes, such as higher academic and learning outcomes, creativity, and well-being, among others (Howard et al., 2021; Koehler & Neubauer, 2020; Ryan & Deci, 2020; Urban & Urban, 2023; Wehmeyer, 2023).

⁵ According to Keyes (2005), mental well-being and mental illness (or the presence of psychopathological symptoms) should be understood as two separate but correlated continua. This means that although a person might experience many psychopathological symptoms or conditions (e.g., schizophrenia), they can still experience high mental well-being (e.g., happiness, purpose in life, self-acceptance, fulfilling relationships) and vice versa.

⁶ In literature on SDT, the term 'flourishing' is often used interchangeably with 'well-being'.

Whether a person is going to be intrinsically or extrinsically motivated is deeply linked with the satisfaction and frustration of three basic psychological needs: autonomy, competence, and relatedness (ARC).

Autonomy “concerns a sense of initiative and ownership in one’s actions” (Ryan & Deci, 2020, p. 1). People experience autonomy when they get to do something they value or that genuinely interests them. However, being controlled externally to do something that is not fully aligned with their goals or values thwarts their sense of autonomy and can result in feelings of inner conflict (Vansteenkiste et al., 2023). Relatedness refers to the “sense of belonging and connection” (Ryan & Deci, 2020, p. 1) and is supported when one feels mutual respect and caring with others. When this need is frustrated or not supported, people can feel socially alienated, excluded, and lonely (Vansteenkiste et al., 2023). Lastly, competence “concerns the feeling of mastery, a sense that one can succeed and grow” (Ryan & Deci, 2020, p. 1). This need is supported in well-structured environments that provide a balanced number of challenges, opportunities for growth, and positive feedback. When this need is not met, people can experience a sense of failure or helplessness (Vansteenkiste et al., 2023).

When these needs are thwarted, motivation quality declines—people either become amotivated and stop engaging in that activity or keep doing it because they are externally motivated, for example by rewards or punishments—which results in reduced well-being (Vansteenkiste et al., 2023). Researchers and practitioners have thus used SDT in numerous settings (including musical settings) to adapt environments to better meet people’s needs (Ryan, 2023).

1.2.2 Autism and well-being

When compared to the general population, autistic individuals are at greater risk of experiencing mental health conditions, such as anxiety and mood disorders (Hollocks et al., 2019; Lai et al., 2019), and the risk seems to be even greater for autistic women compared to men (Lai et al., 2019; Martini et al., 2022; Rødgaard et al., 2021). On average, autistic people also tend to score lower on measures of quality of life and well-being compared to their non-autistic peers (Ayres et al., 2018; Kamio et al., 2013). Furthermore, they experience lower levels of self-determination, not only compared to non-autistic peers (Chou et al., 2017; Weiss & Burnham Riosa, 2015; White et al., 2018) but also certain other disability groups, such as those with sensory disabilities (e.g., sight and sound perception) and learning disabilities, among others (Qian et al., 2022). Self-determination is

“the ability to act as the causal agent in one’s life, to have the capacity to choose and to have choices regarding one’s quality of life free from undue external influence or interference” (Thompson–Hodgetts et al., 2023, p. 2) and is also considered a fundamental human right (United Nations Convention on the Rights of Persons with Disabilities, 2006). Thompson–Hodgetts et al. (2023) have conducted interviews with autistic people and found that they experience barriers to self-determination in discrimination and lack of opportunity, as well as in challenges connected to executive processing differences. While biological mechanisms received much academic attention, we know far less about social and psychological mechanisms that contribute to the mental health and well-being of autistic people (Cooper et al., 2017). Recent findings show the importance of need support (Mason, 2018), social identity and self-esteem (Cooper et al., 2017), as well as social stigma (Caron et al., 2022).

While findings that show lower well-being among autistic people should be taken seriously, it is also important to think about the validity of the used assessment tools. Many existing tools, though validated for other populations, may not accurately reflect the experiences of autistic individuals due to differences in how they interpret certain questions, as well as what they perceive as important for their well-being. Without proper validation, research findings can be misleading, potentially leading to inappropriate intervention targets and inaccurate comparisons between autistic and non-autistic people. Additionally, general quality of life and well-being measures may not adequately capture aspects of well-being, such as sensory sensitivities, autism-related knowledge and acceptance, and access to support services, which are particularly relevant for autistic individuals (McConachie et al., 2020). Validated tools tailored to the unique experiences of autistic individuals are therefore essential for improving their well-being and ensuring meaningful interventions (Mason et al., 2018; McConachie et al., 2018, 2020).

In autism research as well as practice, we are seeing a growing emphasis on well-being related outcomes and efforts to tailor and optimise assessment tools. Support services are starting to employ frameworks that emphasise a person’s strengths and capabilities and focus on adapting the environment to a person’s needs, which can also be seen in music-based interventions and activities (Pickard et al., 2020; Thompson et al., 2020).

1.3 Music

There seem to be widely different definitions of what constitutes “music,” even though relatively few scholars took on the challenge of defining it (Davies, 2012). “Perhaps it is because [...] we are usually highly successful in identifying music as such and don't feel the need of a definition,” remarks Davies (2012, p. 2). Each new definition seems to create a frame to be exceeded, a challenge for artists to create new ways of conceptualising music. This might lead us to side with Rahkonen (in Godt, 2005), who says, “Music [in a given culture] is whatever people say it is.”⁷ While I can see value in leaving music as an art form undefined and free to evolve with the societies that create it, I also understand the need to know what it is we are talking about, especially when we discuss it in terms of somebody's well-being, education, support services, or human rights. In this thesis, I neither provide nor ascribe to any specific definition of music as an art form. Rather, I focus on music as it is being created, perceived, conceptualised, and engaged with by autistic individuals in their respective sociocultural contexts.⁸

1.3.1 Musicking

Small's (1999) concept of “musicking” shifts the focus from music as a static object, such as a musical work or composition, to music as a social process. It highlights that music is fundamentally about participation in social performances—whether through performing, listening, composing, or even setting up the event. To emphasize this, Small (1999) changes the noun “music” into a verb “to musick” (musicked; musicking; musicks). With that, he challenges traditional views that treat musical works as fixed entities and instead focuses on the relationships and interactions that emerge during musical events. As he states, “the essence of music lies not in musical works but in taking part in performance, in social action” (Small, 1999).

At its core, musicking is about engaging in a dynamic social process. Small's concept challenges traditional views that prioritise musical works or the

⁷ To which Godt (2005, p. 83) replies: “His permissiveness is excessive. It springs from a laudable desire to meet unfamiliar cultures on their own terms, free from the prejudices of our own, but it says little to us about our culture. Although we can never free ourselves completely from our own ethnocentricity, does it make sense to adopt the ethnocentricity of others?”

⁸ In the studies that comprise this thesis, we understood music as anything that our participants considered to be music.

composer over the participants' experiences. Instead, it highlights the significance of the communal and social aspects of music engagement, where every participant—whether they are performing, listening, or otherwise engaged—plays a crucial role in shaping the meaning and value of the musical experience. This participation helps individuals explore and affirm their relationships with others, the world, and their own communities. Thus, musicking is not about achieving a finished product but about valuing the process and the social interactions it fosters. It offers a pluralistic view of music engagement that challenges elitist approaches and redefines musical success in terms of social and cultural engagement (Small, 1999).⁹

1.3.2 Musicking and well-being

Musicking is being increasingly recognised as a promotor of well-being and quality of life (Daykin et al., 2020; Fancourt et al., 2020; Gordon-Nesbitt & Howarth, 2020; McCrary et al., 2022). A meta-analysis conducted by McCrary et al. (2022), for example, showed that music-based interventions are associated with significant improvements in health-related quality of life and provide additional significant improvements when combined with standard treatment. There is evidence indicating that musicking can help, among other things, in managing pain (Howlin & Rooney, 2020), stress (Helsing et al., 2016; Theorell et al., 2019, 2023; Viding et al., 2015), anxiety (Nguyen et al., 2022), and depression (Tang et al., 2020). But the benefits can stretch beyond the intra- onto inter-personal levels (Bojner Horwitz, 2018; Bojner Horwitz et al., 2015, 2021; Bojner Horwitz & Thyrén, 2022). For example, musicking can support social bonding (Savage et al., 2021; Tarr et al., 2014) and help in the development of social skills (Kokotsaki & Hallam, 2007; Saarikallio, 2019; Váradi, 2022), while being a part of a social group further protects mental health (Cruwys et al., 2013).

While the mechanisms are not yet fully understood, we know that musicking involves many aspects that are known to promote well-being and health. These are, for example, aesthetic and emotional engagement, involvement of the imagination, sensory activation, cognitive stimulation, physical activity, and social interaction. Because of this, music-based interventions are often used in

⁹ In this thesis, I use the term “musicking” to describe people’s engagement with music in a specific context (playing, listening, dancing, etc.) and the term “music” to refer to the artform more broadly (for example, “autism and music”, “music pedagogy”, “music skills and abilities” or “music-based interventions”).

situations or health conditions where no simple, complete solutions are available. Furthermore, they often show equivalent or greater cost-effectiveness, compared to standard health interventions, and are well worth looking into (Fancourt & Finn, 2019).

Researchers and practitioners often use SDT to explain why people are motivated to musick and how it might affect their well-being (Beebe, 2022; P. Evans, 2015; Koehler et al., 2023; Koehler & Neubauer, 2020; Krause et al., 2019; Krause & Davidson, 2021; Küpers et al., 2014; Strehle, 2023). Even studies that are not explicitly built on SDT (e.g., Creech et al., 2023; Dingle et al., 2021; Perkins et al., 2020, 2021; Saarikallio, 2019; Saarikallio et al., 2019; Sheppard & Broughton, 2020) concur that musicking can raise a sense of agency and accomplishment, as well as facilitate self-development and social engagement. These findings show clear parallels with the BPN—autonomy, relatedness, and competence. There are many ways in which musicking can support BPN (Krause et al., 2019), for example, by supporting the development of different skills and thus self-efficacy and confidence, offering opportunities to exert one's autonomy, be creative, and express oneself, as well as to connect with others through musical activities. These findings are also echoed in studies using large multinational samples.

In a recent meta-ethnographic study, involving over 2,000 participants from different countries, Perkins et al. (2020) investigated how music engagement (excluding music listening) supports mental well-being according to people's experiences. The authors identified four key pathways through which musicking supported mental well-being: managing and expressing emotions, facilitating self-development, providing respite, and fostering connections. Each pathway comprises multiple processes that interact and overlap, illustrating the complex, individualised nature of the effects of musicking. Importantly, the findings reveal that while these pathways may appear generic, their impact is highly personalised, shaped by individual circumstances and cultural contexts. This specificity allows for a deeper understanding of how different groups experience music's benefits uniquely.

When carefully examining the found themes and subthemes, the model (Perkins et al., 2020) shows clear parallels with the BPN, namely autonomy, relatedness, and competence. For example, musicking offers people a place of respite, where they get to do something they enjoy and have protected time just for

themselves, which is closely connected with autonomy. Musicking also facilitates connections with other people, for example through common heritage, or by providing social support and a sense of fellowship—in other words, supporting their need for relatedness. Lastly, musicking helps people to manage their emotions, develop new skills, and support self-discovery while providing a sense of meaning in life and achievement—themes that overlap with the need for competence (Perkins et al., 2020).

Perkins et al.'s (2020) model appears to be readily integrated with SDT, allowing us to connect it to a diverse and interdisciplinary body of literature. Ultimately, this study lays a foundation for future research, encouraging a more nuanced exploration of music's role in mental health and well-being across diverse populations.

1.4 Autism, musicking and well-being

Music and autism research has so far been mainly focused on two broad questions: how do autistic people differ from non-autistic people in their processing of music and how can music-based activities be used to help autistic children? The adult autistic population remains severely understudied, as do their subjective experiences of musicking. Most studies are based on observation, often using a hierarchical perspective with a researcher or a therapist “at the top,” leaving little space for the personal accounts of autistic people, which could help contextualise the observed differences. Lastly, and most importantly, musicking is rarely discussed as a possible source of harm, and music-based interventions rarely check for possible adverse effects.

1.4.1 Musical abilities, emotion processing and neurophysiological responses to music

A lot of the past research on music and autism is basic in nature, and not directly focused on the possible applications of musicking for this population. Most of it falls into three broad categories: research on musical abilities, processing of emotions, and neurophysiological responses to music.

Musical abilities are often presented as one of the strengths of autistic people (Heaton, 2009, In press; Quintin, 2019), and this idea dates back to the very conception of the diagnosis (Kanner, 1943). Their abilities are reported to show in a superior memory of pitches (Heaton et al., 1998) and melodies (Stanutz et al., 2014), as well as better recognition of constituting parts or small differences in

pitches and melody (Bonnell et al., 2010; Bouvet et al., 2016; Heaton, 2003; Mottron et al., 2000). However, Jones et al. (2009) point out that these enhanced abilities might only be present in about 20% of autistic people.

Contradictory evidence exists regarding their auditory processing. While some studies suggest that autistic individuals may have less precise timing and duration processing of auditory events compared to non-autistic peers (Bhatara et al., 2013; Kargas et al., 2015), others indicate that their musical abilities are comparable to, or on par with, non-autistic individuals (Jamey et al., 2019; Quintin et al., 2013).

Although current evidence suggests that autistic individuals may have similar or even superior musical abilities compared to non-autistic peers, findings are inconsistent and marked by significant inter-individual variation (for a scoping review, see Hernandez-Ruiz et al., 2022). Nordoff and Robbins (1964; 1965) were among the first to suggest that these abilities might not be innate. They proposed that autistic children might find musical engagement less threatening than other activities, which could explain their higher involvement in musical activities (Reschke-Hernández, 2011). The variability in findings is not that surprising, considering the heterogeneity of autism phenotypes, as discussed previously.

Another area of research is the emotional processing of music in autistic people. Possibly stemming from the erroneous belief that autistic people lack empathy (Milton, 2012; Milton et al., 2022), many studies have focused on autistic people's ability to recognise or feel emotions in music. A recent review suggests that they in fact recognise and discriminate emotions in a piece of music, and show similar emotional responses to music pieces as their non-autistic peers (Hernandez-Ruiz et al., 2022; Quintin, 2019).

The third area of research is focused on the neurophysiological responses of autistic people to music. Although behavioural responses to heard music are similar in autistic and non-autistic people (Hernandez-Ruiz et al., 2022; Komoriya et al., 2015), they show some differences in neural correlates. While results are diverse and sometimes contradictory, we can find certain consistency in them. For example, autistic people show decreased activity in temporoparietal areas on both sides (Bruneau et al., 2003; Roberts et al., 2019), as well as in the left prefrontal cortex (Lai et al., 2012; Mamashli, 2017; Matsuzaki et al., 2017) and left anterior cingulate cortex (Gomot, 2006), when experiencing novel or

unexpected sounds. Furthermore, they show less top-down regulation (represented by the evoked mismatch field) in noisy situations, which could explain why they have difficulty telling apart the target stimuli in a noisy environment (Andersson et al., 2013; Mamashli et al., 2017; Soskey et al., 2017; Tecchio et al., 2003). The evidence from neurophysiological studies suggests that there might be a different developmental trajectory in autistic people's responses to music (Hernandez-Ruiz et al., 2022).

These neurophysiological observations might give us valuable insights into how human brains process musicking in different ways. However, it is currently difficult to draw any conclusions both because of the heterogeneity in the population of interest (Mottron & Bzdok, 2020), and the lack of knowledge about people's subjective experiences, which would accompany these observations and help us contextualise them (Pantazakos, 2019).

1.4.2 Music(king) as an intervention

The use of music as a therapeutic tool in the autistic population dates back to the 1940s, while the scientific research in this field started in the 1970s (Reschke-Hernández, 2011). Early music interventions (1940–1990) primarily focused on communication and social skills, followed by perceptual motor skills, behaviour, and cognition, while a smaller portion addressed emotional and psychological needs, musical abilities, and sensory sensitivities (Reschke-Hernández, 2011). According to Kern et al. (2013), these focus areas have persisted over time, with 98% of music therapists targeting communication, 91% addressing social skills, and 43% working on emotional regulation when working with autistic individuals. However, goals are being increasingly reconsidered and reframed to focus on a client's strengths and resources (Davies, 2022; Pickard et al., 2020).

Recent systematic literature reviews (Applewhite et al., 2022; Geretsegger et al., 2022; Marquez-Garcia et al., 2022; Mayer-Benarous et al., 2021) show that studies on the effectiveness of music therapy for the autistic population suffer from low methodological quality, limiting the ability to draw firm conclusions. These studies often involve small sample sizes, lack controlled designs, fail to include follow-up assessments, and do not use randomisation. Moreover, most studies focus on children. Despite these limitations, some aggregated results suggest that music therapy may benefit social functioning and communication

(Applewhite et al., 2022; Geretsegger et al., 2022; Marquez-Garcia et al., 2022; Mayer-Benarous et al., 2021).

While improving the methodological rigour of studies is essential, it is equally important to question what is being evaluated. A majority of 23 out of 26 studies included in the review conducted by Geretsegger et al. (2022a) focused on observable autistic traits as their outcome measure, while only three studies assessed quality of life; this focus was echoed across systematic reviews (Applewhite et al., 2022; Marquez-Garcia et al., 2022; Mayer-Benarous et al., 2021). Autistic traits were either assessed through diagnostic tools for autism or through behavioural observations (e.g., observing gestures, eye contact, verbal interactions, imitation, facial expressions, and tone of voice) (Applewhite et al., 2022; Geretsegger et al., 2022; Marquez-Garcia et al., 2022; Mayer-Benarous et al., 2021). This “symptom-focused” approach suggests an underlying goal of “curing” or “reducing” autism, which has been pointed out and criticised by some music therapists in the past (Davies, 2022; Pickard et al., 2020; Straus, 2014), but changes seem to be slow. As Pukki et al. (2022, p. 5) argue, “Changing behaviour, as such, should not be the main goal of clinical research or treatment for autistic people of any age. Appearing autistic or acting in typically autistic ways should not be considered an illness.”

1.4.3 Harms and adverse events

At the moment, we know very little about the possible harms and adverse events of music-based support services, as studies rarely mention or explore them (Geretsegger et al., 2022). This is not only a problem in music-based support services but in interventions for the autistic population in general (Bottema-Beutel et al., 2021). Bottema-Beutel et al. (2021) found that 93% of 150 studies they reviewed never even mentioned or acknowledged the possibility of adverse events. When adverse events are not being monitored, it is unlikely for them to be uncovered. Decades of negligence in this area have led to the use of ethically questionable interventions for autistic people to this day (Dawson & Fletcher-Watson, 2022).

In a recent Cochrane review of music therapy for autistic people, Geretsegger et al. (2022a) report that only two out of 26 trials checked for adverse events and that they found “no differences between music therapy and standard care immediately post-intervention.” (p. 2). However, the adverse events were

assessed through the number of hospitalisations, which makes it possible that more subtle adverse events went unnoticed.

Silverman et al. (2020) have developed a theoretical model of music-induced harms (MIH), which shows how harm could emerge from the interplay between the context, music, the deliverer, and the recipient. According to their model, harm can be affective (e.g., anxiety), behavioural (e.g., maladaptive coping strategies), cognitive (e.g., overstimulation), connected to identity (e.g., harm to self-concept), interpersonal (e.g., isolation), physical (e.g., arousal-related arrhythmia), or spiritual (impaired ability to experience meaning in life). Some of these types of harm can be difficult to observe, which is why it is important to be aware of them in advance and carefully monitor them. Yet, while it is crucial to stay alert to unpredicted harmful side-effects, sometimes the harm can be hiding in plain sight, intertwined in the primary goals of an intervention.

Geretsegger et al. (2022a, p. 2) summarise that “music therapy probably results in a large reduction in total autism symptom severity.” As mentioned previously, the focus on observable autism traits is common across studies in this field (Applewhite et al., 2022; Geretsegger et al., 2022; Marquez-Garcia et al., 2022; Mayer-Benarous et al., 2021). Changes in observed behaviour are especially concerning, because they are not accompanied by data on participants well-being or lived experiences. It is thus difficult to tell whether a participant is developing social skills or masking behaviours, which raises serious concerns. Geretsegger et al. (2022, p. 33) acknowledge that “such approaches might support or even provoke the masking of autistic traits, which has been reported to be associated with negative consequences for mental health, including an increase in the risk of lifetime suicidality.” It is therefore crucial that music-based services for autistic people, including music therapy, are evaluated based on well-being and other outcomes important to the stakeholders while monitoring and avoiding possible harms.

Lastly, it is important to acknowledge that while some harms stem from interventions that directly harm the participants (e.g., punishing autistic behaviour), others arise from the failure to provide important activities and opportunities, as well as from underestimation of the participants’ potential (Dawson & Fletcher-Watson, 2022; Uddholm & Backman Bister, 2019). While musicking might have a promise in raising the empowerment and well-being of some autistic people, we cannot treat it as inherently good and harmless. We

must pay close attention to possible adverse events and, most importantly, collaborate with autistic people when creating activities and interventions.

1.4.4 Subjective experiences of musicking

The first study on subjective experiences of musicking in autistic adults was done by Allen et al. (2009). They found that autistic adults musicked for the same reasons and to satisfy the same needs as non-autistic adults, namely, to alter their moods, ease psychological pain, experience belonging and a sense of achievement, as well as to feel aesthetic pleasure. Interestingly, the authors found that their participants musicked to change the arousal of their emotional states (e.g., from calm to excited or vice versa), but not so much to change their valence (e.g., sad to happy). They also had difficulties describing their emotional responses to music, which the authors ascribed to high rates of alexithymia in the autistic population. It is also important to keep in mind that the study only included adults who could fluently express themselves in written form, leaving a large portion of the population unstudied.

Lived experiences of musicking in autistic people were again brought forth in an ethnomusicological book by Bakan (2018), almost a decade later. It closely follows the life stories of ten autistic people and shows a great heterogeneity in the ways in which they engage in musicking and the meanings it has for them. Another important study was done by Kirby and Burland (2022), who conducted interviews with 11 autistic adolescents and young adults who expressed themselves in different ways (e.g., verbally, through pictures, or through sign language). They found that the participants mainly musick to accompany other activities, manage and express their emotions, develop social relationships, and develop and express their identity. When comparing the results to those obtained from non-autistic adolescents, they concluded that autistic youth musick for largely the same purposes. They found no differences regarding emotional responses to music, as was the case with Allen et al. (2009). The next study was conducted by Venter et al. (2023), who interviewed three autistic adults and found that they musick to cope with auditory sensitivities, get lost in music, find connections to others as well as a companion in the music itself, and lastly, for self-regulation. Their findings echo those of Kirby and Burland (2022) as well as Allen et al. (2009). The most recent study in this field was conducted by Shalit et al. (2024), who focused specifically on musicking in autistic women. They interviewed nine women and found four overarching themes describing the significance of musicking in their lives: it helped them to participate in their

society; it was an expression of their differences; its significance and roles changed throughout their lives; and because of societal pressures, they hid, masked, or even lost certain parts of their identity. More specifically, musicking played significant roles in their emotion regulation, facilitation of connections, and a sense of belonging, providing leisure time and a safe space where they got to understand and accept what they think makes them different. Interestingly, it also created situations where they felt like they needed to hide or mask who they are, sometimes completely letting go of genres or activities they used to enjoy, which was not found in the previous studies.

1.4.5 Research gaps

Research on music and autism reveals several significant gaps. Most studies focus on children, with limited exploration of musicking across the lifespan, particularly in older adults. Additionally, there is an over-reliance on observational data, as many studies primarily assess changes in observable autistic traits, such as eye contact or social interactions, while neglecting participants' well-being, lived experiences, and quality of life, which are essential for understanding the true impact of interventions. Another critical gap is the insufficient monitoring of adverse events; few studies address or track potential harms from music-based activities or support services, making it difficult to ensure their safety. Furthermore, much of the research views autistic individuals as passive "recipients" of music-based activities or support services, overlooking their role as active creators—musicians, music students, pedagogues, or therapists. This neglects the potential for empowerment and self-expression through active participation, underscoring the need for more pluralistic approaches that recognise and value the heterogeneity of the ways in which people musick.

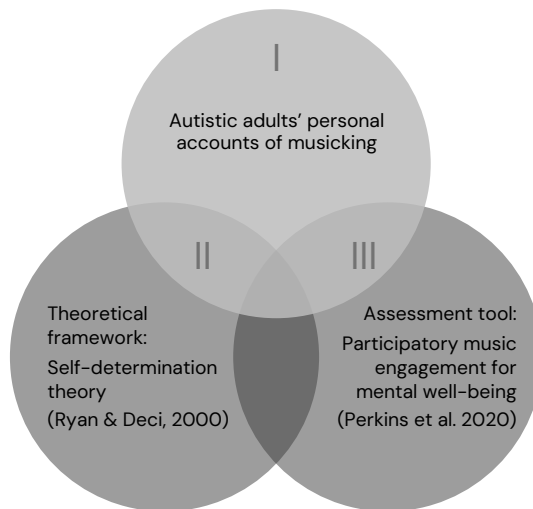
2 Research aims

The overarching aim of this thesis was to investigate the roles of musicking in the lives of autistic adults, particularly in relation to their well-being. In addition to adding new knowledge, our objective was to integrate existing knowledge, contributing to a common framework and assessment tools for future research. Figure 1 offers a visualisation of the doctoral project's focus.

The aim of Study I was to explore autistic adults' personal experiences of musicking (marked I in Figure 1). Our research questions were: (1) What are the roles of musicking in the lives of autistic adults? (2) Under which circumstances can musicking be a source of stress for them?

After concluding the first study, we had a broad overview of how autistic adults experience musicking. We then needed a framework to help us compare and integrate the disparate exploratory findings, as well as a theoretical basis to help us explain the effects of musicking on well-being. We selected SDT due to its parallels with the exploratory studies, its empirical support in predicting well-being, frequent use in music research, and prior application to autistic populations (Andrews et al., 2023; Ryan, 2023; Ryan & Deci, 2000; Tomas et al., 2023).

Figure 1: An overview of the foci of each of the three studies



Note. The light grey circle shows the overall focus of this doctoral thesis, and the areas numbered I, II and III show the foci of studies I, II and III.

The aim of Study II was to examine whether SDT—specifically its mini-theory BPN—can be used as broader framework to understand autistic people’s narratives and experiences with musicking (marked II in Figure 1). More specifically, we focused on the following research question: (1) How is musicking related to the basic psychological needs of autistic adults?

After collecting the initial evidence of the theory’s applicability in Study II, we identified a need to find or develop assessment tools which would allow us to test the applicability our model on larger more heterogenous samples. We have collected a battery of relevant psychometric tools targeting variables such as music engagement, well-being and satisfaction of BPN, however we found no adequate questionnaires which would directly assess how people musick specifically to support their well-being. We therefore decided to create one, for which we used an existing model developed through a large meta-ethnographic study (Perkins et al., 2020) on diverse sample of people (including autistic adults). This model was chosen because of its empirical support, as well as the overlap we found in Study II with existing studies with autistic adults.

The aims of Study III were to develop a questionnaire which assesses how people musick to support their well-being, and to investigate how well the proposed model resonates with autistic adults (marked III in Figure 1). We focused on the following research questions: (1) Do autistic adults find the model relevant to how they experience musicking in connection to well-being? (2) Is the model missing any important ways in which autistic adults support their well-being with music?

3 Materials and methods

This thesis employs a combination of qualitative and mixed-methods research approaches. Mixed-methods research combines qualitative and quantitative approaches to provide a more comprehensive understanding of a research problem. By integrating statistical trends (quantitative data) with lived experiences (qualitative data), researchers can leverage the strengths of both data types, offering a richer and more nuanced perspective than using either method alone (Bryman, 2006).

Mixed-methods research is gaining recognition both broadly (Harrison et al., 2020) and specifically within autism research. Some view it as a rejection of the traditional divide between the objective and subjective, as well as between humanistic and scientific research, thus helping researchers to “frame the research methods around the actual question at hand and use methods which are shaped individually around the needs of the community” (Botha, 2022, p. 85).

This perspective aligns with pragmatist philosophy, which emphasises practical solutions and the utility of research in addressing real-world issues. Pragmatism encourages flexibility in selecting methods that best answer the research questions and capture the complexity of the phenomena being investigated (Legg & Hookway, 2021). It can serve as a bridge between different schools of thought, for example an understanding of the world as an objective reality independent of perception, and an understanding of it as something that is constructed through interactions, subjective experiences and interpretations of each individual (Morgan, 2014). According to John Dewey (1925), one of the central figures in pragmatism, both perspectives are valid: the world around us shapes our experiences, and in turn our interpretations of our experiences filter our understanding of the world.

In this thesis, pragmatism serves as a guiding paradigm, integrating theory and practice to address the research questions. By acknowledging the social context of inquiry, pragmatism not only informs methodological choices but also highlights the moral and political dimensions of research (Morgan, 2014). This is particularly relevant in the context of autism research, where pragmatism encourages us to ask the critical question: “What difference does it make if we acquire knowledge one way or another?”

The following section serves as an overview of the methodological designs of the three studies. Detailed descriptions of the samples, tools, and analyses can be found in associated publications.

3.1 Study I: Exploring the roles of musicking

Study I was an exploratory study based on interviews with autistic adults.

Recruitment. We recruited the participants via the Karolinska Institute's webpage and the magazine Riksförbundet Attention. Participants had to be 18 or older, have a formal autism diagnosis, be able to provide informed consent, and speak fluent Swedish. See Appendix A for the participant information form.

Participants. Thirteen autistic adults participated (seven women, six men) with ages ranging from 24 to 69 (average = 37; SD = 12.49). Among them, seven were employed, three were students, one was unemployed, one was in organised daily activities, and one was retired. We asked the participants about their diagnoses, but we did not verify them with medical records. For detailed demographic information see the associated article.

Procedure. We conducted two semi-structured interviews with each participant via Zoom, each a little less than half an hour long on average. Only the participant and interviewer were present. The interviewer, who holds a PhD in music pedagogy, and master's degree in special pedagogy, was experienced in interviewing people with disabilities. She followed a flexible interview style, adapting questions based on participant responses. The interview guide can be found in Appendix B.

Tools. We recorded the interviews with participants' consent using the videoconferencing service Zoom (Zoom Video Communications, Inc., 2024) and auto-transcribed them using Amberscript (Amberscript Global B.V., 2022). The doctoral student manually checked and corrected the transcripts. To code and analyse the data, we used NVivo (QSR International Pty Ltd., 2020).

Analyses. We analysed and interpreted the data using a hermeneutic-phenomenological approach as outlined by Dibley et al. (2020). This approach focuses on interpreting the lived experiences of people and the researcher where her pre-understandings and her own lived experiences, are considered an integral part of this interpretation (i.e. there is no such thing as analysing "objectively"). Our analysis followed the process proposed by Dibley et al.

(2020), starting with reflections on our pre-understandings, a quick read-through of the transcripts and the writing of brief summaries, followed by several cycles of careful reading and reflecting, which resulted in a list of common themes and the final interpretation.

Hermeneutic-phenomenological approach was picked for its usefulness in uncovering the meaning of experiences and presenting situated narratives and have been employed and advocated for in autism research (Howard et al., 2019; MacLeod, 2019; Nilsson et al., 2019). For detailed description of the analysis see the associated article.

3.2 Study II: Using SDT as a framework

Study II was conducted on the same data as Study I. While we adopted a bottom-up approach in Study I, starting with the data and looking for common themes, we used a top-down approach in Study II. We started with SDT as our framework, or “glasses” through which we examined our data, framing the musicking experiences of autistic adults in a new light.

This revisiting of the transcripts provided an opportunity to see concepts or relationships in data which previously remained in the background. As I firmly believe there is no one way to “find” or rather create meaning from data, the iterative re-examination of data using different tools or frameworks can uncover valuable new insights (Kern & Mustasilta, 2023; Thompson, 2000).

Data. In Study II we used the same interview transcripts that were gathered in Study I, thus no new participants were recruited for this study.

Tools. To code and analyse the data, we used NVivo (QSR International Pty Ltd, 2020).

Analyses. We conducted a directed qualitative content analysis (DQCA) using Assarroudi’s et al. (2018) framework. DQCA was chosen because it is particularly suited for extending a theory to a new context or population (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). We started by creating working definitions of each element of the theory and using the elements to construct a categorization matrix. The matrix described six categories we looked for in the transcripts: the supporting and thwarting of autonomy, relatedness and competence, respectively. Our unit of analysis was a text-excerpt that described a single concept or phenomenon (e.g., musicking to manage anger). We pre-tested the

categorisation matrix, to see whether the definitions need to be more detailed and chose excerpts from the interviews which represented each category the best (called anchor examples) (Assarroudi et al., 2018). The doctoral student and the second author coded the transcripts independently and then had two consensus-building meetings to discuss different perspectives on overlapping codes and look for negative cases.

To enhance the credibility of our findings, we applied the Total Quality Framework outlined by Roller (2019) for evaluating the quality of qualitative content analysis. This included regular peer debriefings, investigator triangulation, and the use of reflexive journaling. We also sought out negative cases and provided authentic citations alongside our results, and generally strived for transparency and detail.

3.3 Study III: Developing a questionnaire

After conducting Study I and II, we recognised a need for assessment tools, which would allow us to further investigate the relationships between musicking and well-being and to test our findings on larger and more diverse samples. Therefore, we have collected a battery of questionnaires that assessed variables such as music engagement, satisfaction of basic psychological needs, emotion regulation, and well-being.¹⁰ In addition to those, we wanted to add a questionnaire assessing how people *perceive* that musicking supports their well-being. Knowing this would provide a valuable additional layer of understanding of the relationship between musicking and well-being. Such a questionnaire did not exist, which is why we decided to create one.

As a framework for developing such a questionnaire, we have chosen Perkins et al.'s (2020) model of participatory music engagement for mental well-being because of the findings from Studies I and II. Firstly, the model demonstrated a significant overlap with the findings from both our study and other exploratory studies conducted with autistic adults. Secondly, the model showed clear

¹⁰ More specifically, the battery consisted of the following questionnaires: the Brief Music in Mood Regulation Scale (B-MMR) (Saarikallio, 2012), Need Satisfaction and Frustration Scale (NSFS) (Longo et al., 2016), Emotion Regulation Inventory (ERI) (Roth et al., 2009), Mental Health Continuum – Short Form (MHC-SF) (C. L. M. Keyes, 2005), and parts of A Modular Tool for Measuring Multiple Dimensions of Music Engagement (MUSEBAQ) (Chin et al., 2018).

parallels to SDT, encompassing all three basic psychological needs we were interested in and thus allowing for possible future integration with SDT.

In Study III, we have therefore focused on developing the questionnaire and investigating how well the model developed by Perkins et al. (2020) resonates with autistic adults and how well our questionnaire captures their experiences.

Recruitment. The respondents were recruited through three channels: invitations posted on Karolinska Institute's webpage, posters in health-care centres, neuropsychiatric clinics, and universities in Stockholm region, and paper-and-pen questionnaires handed out by staff at Adult-Rehabilitation Centre Örebro and Neuropsychiatric clinic Stockholm. The questionnaire was available in both a physical and a digital format, with only four respondents sending the physical form. See Appendix C for the participant information form.

Participants. We included 63 respondents who either had a formal autism diagnosis (86%) or identified as autistic (13%). Fifty-seven percent reported co-occurring ADHD. Their ages ranged between 19 and 69 (mean = 33.7; SD = 12.4), 60% identified as women, 30% as men and 10% as non-binary. For more detailed demographic information about their gender, diagnosis, occupation and education refer to the associated article.

Procedure. We created PaMEW based on the themes found in the meta-ethnographic study by Perkins et al. (2020). The subthemes were condensed into 22 items and reviewed by the first author of the meta-ethnographic study. PaMEW was distributed in both digital and physical form and was part of the previously mentioned battery consisting of five additional questionnaires, which were not included in the analyses in Study III. The full questionnaire battery is included in Appendix D.

Tools. The Participatory Music Engagement for Mental-Wellbeing questionnaire (PaMEW) covers 22 items and four subscales: managing and expressing emotion (items 1–6), facilitating self-development (items 7–12), providing respite (items 13–16) and facilitating connections (items 17–22) (see Appendix D). For each statement, respondents were asked two questions: *how often* they do what the statement is describing ('frequency') and *how important* that is to them ('importance'; example of a statement: "I engage with music to cope with emotions."). They answered each question on a five-point Likert-type scale. The answer alternatives for frequency were: 1 – Never or almost never, 2 – Once or a

few times per year, 3 – Once or twice per month, 4 – Once or twice per week, 5 – Almost every day. The answer alternatives for importance were: 1 – Not at all important, 2 – Somewhat important, 3 – Important, 4 – Very important, 5 – Extremely important.

We posed three additional, open-ended questions at the end of the questionnaire battery. We asked: a) Were the questions relevant to how you experience the connection between music and your well-being? b) Were the questions clear? Do you think we should change any of the questions? If yes, which ones? c) Would you like to add anything about music and your well-being? The length of respondents' answers was not limited.

Analyses. We used Microsoft Excel for Macintosh, version 16.86 (Microsoft, 2024) and SPSS Statistics for Macintosh, Version 28.0 (IBM Corp., 2021) to perform statistical analyses. We used listwise deletion when dealing with the missing data, to avoid introducing bias and because the percentage of missing data was small (2%) (Fitzmaurice, 2008). As our data was ordinal, and non-normally distributed, we used Spearman's test ($\alpha = 0.05$) to analyse relationships between the variables (Spearman, 1987).

To explore the dimensionality of the questionnaire, we used exploratory factor analysis, often used for preliminary evaluations of new measures (Conway & Huffcutt, 2003). Because our aim was to reveal the latent structure of measured variables, we used Principal Axis Factoring (Mvududu & Sink, 2013) and considered factor loadings of .30 as a lower threshold (Tavakol & Wetzell, 2020). We used an oblique rotation (Promax rotation with Kaiser Normalization) because the factors may be correlated (Reio & Shuck, 2015) according to the model (Perkins et al., 2020) that inspired the creation of PaMEW. When deciding on the number of factors to retain, we have used several different methods because each has been shown to have its own limitations (Fabrigar et al., 1999); we considered the interpretability of the results (Bandalos, 2018), eigen values greater than one (Kaiser, 1958), the slope of the scree plot (Cattell, 1966) and percentage of explained variance. We followed the recommendation that the extracted factors should explain at least 40% of the total variance in the original variables (Reio & Shuck, 2015). To assess the reliability of PaMEW, we used Cronbach's alpha (using .70 as a lower threshold) and Corrected Item-total Correlation to assess the internal reliability of the questionnaire (Nunnally & Bernstein, 1994; Peat & Barton, 2005).

For the analysis of the open-ended responses, we employed directed qualitative content analysis (DQCA) as outlined by Assarroudi et al. (2018). Using the model developed by Perkins et al. (2020), we constructed a categorization matrix to systematically code the responses. We specifically looked for excerpts that aligned with the themes identified in the model: emotions, self-development, respite, and connections. After coding and reviewing all the texts multiple times, we then examined the excerpts that remained uncategorized to identify potential uses of musicking not covered by the existing model. This initial analysis was conducted by the doctoral student and subsequently reviewed by a co-author who is autistic.

3.4 Overarching ethical considerations

The ethical approval for the studies was obtained from the Swedish Ethics Authority under the project number 2021 – 01121.

When planning and conducting the studies, we closely followed WHO's principles of good clinical practice (World Health Organization, 2005). Here follows a reflection on the first principle, which combines the three basic ethical principles from the Declaration of Helsinki: respect for persons, beneficence, and justice.

“Respect for persons” means that individuals should be treated as autonomous agents and should be able to choose what happens to them or not. In cases of diminished autonomy, they should be provided protection (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979)¹¹. We applied this principle by informing our participants in writing about the aims of the studies, procedures, handling of information, possible risk and benefits and their right to revoke their participation at any time without consequences; this information was repeated verbally before starting with the interviews.

“Beneficence” concerns maximising benefits while minimising harm and ensuring that risks are reasonable in the light of potential benefits. We applied this principle by weighing possible risks and benefits in advance. The risks mainly involved unauthorised access to sensitive data, and the cognitive and emotional strain that can come from reflecting on one's well-being through answering

¹¹ For the definitions, WHO refers to The Belmont Report, which is why it is used here as well.

interview or survey questions. Therefore, we informed our participants about the topic of questions in advance, so they could make an informed decision, and reminded them that they can stop participating at any point. To lessen the strain, we divided the interview into two parts. Regarding the survey, we tried to keep it short by including the by limiting the number of questionnaires, and when available, choosing a short version of a questionnaire. To protect the participants' privacy, we stored the interview recordings and transcripts under pseudonyms in password protected file on a cloud storage accessed by two-factor authentication. The survey data was anonymous, and we did not collect data on the identity of a respondent or their IP address.

"Justice" refers to the obligation to fair procedures and outcomes in the selection of research participants both on the level of an individual and a social group (The Belmont Project). This means that vulnerable individuals or groups should not be deprived of benefits or face greater risks in research than others. We applied this principle by not excluding any volunteers based on characteristics other than autism and legal age (for which we had a scientific reason).

4 Results

This section is organised in four parts; the first three parts present summarised results of each of the three studies, and the fourth one integrates the findings across the three studies.

4.1 Study I: Exploring the roles of music

In Study I, thirteen autistic adults shared with us what musicking means to them, how they engage with it, and why. The aim was to build a detailed understanding not only of how musicking enriches their lives but also how it might negatively affect them.

As shown in Table 1, we found four overarching themes: they musicked to support their well-being, promote self-development, and feel connected, but in certain situations it also caused various negative experiences.

Table 1: Overview of the found themes and subthemes in Study I

Themes	Sub-themes
Well-being	Emotions and physiological arousal
	Cognitive functions
	Auditory environment
	Respite
	Hope and perseverance
Identity and self-development	Identity and self-expression
	Creativity
	Curiosity
	Self-competence
Connecting	Connecting with others
	Sharing experiences
	Sense of belonging
Negative experiences	Emotion
	Characteristics of the music
	Setting
	Critique

Note. The table is reproduced with the journal's permission from Korošec et al. (2022)

The subthemes are described in detail and illustrated with quotes in Korošec et al. (2022). The next four paragraphs provide a brief summary of the themes and sub-themes listed in Table 1.

The interviewees described how musicking supports their well-being across five key sub-themes: 1) It helps them regulate emotions and physiological states, offering both energy and calm while also providing a means to process and express complex feelings; 2) It facilitates cognitive functions by improving focus, promoting the organization of routines, and enhancing the enjoyment of routine tasks; 3) It offers some control over their auditory environment, providing a way to block unwanted noise or cope by engaging with it through musical expression; 4) It provides a safe space for rest and escape, offering comfort through predictability and familiarity; 5) Lastly, it offers a source of joy and motivation, providing something to look forward to even in difficult times.

The second theme covers ways in which musicking supports their identity and self-development, where we found four sub-themes: 1) Musicking can be seen as an extension of themselves, allowing them to express their inner worlds; 2) It serves as a creative outlet, inspiring them to compose, perform, or engage in other creative tasks like writing or painting, providing a space for freedom and self-expression; 3) It sparks curiosity, drawing them to explore intricate details, new genres, and novel experiences, offering a comfortable way to embrace both familiarity and novelty; 4) Musicking fosters a sense of accomplishment and self-worth, as completing musical projects boosts their confidence and provides a source of pride.

The theme "connecting" covers three sub-themes describing different ways in which the interviewees nourish a sense of belonging through musicking: 1) It facilitates social interactions, especially in situations where conversation might be difficult, by providing a common ground for interaction, whether at concerts, exhibitions, or during group activities like choir practice; 2) It allows them to share enjoyable moments with friends and loved ones, as well as to connect over shared emotions, both positive and negative; 3) Musicking helps them foster a broader sense of belonging, making them feel connected not just to specific individuals but also to humanity, nature, or the music itself.

The last theme encompasses negative experiences with musicking, which sometimes stem from musicking and sometimes from the context in which people musick. We found four sub-themes: 1) Listening to music sometimes

unexpectedly evokes overwhelming emotions, and even enjoyable musicking (e.g., composing, playing) sometimes leads to hyperfocus, disrupting their daily routines and causing a "crash" in their mood afterwards; 2) When lacking control over which music they are exposed to, factors such as genre, high volume, or poor sound quality makes participants feel distracted, frustrated, or overstimulated; 3) Unpredictable settings, with unclear social norms as well as crowded or loud venues, make musicking stressful or inaccessible; 4) Concerns about others' judgements, past negative feedback, and self-criticism sometimes make sharing or performing music anxiety-inducing and stressful.

The main finding of Study I is that musicking has the potential for both positive and negative effects. Its impact is neither inherently beneficial nor harmful but is dependent on contextual factors. For instance, musicking can be a source of both pride and anxiety about how others perceive one's skills. It can offer a place of respite or serve as an unsustainable distraction from negative thoughts and emotions. And while it can help individuals manage overstimulation from surrounding sounds, it can also make them feel disconnected from their environment.

4.2 Study II: Using SDT as a framework

In the narratives of our interviewees, we found examples of how musicking can both support as well as thwart autonomy, relatedness, and competence. A more detailed description of our findings and accompanying quotes can be found in Korošec et al. (2024).

Musicking supports the interviewees' need for autonomy by offering a channel for self-expression, reflecting their personal experiences, values, and preferences, and providing them with a safe space to be themselves. However, they felt that their autonomy is undermined when music in public spaces feels intrusive, when they feel stuck in musicking (e.g., composing) or need to make compromises in collaborative musical activities.

Musicking supports the interviewees need for relatedness by fostering connection through shared experiences, common interests, and non-verbal communication, helping people feel linked to others and the broader world. However, it also has the potential to disrupt social interactions or makes individuals feel isolated from their surroundings.

In terms of competence, musicking can help with task management, focus, emotion regulation, and skill development, fostering creativity and curiosity. However, it sometimes hinders competence by distracting from a task at hand or causing self-doubt in one's musical abilities.

One of the main findings of Study II was that the thwarting of basic psychological needs can be used to explain negative experiences we found in Study I. For musicking to be a positive experience for autistic adults, it needs to be tailored to their needs and preferences, allowing them to be autonomous and in control of how they engage in musicking.

The findings provided us with a framework to better understand when and why musicking might have positive or negative effects on a person's well-being. They also provided a theoretical "red thread," allowing us to connect the handful of existing studies investigating the same question and establishing a firm focus on how we can change an environment to better meet an autistic person's needs instead of changing the person to fit into an environment.

4.3 Study III: Developing a questionnaire

In study III, we investigated how well PaMEW, with its four sub-scales—emotions, respite, self-development, and connections—reflects autistic adults' experiences of musicking and well-being. We found that the most frequent and important reason to musick was to manage emotions and find respite, followed by personal development and lastly, social connectedness.

Our primary finding was that respondents reported that the items accurately reflected their experience of the connection between musicking and well-being. When asked to reflect about their experiences and add things they missed among the items, their open-ended answers fit the four pathways found by Perkins et al. (2020), which indicated that the structure was relevant.

The results of an exploratory factor analysis also suggested a four-factor structure across several criteria. We deemed this solution best based on the number of factors with eigenvalues above one, visual inspection of the scree plot, cumulative variance (which was 63% and thus above our chosen threshold of 40%), and according to the interpretability of the results. All but three items (10, 15, and 16) loaded on the same factors as proposed by meta-ethnographic study (Perkins, et al. 2020). For the pattern matrix, see manuscript III. The

correlation matrix, eigenvalues, explained variance, and the scree plot are in Appendix E.

However, while the respondents' examples aligned with the four pathways in the model (Perkins et al., 2020), the questionnaire's items did not encompass all examples. The items did not include the following examples: musicking to identify and decode emotions, regulate attention and other executive functions, address sensory needs, create a sense of predictability and structure, and lastly, musicking to find a safe space to unmask and be one's authentic self.

In summary, our findings suggest that autistic adults regard the questionnaire, as well as the underlying model, as relevant to their experiences. We have also found some preliminary quantitative evidence suggesting a four-factor structure. However, not all examples of musicking for well-being that were provided by our respondents were covered by the items in the current version of PaMEW.

4.4 Integrated findings

Taking a step back and looking at our results collected over the four years, we can distil them into several overarching findings. Firstly, autistic adults from our studies musicked for a variety of reasons: to nourish their social needs, regulate their behaviour and internal processes (attention, emotions, etc.), promote self-development, as well as for aesthetic reasons and the enjoyment of musicking itself. Secondly, whether musicking is going to be experienced as positive or negative depends on the context. Thirdly, SDT, or more specifically, the BPN theory, seems like a promising framework to explain *why* autistic adults musick, as well as *when* it is experienced as positive or negative. And lastly, models explaining musicking and well-being in the general population—specifically the PaMEW model—seems largely applicable to autistic people, which can facilitate the creation of common assessment tools used for different populations.

Figure 2 offers a visual overview of the findings. The black boxes contain the three basic psychological needs, which we used as a framework to analyse our data in Study II. The grey boxes show the four pathways found by Perkins et al. (2020) through which musicking supports well-being. We used this model to build the questionnaire we tested in Study III. Each pathway (grey boxes) is positioned under the basic psychological need (black boxes) that it most directly addresses or satisfies. This is just an approximation to illustrate how the

model might fit under the BPN theory, and in practice the pathways could be connected to several basic psychological needs at a time. Under the boxes are examples of how musicking supports well-being from the interviews we conducted in Study I. Each column of examples is connected to its respective basic psychological need. Circles mark examples of how musicking supports a certain basic need, and hyphens mark examples of how musicking thwarts a certain basic need.

Figure 2: Integrated overview of the findings

AUTONOMY	COMPETENCE	RELATEDNESS	BPN
Providing respite	Emotion regulation and expression	Facilitating connections	PaMEW model
Facilitating self-development			Examples from qualitative data
<ul style="list-style-type: none"> • A safe space • Providing hope and perseverance • Part of identity and self-expression 	<ul style="list-style-type: none"> • Managing emotions and executive functions • Addressing sensory needs • Creativity, curiosity • Developing skills • Sense of pride and accomplishment 	<ul style="list-style-type: none"> • Sharing meaningful experiences • A common interest • No need for verbal communication • Feeling understood • A sense of belonging 	
<ul style="list-style-type: none"> - Feeling manipulated - Making compromises - Feeling stuck 	<ul style="list-style-type: none"> - Feeling distracted, overwhelmed - Doubting one's (musical) skills 	<ul style="list-style-type: none"> - Fearing what others might think - Feeling disconnected 	

5 Discussion

The aims of this doctoral project were to investigate the roles of musicking in the lives of autistic adults and to find frameworks that would allow us to integrate existing findings and offer a basis for future research.

So far, studies with autistic people have been almost exclusively focused on the positive effects of musicking, which gives a lopsided understanding of its broader effects. This thesis contributes to the existing literature by incorporating the negative effects and providing a potential theoretical explanation for *why* and *when* musicking might be experienced as positive or negative.

The handful of previous studies that explored what musicking means to autistic adults found a plethora of ways in which it enriches their lives. From simplifying tedious chores to providing hope for the future, musicking was for many an important part of their lives. However, the findings were difficult to integrate, as they lacked a common theoretical framework. We found that SDT—specifically BPN mini-theory (Ryan, 2023; Ryan & Deci, 2000)—provided a possible common framework for current findings and a potential common vocabulary.

5.1 Autonomy, relatedness and competence

Our findings suggest that musicking can both support as well as thwart the need for autonomy, which also resonates with the previous literature in this field. Taken together, the existing findings suggest that musicking helps some autistic people form and express their identity, provides aesthetic appreciation as well as enjoyment without any external reward or pressure, and facilitates self-exploration and personal growth (Allen et al., 2009; Kirby & Burland, 2022; Korošec et al., in press; Levstek & Banerjee, 2021; Venter et al., 2023). Autonomy seems to be crucial for autistic adults to experience musicking as something enjoyable or beneficial (much like for non-autistic adults) (Koehler et al., 2023; Koehler & Neubauer, 2020). They need to be the ones who choose to engage in musicking, and the activity needs to align with their preferences, goals, and values. If the activity is misaligned—for example, if they are exposed to unwanted background music in a shop—they are likely to experience it as negative (e.g., feel distracted).

Similarly, autistic people report different examples of how musicking can support or thwart relatedness. It can help them connect with others via

common interests or share meaningful experiences with family and friends (Kirby & Burland, 2022; Korošec et al., 2022, in press; Venter et al., 2023). For some, it can make interacting easier by not having to rely on verbal communication as much (Korošec et al., 2022), and it seems to provide a sense of connection and belonging even when other people are not present (Allen et al., 2009; Korošec et al., 2022, in press; Venter et al., 2023). Our studies were so far the only ones that showed that musicking can also thwart relatedness by distracting individuals from a conversation or making them feel disconnected from people around them. In Study III, respondents rated social aspects as the least frequent and the least important reason to engage with musicking. However, we need to be cautious when interpreting these results. The questionnaire (PaMEW) was built on a model from the general population, which is why the items might not have been sufficiently relevant for autistic adults. Though universally important (Ryan, 2023), there is great variety in how people meet their need to feel connected. Sociality can be seen as a “range of possibilities” (Ochs & Solomon, 2010). One such example is interest-based sociality, which Bertilsdotter Rosqvist (2019; 2015) found was more common in spaces dominated by autistic people. In the future, PaMEW can be further improved by collaborating with the autistic people in adapting the items so that they better capture the various ways in which musicking might support a person’s social needs.

The last of the three basic psychological needs is the need for competence, and our findings show that musicking can support as well as thwart this need in different ways. Previous studies with autistic adults echo our findings, showing that musicking helps people regulate their emotions and attention, express themselves, develop new skills, cope with sensory needs, and provide a sense of achievement and self-competence (Allen et al., 2009; Kirby & Burland, 2022; Venter et al., 2023). On the other hand, musicking can also be detrimental to one’s sense of competence, as we have seen in our studies. This can happen especially in situations where people do not feel in control, such as when they are exposed to music in public spaces, which can make them feel overstimulated and distracted, making it harder to follow a task at hand. While music is a sought-after stimulus for many autistic adults, about 75% also report that they are hyperreactive to it (MacLennan et al., 2021), which makes it critical to explore sensory experiences in greater depth if we want to create accessible environments for all. Our findings also indicate that individuals who engage in

performance activities, such as playing, singing, or other forms of public performance, may sometimes experience self-doubt regarding their competence or fear of external criticism. As musicking does seem to be relevant to one's sense of competence, we see a need for further studies to understand its roles in greater detail, especially as approaches that focus on autistic people's capabilities and strengths are gaining more attention (Pellicano et al., 2022).

5.2 Considering the full spectrum of effects

As Silverman et al. (2020) point out, the negative effects of musicking, or "music-induced harm" (MIH), are poorly understood and unresearched. Musicking is a "communicative, affective, social, and multisensory" (p. 252) activity that is far too complex and varied to be beneficial or harmful per se. Our findings show that some autistic adults experience musicking as something that can deeply affect emotional, cognitive, and social processes, which is neither inherently beneficial nor harmful. For example, as musicking can help them improve their mood, it can also unexpectedly evoke negative emotions, and as it helps them focus, it can be distracting in different circumstances.

So far, existing research with autistic adults has not explicitly addressed possible negative effects of musicking. Our findings (Korošec et al., 2022, in press) thus need to be corroborated by additional studies before we can draw any reliable conclusions. However, our interviewees have reported experiencing negative effects of musicking on the following areas:

- Cognitive: being distracted, having difficulty communicating, feeling overstimulated
- Behavioural: using maladaptive coping strategies such as denial and distraction, feeling stuck and unable to start a different task
- Affective: rumination, unexpectedly inducing intense (negative) emotions, feeling overwhelmed or depleted
- Interpersonal: feeling socially isolated, fearing other people's judgements, experiencing stress because of unclear social norms

Our findings suggest possible cognitive, behavioural, affective and interpersonal negative effects. Interpersonal negative effects were also briefly mentioned by Kirby and Burland (2022), while Shalit et al. (2024) found harms related to identity. Autistic women interviewed in their study (Shalit et al., 2024) reported

that they sometimes conceal or modify their musicking preferences because of social rejection or criticism, sometimes completely abandoning activities that used to bring them joy. This was accompanied by feelings of rejection and loss of musical identity.

The positive and negative effects of musicking should be researched in a more integrated fashion, as they can derive from the same mechanisms that give rise to different outcomes depending on the context. Focusing on all effects of musicking (positive and negative) will thus likely help us get a more nuanced understanding of the mechanisms that explain how musicking affects one's well-being.

5.3 SDT as a common framework

This thesis provides evidence suggesting that SDT could also be extended to the autistic population when trying to explain why people engage in musicking and how it affects their well-being. In parallel, yet independently of this doctoral project, SDT was also used to explain the effects of inclusive music-making activities for marginalised youth, some of which were autistic adolescents and young adults (Levstek & Banerjee, 2021). Levstek and Banerjee used BPN to explain how marginalised youth develop confidence and emotional and social competence through inclusive music-making activities. This study provides additional evidence suggesting that SDT could be used as a common framework in music and autism research (and possibly practice).

5.3.1 Distinct roles of musicking in the autistic population?

While this thesis did not focus on comparing autistic and non-autistic people, our findings on musicking and well-being parallel those from the general population (Krause et al., 2019; Perkins et al., 2020). When it comes to what musicking means to a person, the two populations seem more alike than different. As we have seen in Study III, however, more distinction and variability might arise as we increase the level of detail with which we observe a phenomenon. For example, many autistic and non-autistic adults seem to musick to create a safe space and a place of respite (Korošec et al., 2022, in press; Perkins et al., 2020; Venter et al., 2023). However, some of our respondents emphasised that musicking provides the only place where they get to “unmask,” express themselves authentically, and truly “be themselves”—something that is of particular concern when it comes to autistic people (Cage & Troxell-Whitman, 2019; Cassidy et al., 2020; Hull et al., 2019). Another such

example is the use of musicking to address sensory needs and experiences, which can be different between autistic and non-autistic people (MacLennan et al., 2021).

In future studies, we might find more examples of distinctive ways in which autistic individuals musick to support their well-being. Our findings suggest several areas that warrant further study: musicking as a support for creating and following routines, creating a sense of familiarity and predictability, decoding and identifying emotion, and coping with sensory needs. There is great heterogeneity in how autistic people musick (just like there is in how non-autistic people musick). By further refining our understanding of the relationship between musicking and well-being, we will be able to develop more tailored policies and services for *all* people.

Our objective was not to replace the need for models and theories developed specifically by, with, and for autistic adults, only to position our current knowledge in the wider context. Using robust theoretical and empirical frameworks developed on the general population, allowed us to 1) add autistic people's perspectives to models created on the general population; 2) check areas that might not come up if only investigated on a small group of autistic adults; and 3) provide a common vocabulary across a multitude of studies and research areas. While such broad frameworks can help us build a common vocabulary and provide a robust starting point for future studies, there is still a need to develop tailored models in close collaboration with autistic people, to capture the nuance and variation in how musicking affects people's well-being.

5.3.2 Focus on the environment

A particular strength of using SDT as a framework to understand musicking in autistic populations is its focus on how an environment can better support an individual. Many support services for autistic people focus on changing the individual and their behaviour (e.g., communication skills, social skills, emotion regulation, etc.), and while personal development is important, so is a person's situatedness in a sociocultural context (Anderson, 2023; Dawson & Fletcher-Watson, 2022; Green, 2023; McLean et al., 2024; Pantazakos, 2019; The Autistic Self Advocacy Network, 2022). As previously pointed out, focusing solely on a person's "deficits" can lead to greater stigmatisation, higher rates of camouflaging, and consequently poorer mental health. Support services are therefore broadening and shifting their focus to emphasise a person's strengths,

(self)acceptance of diversity, as well as the effects of different socio-cultural environments.

SDT is currently gaining recognition as a framework that can help researchers and clinicians adapt environments to better meet people's needs, as well as to raise their well-being and empowerment (Ryan et al., 2024; Thompson-Hodgetts et al., 2023).

5.3.3 Other relevant models and theories?

Though this project shows how SDT might help us organise and integrate existing findings, we must keep in mind that our studies were not designed to falsify the applicability of SDT. This remains a goal for future studies, which will be possible to conduct once we have an adequate repertoire of validated assessment tools to use with autistic people. Because of its breadth (perhaps even vagueness), SDT might not only prove difficult to try and falsify in the future but might also prove too vague to offer a robust detailed enough understanding of the relationships between musicking and well-being.

In the interim, there is a critical need to shift research away from music-based interventions that focus exclusively on modifying individuals, and toward approaches that emphasize broader contextual factors and the adaptation of environments to better accommodate diverse needs. SDT provides a useful framework for initiating such efforts. A recent meta-analysis supports SDT as an effective framework for interventions aimed at promoting health and well-being. (Ntoumanis & Moller, 2023). The breadth of SDT might also be seen as positive, as it allows for integration with many narrower models and theories. (Ryan, 2023). SDT might perhaps serve as the first step, or a base upon which we can graft other models and theories, which will eventually outgrow SDT and provide a more detailed understanding of the relationships between musicking and well-being in autistic adults. An example of such a model might be the Access-Awareness-Agency (AAA) Model of music-based social-emotional competence (Saarikallio, 2019), which shows general parallels with SDT while also offering more detail and depth on a limited area relevant to well-being, namely, social-emotional competence.

Therefore, it is essential for future research not only to examine the boundaries of SDT's applicability in this domain but also remain receptive to alternative theories or models that may contribute to a more comprehensive understanding.

5.4 Musicking beyond well-being

Research on music and autism has predominantly centred around autistic individuals as recipients of musical interventions, particularly in therapeutic or medical contexts. While such studies emphasise the role of musicking in supporting social, emotional, and cognitive development, they often overlook autistic people as active creators of music. Rarely are autistic individuals considered in roles such as musicians, music educators, or music therapists (e.g., Davies, 2022). This gap is significant if we value the right to participate equally in cultural life, as outlined in the United Nations Convention on the Rights of Persons with Disabilities (CRPD). This document calls for ensuring that persons with disabilities “take part on an equal basis with others in cultural life,” and “have the opportunity to develop and utilise their creative, artistic, and intellectual potential, not only for their own benefit but also for the enrichment of society” (United Nations Convention on the Rights of Persons with Disabilities (CRPD), 2006).

In this context, the concept of cultural citizenship becomes highly relevant. Cultural citizenship refers to the right to participate fully in cultural life and is closely tied to concepts of representation, belonging, and expression in democratic societies (Ferm Almquist, 2019). For autistic individuals, cultural citizenship means not only having access to cultural forms like music but also being recognised as contributors to the cultural fabric of society. Cultural citizenship encompasses common experiences and discourses of empowerment, stressing that individuals need to be seen, heard, and included in the public sphere. For autistic individuals, whose modes of communication and self-expression may differ from the norms in their specific sociocultural contexts, this is particularly significant. Their active participation in music as creators and educators would challenge traditional conceptions of competence and broaden the musical landscape to reflect diverse ways of thinking and creating.

Furthermore, cultural citizenship underscores the necessity of equal participation and respect for differences in cultural and artistic spaces (Beaman, 2016; Gall & Backman Bister, In press; Kuttner, 2015; Pakulski, 1997). When autistic individuals are empowered to express themselves through music, not only do they benefit personally, but their contributions enrich society as a whole. Creating inclusive musical spaces where autistic individuals can engage as both learners and creators fosters a sense of belonging and affirms their role in the

cultural sphere, which aligns with the broader goals of fostering democratic and pluralistic societies (Rosas et al., 2022; Uddholm & Backman Bister, 2019).

Therefore, expanding research to include autistic individuals as active agents in the music world is crucial, not just for their empowerment but for the enrichment of broader cultural and musical landscapes.

5.5 Methodological considerations

When weighing and contextualising the findings of this thesis, it is important to keep several methodological considerations in mind. Firstly, Study I and II were done exclusively with speaking adults, who agreed to be interviewed by a person they have never met before, and Study III with those who could read the survey and provide written answers. This means that we do not have data from people who communicate in non-traditional ways, people who would find speaking to a stranger too stressful (for example because of social anxiety or the unpredictability of a novel situation), and other people whose support needs might have prevented them from accessing the studies. In future studies, it is important to broaden our participant pool to include individuals who use non-traditional methods of communication, such as writing, picture cards, or sign language, and accommodate for other support needs. This would ensure a more comprehensive representation of the autistic population and enable us to capture a wider range of experiences.

Secondly, we have reason to believe that predominantly people who value musicking decided to participate in the studies. Almost three-quarters of respondents in Study III said musicking was extremely important to them. While this is not problematic to implement the findings in settings where people choose to musick, we need further studies with people who are less keen on musicking if we want to apply the findings in broader settings, such as policymaking. It might be that background music in public spaces is even more disturbing to this group of people or that it has negative effects that we have not found in our studies. Given that individuals who are indifferent to musicking are less likely to participate in a study exclusively focused on this activity, a potential approach would be to select a core set of the most relevant questions and integrate them into a broader survey or interview that does not specifically center on music.

Thirdly, women—whose phenotypes can be different from those of men when it comes to autistic traits (Lundin Remnélius, 2023)—made up over half of our

combined samples, even though they are four times less likely to have an autism diagnosis compared to men (Zeidan et al., 2022). This means that our studies were comprised of a specific slice of the autistic population, where the participants were more likely to be women, highly value musicking, use traditional modes of communication, and have finished at least high school education. In the future, we therefore need to investigate the experiences of musicking on more heterogenous samples to get a fuller picture.

While including individuals both with and without a formal diagnosis makes it more difficult to control the parameters of a sample, we chose to include them for a reason. Limiting our sample to those with a formal diagnosis would ensure that qualified experts confirmed that the respondents have relevant characters in common, which is especially important when validating a questionnaire or establishing norms for a new population. However, our primary goal was to understand how the model resonates with autistic adults, including those who remain undiagnosed for various reasons. Many face barriers to a formal diagnosis, such as geographical inaccessibility or difficulty communicating their symptoms (Lewis, 2017). Certain demographics—such as women, older adults, and employed individuals—are more likely to be overlooked (McDonald, 2020), and healthcare providers are struggling to meet the growing demand for neuropsychiatric evaluations (Jablonska et al., 2022). Moreover, we do not want to assume that everyone meeting the diagnostic criteria perceives a formal diagnosis as something beneficial to them (Fletcher-Watson, 2024). In our study, the value of insights from undiagnosed autistic adults outweighs the risk of including participants who may not be autistic. This approach allows us to capture a broader range of experiences and perspectives, which is essential for a comprehensive understanding of the model's relevance.

Warranting additional consideration is also the fact that we used the same data set for Studies I and II. We chose SDT as the framework for Study II, largely (but not exclusively) based on the findings from Study I. This means that the data from Study I was already found to show some parallels with SDT, rendering it inappropriate for aims such as falsification. Therefore, we would not consider Study II as a study where the fit of SDT was tested (in the sense of testing a falsifiable hypothesis), but an exploratory study, investigating how SDT could be used to frame narratives about musicking and suggesting a common vocabulary to facilitate the integration of current findings. The methodological approaches employed in Studies I and II complement one another by facilitating diverse

perspectives and insights in the interpretation of the data. Firstly, a bottom-up approach, which is expansive, allowing for a variety of interpretations, and where the analyst's knowledge and experiences are a more integral part of the analytical process. Secondly, a top-down approach that imposes an external structure upon the data, thus pushing the analyst to consider the data in a new light. It is worth noting, that SDT is an exceptionally broad theory (a meta-theory), which might make it easy to see its elements in qualitative data yet difficult to falsify. To rigorously assess the applicability of SDT, a different study design, along with validated assessment tools, would be required. This necessity prompted the development of such tools following Study III.

Regarding Study III, I want to emphasize that in order to discuss the structural validity of PaMEW based on statical findings, we need additional studies with larger samples and a more comprehensive repertoire of statistical analyses. There is little consensus on the sample size needed to conduct factor analysis, and the recommendations range from 3 to 20 cases per variable (Mvududu & Sink, 2013), which means 66–440 participants in the case of PaMEW. With an adequate sample, PaMEW's structure can be further investigated by using confirmatory factor analysis (CFA) to test the degree of fit between the data and the underlying model proposed by Perkins et al. (2020), for example, by using indices such as comparative fit index (CFI), standardised root-mean-square residual (SRMR), or root-mean-square error of approximation (RMSEA) (Knekta et al., 2019). Conversely, the purpose of Study III was to explore respondents' perspectives and gather preliminary insights to identify priority areas and inform the future development of PaMEW.

5.6 Ethical considerations

In the planning and conducting of the studies, we have paid close attention to the three basic ethical principles from the Declaration of Helsinki: respect for persons, beneficence, and justice (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). However, it is important to consider who decides what is respectful, beneficial, and just. Ethical guidelines, such as the Belmont Report, have been criticised for being biased towards valuing the importance of pursuing new knowledge through scientific research and centred around Western understandings of morality and ethics (Siddiqui & Sharp, 2021). Weighing of risks and benefits, for example, mostly happens among highly educated people holding academic positions in the name of research populations who might weigh them very differently.

This consideration is especially important in autism research, which is facing ethical challenges on many levels (Botha, 2022; Bovell, 2020; Natri et al., 2023; Wilkenfeld & McCarthy, 2020). The field is going through significant shifts (Pellicano et al., 2018), particularly concerning the ethical dimensions and the involvement of autistic individuals in the research process. Central to this shift is the ethical imperative to include autistic individuals in the research process—not just as subjects but as collaborators. This inclusion challenges the traditional power dynamics in research, empowering autistic people to help determine which questions are relevant and ensuring that research outcomes better reflect their lived experiences and needs (Roche et al., 2021).

One of the key ethical questions in this evolving field is who gets to decide what is considered important in autism research. Increasingly, there is recognition that autistic people themselves should have a central role in setting research agendas (Benevides et al., 2020; Pukki et al., 2022; Roche et al., 2021; The Autistic Self Advocacy Network, 2022). This is part of a broader movement towards participatory research models, where the subjects of research are involved in the design and execution of studies, ensuring that the research is both respectful and relevant to their lives.

Overall, these changes signify an approach to autism research that emphasizes representation, one that respects the autonomy and voices of autistic individuals, aligns research with their priorities, and seeks to enhance their quality of life rather than merely attempting to fit them into normative societal expectations. However, this shift does not only call for practical changes, which researchers could implement individually or inside their research group, but also systemic changes, for example, in the way research is being funded (Nicolaidis et al., 2019).

Collaborating with autistic people on equal terms, can be challenging in contexts such as a doctoral project. Autistic people were not involved in the planning of the present doctoral project, since detailed study plans were a prerequisite to applying for the position. After starting, the Swedish Ethical Review Authority had to approve the study plans before we had any contact with our target population, and subsequent changes to the plans were costly and time-consuming. Because of institutional barriers, it is also difficult to reimburse co-researchers from the community, which is imperative if we want to collaborate on an equal footing. Therefore, this doctoral project did not include autistic

people as co-researchers (except for Study III) but was still guided by the needs and preferences expressed by participants in all three studies.

We strove for a balance between structure and flexibility, which allowed us to include the community input in different steps of the doctoral project. We started the project by conducting in-depth interviews, and our interviewees' narratives guided the choice of variables and questions in the subsequent studies. Their input was especially important in the development of a new questionnaire, where the most weight was put on how the respondents perceived the clarity and relevance of the items.

Collaborating with the autistic community in autism research enriches our collective understanding of autism by integrating the lived experiences and insights of autistic individuals, leading to more relevant and impactful outcomes. This approach aligns closely with the philosophy of pragmatism, which asserts that knowing the world is inseparable from agency within it (Legg & Hookway, 2021). By involving autistic individuals as active collaborators rather than passive subjects, researchers not only produce knowledge that is more contextually grounded but also ensure that this knowledge directly informs and improves practices that affect the autistic community. This partnership exemplifies pragmatism's emphasis on the interplay between theory and practice, where the process of inquiry is both informed by and contributes to the lived realities of those involved. Thus, such collaboration is not just a methodological choice but a philosophical commitment to creating knowledge that is deeply relevant, socially just, and practically useful.

6 Conclusions

After eight decades of academic and clinical interest in music and autism and a decade of silence following the first study focusing on autistic people's lived experiences of musicking (Allen et al., 2009), we are witnessing a bloom of studies engaging with this question (Bakan, 2018; Kirby & Burland, 2022; Shalit et al., 2024; Venter et al., 2023). These studies—in line with the findings presented in this thesis—show a great heterogeneity among autistic adults (like there is among non-autistic adults) in how they engage in musicking and how it affects their well-being.

This thesis presents an example of how theories (SDT) and models (PaMEW) developed on the general population might be applied to the autistic population. It illustrates that autistic and non-autistic adults nourish similar needs to improve their well-being through musicking. However, while an underlying need might be the same, people satiate it in a variety of different ways. Our research suggests that theories and models developed for the general population may not adequately reflect specific music-based well-being strategies that some autistic adults find significant.

Another contribution of this thesis is the investigation of negative experiences of musicking, which have so far largely been neglected. It highlights the fact that musicking has the potential to deeply affect an individual, but whether the individual is going to experience it as something pleasant or beneficial depends on whether they get to engage in musicking on their own terms. Instead of approaching autistic people as passive “recipients” of music's effects, this thesis underscores the active roles they play in the process of musicking, emphasising the importance of their self-determination. Additionally, it highlights the importance of adapting psychosocial environments to better meet a person's needs.

In conclusion, integrating diverse perspectives and being mindful of potential harms in musicking practices is crucial in supporting autistic people's self-determination, empowerment, and right to cultural resources. Pluralism is key to fostering environments where diverse approaches to musicking are valued and can thrive, supporting the well-being of *all* individuals in their respective societies.

7 Points of perspective

7.1 Implications

This thesis has implications for music-based activities and support services, policymaking, access to cultural resources for autistic people, and their role as creators in the arts, highlighting the nuanced and heterogeneous roles of musicking in the lives of autistic adults. The studies shed light on the dual nature of musicking—its potential for both positive and negative experiences—and underscore the need to consider the full spectrum of outcomes when shaping interventions, services, and policies.

Policymaking around music in public spaces should take into account the diversity of sensory experiences among people. The thesis illustrates that the involuntary imposition of music in public spaces, such as retail environments, may result in adverse effects. Policymakers should consider implementing guidelines that ensure autistic people equal access to public spaces, irrespective of their sensory needs. This might involve creating sensory-friendly zones or offering alternative environments that allow individuals to avoid background music in commercial or public settings.

The thesis illustrates how important musicking can be for some autistic people, highlighting the need to further explore and, if needed, improve the accessibility of cultural resources. Cultural policies should emphasise the right of autistic people to access not only therapeutic music programs but also broader cultural resources where they can actively engage in musicking on their terms. This includes attending concerts, participating in music groups, and using music as a means of self-expression and connection in social and non-social contexts.

When it comes to support services, this thesis further supports the need for individualised, autonomy-centred approaches. It demonstrates that musicking can support important psychological needs, but only when aligned with personal preferences, values, and goals. Given that musicking can also induce negative effects, support services should account for and mitigate possible adverse events. Tailoring interventions to each person's sensory needs is essential, as is recognising when musicking may inadvertently hinder rather than help. Likewise, policies aimed at integrating musicking into therapeutic or educational settings should be informed by the need for autonomy. Mandating or imposing music-based interventions without consulting autistic individuals on their preferences

may negate potential benefits. A shift toward policymaking that represents autistic voices in decision-making processes will be key.

A major implication of this thesis is the recognition that autistic people should not only be viewed as recipients of musical interventions but also as active creators of music and cultural resources. The current focus on autistic individuals as subjects of interventions overlooks their potential as musicians, therapists, researchers, and educators. Aligning with the principles of the United Nations Convention on the Rights of Persons with Disabilities (2006), there is a need to promote opportunities for autistic individuals to engage in creative work as equals in the cultural sphere. Expanding research and practice to include autistic individuals in creative roles—whether as performers, teachers, or music therapists—would not only honour their contributions but also challenge the stereotypes that confine them to passive roles in musical contexts. This shift would necessitate changes in both public perception and the structural barriers that might prevent autistic people from pursuing professional or amateur careers in the arts.

7.2 New questions, hypotheses and future studies

The findings presented in this thesis open several avenues for future research and raise new questions that merit further exploration. One of the central questions concerns the applicability of SDT as a robust framework for understanding how musicking impacts autistic individuals. While the thesis shows promising initial evidence that SDT can be used to frame our understanding of how musicking supports autonomy, relatedness, and competence in autistic adults, further studies are necessary to test the theory on more heterogeneous and larger samples. These expanded studies would help us gauge whether SDT can account for the diverse experiences of autistic people across different contexts.

Moreover, there is a need to test how well SDT can predict music-related well-being in autistic adults. The thesis suggests that the degree to which musicking aligns with an individual's preferences, goals, and values can influence whether it is experienced as beneficial or harmful. Future research could aim to develop predictive models that assess how closely the satisfaction of autonomy, relatedness, and competence needs through musicking correlates with well-being outcomes. Such studies would provide valuable insights into whether SDT

can be used as a reliable tool for developing music-based interventions or support services for autistic people.

Another key area that requires further investigation is the potential negative effects of musicking. While the positive effects of musicking have been well-documented, this thesis highlights that musicking can also lead to negative experiences. Future research could focus on identifying specific circumstances and factors that increase the likelihood of negative outcomes. The PaMEW questionnaire, which currently only assesses positive aspects of musicking and well-being, could in the future be broadened to include negative effects. PaMEW was developed based on a comprehensive meta-ethnographic study (Perkins et al., 2020), and there is no comparable study focusing on the negative effects of musicking on well-being. To extend PaMEW in the future, we could potentially use theoretical models, such as the Model of music-induced harm by Silverman et al. (2020). A specific context that would be interesting to explore in future studies is the well-being of autistic musicians. In the field of music and well-being, we are namely witnessing a stark contrast between research showing that musicking can improve well-being and evidence that professional musicians often experience high levels of mental ill-health, including anxiety and depression (Musgrave, 2022). While music is widely promoted as beneficial for well-being, the realities of building a career in music can be challenging, suggesting that the positive effects of musicking are more complex and unevenly distributed, especially for professional musicians. While there is little evidence, we might speculate that autistic musicians face pronounced or slightly different career-related challenges as well as strengths, and understanding the diversity and breadth of them would be valuable in developing better support for *all* musicians.

In addition, the thesis raises the question of whether there are notable differences in how autistic and non-autistic individuals engage with musicking and how it affects their well-being. Although initial findings suggest that both groups may experience similar positive and negative effects, future research could delve deeper into potential distinctions. Autistic adults, for instance, may rely on musicking as a unique space for "unmasking" and authentic self-expression, which may not be as prominent in non-autistic populations. Research comparing these two groups might help us broaden our understanding of the different ways in which musicking can affect well-being.

Gender-related differences also emerge as an area of potential exploration. The thesis cites studies where autistic women reported altering their musical preferences to avoid social rejection, leading to identity-related harms. Investigating whether and how gender influences the way autistic individuals experience and engage in musicking could yield important insights into identity formation, social pressures, and the different ways that musicking can either support or hinder well-being. This also applies to other aspects of an individual's identity or traits, making it crucial to add a lens of intersectionality to future research (Crenshaw, 2019).

The findings of this thesis open several avenues for future research and call for a broader, more pluralistic approach to understanding the roles of musicking in people's lives. In the future, it would be valuable to gain a deeper understanding of how socio-cultural environments and intersectional factors, such as gender, race, and socioeconomic status, shape autistic people's experiences with musicking. There is a need for a comprehensive testing of SDT as a possible umbrella framework for this area of research, while also considering other theoretical frameworks that might prove useful. Research should focus on identifying barriers that limit access to cultural resources and opportunities for autistic people, as well as potential music-related harms they may encounter. Recognising autistic people not only as "recipients" but as creators of music and equal cultural citizens is not only fair but also critical if we want to better understand the variety of roles that music plays in human lives.

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9 References

- Allen, R., Hill, E., & Heaton, P. (2009). 'Hath charms to soothe. . .': An exploratory study of how high-functioning adults with ASD experience music. *Autism, 13*(1), 21–41. <https://doi.org/10.1177/1362361307098511>
- Amberscript Global B.V. (2022). *Amberscript* [Computer software]. Amberscript Global B.V. <https://www.amberscript.com/en/>
- American Psychiatric Association. (1980). *Diagnostic and Statistical Manual of Mental Disorders, Third edition*. American Psychiatric Association.
- American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders: DSM-5-TR* (5th edition, text revision.). American Psychiatric Association Publishing. <https://doi/book/10.1176/appi.books.9780890425787>
- Anderson, L. K. (2023). Autistic experiences of applied behavior analysis. *Autism, 27*(3), 737–750. <https://doi.org/10.1177/1362361322118216>
- Andersson, S., Posserud, M.-B., & Lundervold, A. J. (2013). Early and late auditory event-related potentials in cognitively high functioning male adolescents with autism spectrum disorder. *Research in Autism Spectrum Disorders, 7*(7), 815–823. <https://doi.org/10.1016/j.rasd.2013.03.007>
- Andrews, H. E., Hedley, D., & Bury, S. M. (2023). The Relationship Between Autistic Traits and Quality of Life: Investigation of Indirect Effects Through Self-Determination. *Autism in Adulthood, 6*(2). <https://doi.org/10.1089/aut.2022.0117>
- Applewhite, B., Cankaya, Z., Heiderscheit, A., & Himmerich, H. (2022). A Systematic Review of Scientific Studies on the Effects of Music in People with or at Risk for Autism Spectrum Disorder. *International Journal of Environmental Research & Public Health, 19*, Article 5150. <https://doi.org/10.3390/ijerph19095150>
- Arvidsson, O., Gillberg, C., Lichtenstein, P., & Lundström, S. (2018). Secular changes in the symptom level of clinically diagnosed autism. *Journal of Child Psychology and Psychiatry, 59*(7), 744–751. <https://doi.org/10.1111/jcpp.12864>
- Assarroudi, A., Heshmati Nabavi, F., Armat, M. R., Ebadi, A., & Vaismoradi, M. (2018). Directed qualitative content analysis: The description and elaboration of its underpinning methods and data analysis process. *Journal of Research in Nursing, 23*(1), 42–55. <https://doi.org/10.1177/1744987117741667>
- Avlund, S. H., Thomsen, P. H., Schendel, D., Jørgensen, M., & Clausen, L. (2021). Time Trends in Diagnostics and Clinical Features of Young Children Referred on Suspicion of Autism: A Population-Based Clinical Cohort Study, 2000–2010. *Journal of Autism and Developmental Disorders, 51*(2), 444–458. <https://doi.org/10.1007/s10803-020-04555-8>
- Ayres, M., Parr, J. R., Rodgers, J., Mason, D., Avery, L., & Flynn, D. (2018). A systematic review of quality of life of adults on the autism spectrum. *Autism, 22*(7), 774–783. <https://doi.org/10.1177/1362361317714988>

- Bakan, M. B. (2018). *Speaking for Ourselves: Conversations on Life, Music, and Autism*. Oxford University Press.
- Bandalos, D. L. (2018). *Measurement Theory and Applications for the Social Sciences* (1st edition). The Guilford Press.
- Barnes, E. (2009). Disability, Minority, and Difference. *Journal of Applied Philosophy*, 26(4), 337–355. <https://doi.org/10.1111/j.1468-5930.2009.00443.x>
- Beaman, J. (2016). Citizenship as cultural: Towards a theory of cultural citizenship. *Sociology Compass*, 10(10), 849–857. <https://doi.org/10.1111/soc4.12415>
- Beebe, K. (2022). Perceptions of Self-Determination in Music Therapy for Individuals Diagnosed with Intellectual Disabilities: A Survey of Music Therapists. *Music Therapy Perspectives*, 40(1), 94–103. <https://doi.org/10.1093/mtp/miac004>
- Benevides, T. W., Shore, S. M., Palmer, K., Duncan, P., Plank, A., Andresen, M.-L., Caplan, R., Cook, B., Gassner, D., Hector, B. L., Morgan, L., Nebeker, L., Purkis, Y., Rankowski, B., Wittig, K., & Coughlin, S. S. (2020). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism: The International Journal of Research & Practice*, 24(4), 822–833. <https://doi.org/10.1177/1362361320908410>
- Bertilsdotter Rosqvist, H. (2019). Doing things together: Exploring meanings of different forms of sociality among autistic people in an autistic work space. *Alter*, 13(3), 168–178. <https://doi.org/10.1016/j.alter.2019.03.003>
- Bertilsdotter Rosqvist, H., Brownlow, C., & O, L. (2015). “What’s the point of having friends?”: Reformulating Notions of the Meaning of Friends and Friendship among Autistic People. *Disability Studies Quarterly*, 35(4), Article 4. <https://doi.org/10.18061/dsq.v35i4.3254>
- Bhatara, A., Babikian, T., Laugeson, E., Tachdjian, R., & Sininger, Y. S. (2013). Impaired Timing and Frequency Discrimination in High-functioning Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 43(10), 2312–2328. <https://doi.org/10.1007/s10803-013-1778-y>
- Bleuler, E. (1950). *Dementia praecox; or, The group of schizophrenias*. New York, International Universities Press. <http://archive.org/details/dementiapræcoxo0000bleu>
- Bojner Horwitz, E. (2018). Humanizing the working environment in health care through music and movement – The importance of embodied leadership: Chapter 12. In L. O. Bonde & T. Theorell (Eds.), *Music and Public Health—A Nordic Perspective*. Springer. <http://urn.kb.se/resolve?urn=urn:nbn:se:kmh:diva-3655>
- Bojner Horwitz, E., Lennartsson, A.-K., Theorell, T. P. G., & Ullén, F. (2015). Engagement in dance is associated with emotional competence in interplay with others. *Frontiers in Psychology*, 6, Article 1096. <https://doi.org/10.3389/fpsyg.2015.01096>
- Bojner Horwitz, E., Rehnqvist, K., Osika, W., Thyrén, D., Åberg, L., Kowalski, J., & Theorell, T. (2021). Embodied learning via a knowledge concert: An exploratory intervention

- study. *Nordic Journal of Arts, Culture and Health*, 3(1–2–2021), 34–47.
<https://doi.org/10.18261/issn.2535-7913-2021-01-02-04>
- Bojner Horwitz, E., & Thyrén, D. (2022). Developing a Sustainable and Healthy Working Life with the Arts: The HeArtS Programme—A Research Dialogue with Creative Students. *Creative Education*, 13(5), Article 5. <https://doi.org/10.4236/ce.2022.135105>
- Bonnel, A., McAdams, S., Smith, B., Berthiaume, C., Bertone, A., Ciocca, V., Burack, J. A., & Mottron, L. (2010). Enhanced pure-tone pitch discrimination among persons with autism but not Asperger syndrome. *Neuropsychologia*, 48(9), 2465–2475.
<https://doi.org/10.1016/j.neuropsychologia.2010.04.020>
- Botha, M. (2022). Community psychology as reparations for violence in the construction of autism knowledge. In S. Ryan & D. Milton (Eds.), *The Routledge International Handbook of Critical Autism Studies* (1st Edition, pp. 76–94). Routledge.
- Botha, M., Chapman, R., Giwa Onaiwu, M., Kapp, S. K., Stannard Ashley, A., & Walker, N. (2024). The neurodiversity concept was developed collectively: An overdue correction on the origins of neurodiversity theory. *Autism*, 28(6), 1591–1594.
<https://doi.org/10.1177/13623613241237871>
- Botha, M., & Frost, D. M. (2020). Extending the Minority Stress Model to Understand Mental Health Problems Experienced by the Autistic Population. *Society and Mental Health*, 10(1), 20–34. <https://doi.org/10.1177/2156869318804297>
- Bottema-Beutel, K., Crowley, S., Sandbank, M., & Woynaroski, T. G. (2021). Adverse event reporting in intervention research for young autistic children. *Autism*, 25(2), 322–335.
<https://doi.org/10.1177/1362361320965331>
- Bouvet, L., Mottron, L., Valdois, S., & Donnadieu, S. (2016). Auditory Stream Segregation in Autism Spectrum Disorder: Benefits and Downsides of Superior Perceptual Processes. *Journal of Autism and Developmental Disorders*, 46(5), 1553–1561.
<https://doi.org/10.1007/s10803-013-2003-8>
- Bovell, V. (2020). Is there an ethical case for the prevention and/or cure of autism? In H. Bertilsdotter Rosqvist, N. Chown, & A. Stenning (Eds.), *Neurodiversity Studies: A New Critical Paradigm* (1st Edition, pp. 39–54). Routledge.
- Bryman, A. (2006). Integrating quantitative and qualitative research: How is it done? *Qualitative Research*, 6(1), 97–113. <https://doi.org/10.1177/1468794106058877>
- 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>
- Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism*, 9, Article 42. <https://doi.org/10.1186/s13229-018-0226-4>
- Cassidy, S., Gould, K., Townsend, E., Pelton, M., Robertson, A. E., & Rodgers, J. (2020). Is Camouflaging Autistic Traits Associated with Suicidal Thoughts and Behaviours? Expanding the Interpersonal Psychological Theory of Suicide in an Undergraduate

- Student Sample. *Journal of Autism and Developmental Disorders*, 50(10), 3638–3648. <https://doi.org/10.1007/s10803-019-04323-3>
- Cervantes, P. E., Matheis, M., Estabillo, J., Seag, D. E. M., Nelson, K. L., Peth-Pierce, R., Hoagwood, K. E., & Horwitz, S. M. (2021). Trends Over a Decade in NIH Funding for Autism Spectrum Disorder Services Research. *Journal of Autism and Developmental Disorders*, 51(8), 2751–2763. <https://doi.org/10.1007/s10803-020-04746-3>
- Chapman, R. (2020a). Defining neurodiversity for research and practice. In H. Bertilsdotter Rosqvist, N. Chown, & A. Stenning (Eds.), *Neurodiversity Studies: A Critical New Paradigm* (1st Edition, pp. 218–220). Routledge.
- Chapman, R. (2020b). Neurodiversity, disability, wellbeing. In H. B. Bertilsdotter Rosqvist, N. Chown, & A. Stenning (Eds.), *Neurodiversity Studies: A New Critical Paradigm* (1st Edition, pp. 57–72). Routledge.
- Chin, T.-C., Coutinho, E., Scherer, K., & Rickard, N. (2018). MUSEBAQ: A Modular Tool for Music Research to Assess Musicianship, Musical Capacity, Music Preferences, and Motivations for Music Use. *Music Perception: An Interdisciplinary Journal*, 35(3), 376–399. <https://doi.org/10.1525/mp.2018.35.3.376>
- Chou, Y.-C., Wehmeyer, M. L., Palmer, S. B., & Lee, J. (2017). Comparisons of Self-Determination Among Students With Autism, Intellectual Disability, and Learning Disabilities: A Multivariate Analysis. *Focus on Autism and Other Developmental Disabilities*, 32(2), 124–132. <https://doi.org/10.1177/1088357615625059>
- Chown, N., Beardon, L., Murphy, S. L., Suckle, E., & Baker-Rogers, J. (2023). Autism Community Research Priorities: The Potential of Future Research to Benefit Autistics. *Canadian Journal of Educational and Social Studies*, 3(2), Article 2. <https://doi.org/10.53103/cjess.v3i2.118>
- Conway, J. M., & Huffcutt, A. I. (2003). A Review and Evaluation of Exploratory Factor Analysis Practices in Organizational Research. *Organizational Research Methods*, 6(2), 147–168. <https://doi.org/10.1177/1094428103251541>
- Cook, J., Crane, L., Hull, L., Bourne, L., & Mandy, W. (2022). Self-reported camouflaging behaviours used by autistic adults during everyday social interactions. *Autism*, 26(2), 406–421. <https://doi.org/10.1177/13623613211026754>
- Cook, J., Hull, L., Crane, L., & Mandy, W. (2021). Camouflaging in autism: A systematic review. *Clinical Psychology Review*, 89, Article 102080. <https://doi.org/10.1016/j.cpr.2021.102080>
- Cooper, K., Smith, L. G. E., & Russell, A. (2017). Social identity, self-esteem, and mental health in autism: Social identity, self-esteem, and mental health in autism. *European Journal of Social Psychology*, 47(7), 844–854. <https://doi.org/10.1002/ejsp.2297>
- Creech, A., Larouche, K., Generale, M., & Fortier, D. (2023). Creativity, music, and quality of later life: A systematic review. *Psychology of Music*, 51(4), 1080–1100. <https://doi.org/10.1177/0305735620948114>

- Crenshaw, K. (2019). 'Difference' through intersectionality. In S. Arya & A. S. Rathore (Eds.), *Dalit Feminist Theory* (1st Edition). Routledge India.
- Cruwys, T., Dingle, G. A., Haslam, C., Haslam, S. A., Jetten, J., & Morton, T. A. (2013). Social group memberships protect against future depression, alleviate depression symptoms and prevent depression relapse. *Social Science & Medicine*, *98*, 179–186. <https://doi.org/10.1016/j.socscimed.2013.09.013>
- Davies, H. (2022). 'Autism is a way of being': An 'insider perspective' on neurodiversity, music therapy and social justice. *British Journal of Music Therapy*, *36*(1), 16–26. <https://doi.org/10.1177/13594575221090182>
- Davies, S. (2012). On Defining Music: *The Monist*, *95*(4), 535–555. <https://doi.org/10.5840/monist201295427>
- Dawson, M., & Fletcher-Watson, S. (2022). When autism researchers disregard harms: A commentary. *Autism*, *26*(2), 564–566. <https://doi.org/10.1177/13623613211031403>
- Daykin, N., Mansfield, L., Meads, C., Gray, K., Golding, A., Tomlinson, A., & Victor, C. (2020). The role of social capital in participatory arts for wellbeing: Findings from a qualitative systematic review. *Arts & Health*, *13*(2), 134–157. <https://doi.org/10.1080/17533015.2020.1802605>
- Deci, E. L. (1975). *Intrinsic Motivation*. Plenum Press. <https://doi.org/10.1007/978-1-4613-4446-9>
- Deci, E. L., & Ryan, R. M. (2000). The 'What' and 'Why' of Goal Pursuits: Human Needs and the Self-Determination of Behavior. *Psychological Inquiry*, *11*(4), 227–268. https://doi.org/10.1207/S15327965PLI1104_01
- den Houting, J., Higgins, J., Isaacs, K., Mahony, J., & Pellicano, E. (2021). 'I'm not just a guinea pig': Academic and community perceptions of participatory autism research. *Autism*, *25*(1), 148–163. <https://doi.org/10.1177/1362361320951696>
- Dibley, L., Dickerson, S., Duffy, M., & Vandermause, R. (2020). *Doing hermeneutic phenomenology research: A practical guide* (1st Edition). SAGE Publications.
- Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction With Life Scale. *Journal of Personality Assessment*, *49*(1), 71–75. https://doi.org/10.1207/s15327752jpa4901_13
- Dingle, G. A., Sharman, L. S., Bauer, Z., Beckman, E., Broughton, M., Bunzli, E., Davidson, R., Draper, G., Fairley, S., Farrell, C., Flynn, L. M., Gomersall, S., Hong, M., Larwood, J., Lee, C., Lee, J., Nitschinsk, L., Peluso, N., Reedman, S. E., ... Wright, O. R. L. (2021). How Do Music Activities Affect Health and Well-Being? A Scoping Review of Studies Examining Psychosocial Mechanisms. *Frontiers in Psychology*, *12*, Article 713818. <https://doi.org/10.3389/fpsyg.2021.713818>
- Dwyer, P. (2022a). Heterogeneity and clustering in autism: An introduction for critical scholars. In D. Milton & S. Ryan (Eds.), *The Routledge International Handbook of Critical Autism Studies* (1st Edition, pp. 42–55). Routledge.

- Dwyer, P. (2022b). The Neurodiversity Approach(es): What Are They and What Do They Mean for Researchers? *Human Development*, 66(2), 73–92.
<https://doi.org/10.1159/000523723>
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107–115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
- Evans, B. (2013). How autism became autism: The radical transformation of a central concept of child development in Britain. *History of the Human Sciences*, 26(3), 3–31.
<https://doi.org/10.1177/0952695113484320>
- Evans, P. (2015). Self-determination theory: An approach to motivation in music education. *Musicae Scientiae*, 19(1), 65–83.
<https://doi.org/10.1177/1029864914568044>
- Fabrigar, L. R., Wegener, D. T., MacCallum, R. C., & Strahan, E. J. (1999). Evaluating the use of exploratory factor analysis in psychological research. *Psychological Methods*, 4(3), 272–299. <https://doi.org/10.1037/1082-989X.4.3.272>
- Fancourt, D., & Finn, S. (2019). *What is the evidence on the role of the arts in improving health and well-being? A scoping review*. WHO Regional Office for Europe.
<http://www.ncbi.nlm.nih.gov/books/NBK553773/>
- Fancourt, D., Warran, K., & Aughterson, H. (2020). *Evidence Summary for Policy—The role of arts in improving health & wellbeing* (Report to the Department for Digital, Culture, Media & Sport). Department of Behavioural Science & Health.
<https://www.gov.uk/government/publications/evidence-summary-for-policy-the-role-of-arts-in-improving-health-and-wellbeing>
- Ferm Almqvist, C. (2019). Cultural Citizenship through aesthetic communication in Swedish schools. *European Journal of Philosophy in Arts Education*, 1(1), 68–94.
<https://doi.org/10.5281/zenodo.3384904>
- Fitzmaurice, G. (2008). Missing data: Implications for analysis. *Nutrition*, 24(2), 200–202.
<https://doi.org/10.1016/j.nut.2007.10.014>
- Fletcher-Watson, S. (2024). What's in a name? The costs and benefits of a formal autism diagnosis. *Autism*, 28(2), 257–262. <https://doi.org/10.1177/13623613231213300>
- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, 23(4), 943–953.
<https://doi.org/10.1177/1362361318786721>
- Gall, M. R. Y., & Backman Bister, A. (In press). Musical Becoming for Cultural Citizenship. In M. Petrovic & I. Malmberg (Eds.), *Music and Meaning* (Vol. 12). Innsbruck: Helbling Verlagsgesellschaft mbH.
- Geretsegger, M., Fusar-Poli, L., Elefant, C., Mössler, K. A., Vitale, G., & Gold, C. (2022). Music therapy for autistic people. *Cochrane Database of Systematic Reviews*, 5, Article CD004381. <https://doi.org/10.1002/14651858.CD004381.pub4>

- Godt, I. (2005). Music: A practical definition. *The Musical Times*, 146(1890), 83–88.
<https://doi.org/10.2307/30044071>
- Gordon–Nesbitt, R., & Howarth, A. (2020). The arts and the social determinants of health: Findings from an inquiry conducted by the United Kingdom All–Party Parliamentary Group on Arts, Health and Wellbeing. *Arts & Health*, 12(1), 1–22.
<https://doi.org/10.1080/17533015.2019.1567563>
- Green, J. (2023). Debate: Neurodiversity, autism and healthcare. *Child and Adolescent Mental Health*, 28(3), 438–442. <https://doi.org/10.1111/camh.12663>
- Han, E., Scior, K., Heath, E., Umagami, K., & Crane, L. (2023). Development of stigma-related support for autistic adults: Insights from the autism community. *Autism*, 27(6), 1676–1689. <https://doi.org/10.1177/13623613221143590>
- Harris, L., Gilmore, D., Longo, A., & Hand, B. N. (2021). Short report: Patterns of US federal autism research funding during 2017–2019. *Autism*, 25(7), 2135–2139.
<https://doi.org/10.1177/13623613211003430>
- Harrison, R. L., Reilly, T. M., & Creswell, J. W. (2020). Methodological Rigor in Mixed Methods: An Application in Management Studies. *Journal of Mixed Methods Research*, 14(4), 473–495. <https://doi.org/10.1177/1558689819900585>
- Heaton, P. (2003). Pitch memory, labelling and disembedding in autism. *Journal of Child Psychology and Psychiatry*, 44(4), 543–551. <https://doi.org/10.1111/1469-7610.00143>
- Heaton, P. (2009). Assessing musical skills in autistic children who are not savants. *Philosophical Transactions of the Royal Society B: Biological Sciences*, 364(1522), 1443–1447. <https://doi.org/10.1098/rstb.2008.0327>
- Heaton, P. (In press). *The Psychology of Music and Autism: Hearing, Feeling, Thinking, Doing*. Palgrave Macmillan.
- Heaton, P., Hermelin, B., & Pring, L. (1998). Autism and pitch processing: A precursor for savant musical ability? *Music Perception*, 15(3), 291–305.
<https://doi.org/10.2307/40285769>
- Helsing, M., Västfjäll, D., Bjälkebring, P., Juslin, P., & Hartig, T. (2016). An Experimental Field Study of the Effects of Listening to Self–selected Music on Emotions, Stress, and Cortisol Levels. *Music and Medicine*, 8(4), Article 4.
<https://doi.org/10.47513/mmd.v8i4.442>
- Hernandez–Ruiz, E., Qi, R., Welsh, E., Wampler, M., & Bradshaw, L. (2022). Psychological and Neural Differences of Music Processing in Autistic Individuals: A Scoping Review. *Journal of Music Therapy*, 59(1), 87–124. <https://doi.org/10.1093/jmt/thab020>
- Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser–Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: A systematic review and meta-analysis. *Psychological Medicine*, 49(4), 559–572.
<https://doi.org/10.1017/S0033291718002283>
- Howard, J. L., Bureau, J. S., Guay, F., Chong, J. X. Y., & Ryan, R. M. (2021). Student Motivation and Associated Outcomes: A Meta–Analysis From Self–Determination

- Theory. *Perspectives on Psychological Science*, 16(6), 1300–1323.
<https://doi.org/10.1177/1745691620966789>
- Howard, K., Katsos, N., & Gibson, J. (2019). Using interpretative phenomenological analysis in autism research. *Autism*, 23(7), 1871–1876.
<https://doi.org/10.1177/1362361318823902>
- Howlin, C., & Rooney, B. (2020). The Cognitive Mechanisms in Music Listening Interventions for Pain: A Scoping Review. *Journal of Music Therapy*, 57(2), 127–167.
<https://doi.org/10.1093/jmt/thaa003>
- Hsieh, H.-F., & Shannon, S. E. (2005). Three Approaches to Qualitative Content Analysis. *Qualitative Health Research*, 15(9), 1277–1288.
<https://doi.org/10.1177/1049732305276687>
- Hull, L., Mandy, W., Lai, M.-C., Baron-Cohen, S., Allison, C., Smith, P., & Petrides, K. V. (2019). Development and Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q). *Journal of Autism and Developmental Disorders*, 49(3), 819–833.
<https://doi.org/10.1007/s10803-018-3792-6>
- IBM Corp. (2021). *SPSS Statistics for Macintosh (Version 28.0) [Macintosh]*. IBM Corp.
- Jablonska, B., Ohlis, A., & Dal, H. (2022). Autismspektrumtillstånd och adhd bland barn och ungdomar i Stockholms län: Förekomst i befolkningen samt vårdkonsumtion. En uppföljningsrapport (2022:5). Centrum för epidemiologi och samhällsmedicin, Region Stockholm.
- Jamey, K., Foster, N. E. V., Sharda, M., Tuerk, C., Nadig, A., & Hyde, K. L. (2019). Evidence for intact melodic and rhythmic perception in children with Autism Spectrum Disorder. *Research in Autism Spectrum Disorders*, 64, 1–12.
<https://doi.org/10.1016/j.rasd.2018.11.013>
- John Dewey. (1925). *Experience and nature*. George Allen and Unwin, Limited.
<http://archive.org/details/experienceandnature>
- Jones, C. R. G., Happé, F., Baird, G., Simonoff, E., Marsden, A. J. S., Tregay, J., Phillips, R. J., Goswami, U., Thomson, J. M., & Charman, T. (2009). Auditory discrimination and auditory sensory behaviours in autism spectrum disorders. *Neuropsychologia*, 47(13), 2850–2858. <https://doi.org/10.1016/j.neuropsychologia.2009.06.015>
- Kaiser, H. F. (1958). The varimax criterion for analytic rotation in factor analysis. *Psychometrika*, 23(3), 187–200. <https://doi.org/10.1007/BF02289233>
- Kamio, Y., Inada, N., & Koyama, T. (2013). A nationwide survey on quality of life and associated factors of adults with high-functioning autism spectrum disorders. *Autism: The International Journal of Research and Practice*, 17(1), 15–26.
<https://doi.org/10.1177/1362361312436848>
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217–250.
- Kargas, N., López, B., Reddy, V., & Morris, P. (2015). The Relationship Between Auditory Processing and Restricted, Repetitive Behaviors in Adults with Autism Spectrum

- Disorders. *Journal of Autism and Developmental Disorders*, 45(3), 658–668.
<https://doi.org/10.1007/s10803-014-2219-2>
- Keating, C. T. (2021). Participatory Autism Research: How Consultation Benefits Everyone. *Frontiers in Psychology*, 12, Article 713982.
<https://doi.org/10.3389/fpsyg.2021.713982>
- Kern, F. G., & Mustasilta, K. (2023). Beyond Replication: Secondary Qualitative Data Analysis in Political Science. *Comparative Political Studies*, 56(8), 1224–1256.
<https://doi.org/10.1177/00104140221139388>
- Kern, P., Rivera, N. R., Chandler, A., & Humpal, M. (2013). Music Therapy Services for Individuals with Autism Spectrum Disorder: A Survey of Clinical Practices and Training Needs. *Journal of Music Therapy*, 50(4), 274–303.
<https://doi.org/10.1093/jmt/50.4.274>
- Keyes, C. L. M. (2005). Mental illness and/or mental health? Investigating axioms of the complete state model of health. *Journal of Consulting and Clinical Psychology*, 73(3), 539–548. <https://doi.org/10.1037/0022-006X.73.3.539>
- Keyes, C., Wissing, M., Potgieter, J. P., Temane, M., Kruger, A., & van Rooy, S. (2008). Evaluation of the mental health continuum–short form (MHC–SF) in setswana-speaking South Africans. *Clinical Psychology & Psychotherapy*, 15(3), 181–192.
<https://doi.org/10.1002/cpp.572>
- King, M., & Bearman, P. (2009). Diagnostic change and the increased prevalence of autism. *International Journal of Epidemiology*, 38(5), 1224–1234.
<https://doi.org/10.1093/ije/dyp261>
- Kirby, M. L., & Burland, K. (2022). Exploring the functions of music in the lives of young people on the autism spectrum. *Psychology of Music*, 50(2), 562–578.
<https://doi.org/10.1177/03057356211008968>
- Knekta, E., Runyon, C., & Eddy, S. (2019). One Size Doesn't Fit All: Using Factor Analysis to Gather Validity Evidence When Using Surveys in Your Research. *CBE—Life Sciences Education*, 18(1), Article rm1. <https://doi.org/10.1187/cbe.18-04-0064>
- Koehler, F., & Neubauer, A. B. (2020). From music making to affective well-being in everyday life: The mediating role of need satisfaction. *Psychology of Aesthetics, Creativity, and the Arts*, 14(4), 493–505. <https://doi.org/10.1037/aca0000261>
- Koehler, F., Warth, M., Ditzen, B., & Neubauer, A. B. (2023). Motivation to make music matters: Daily autonomous motivation, flow, and well-being in hobby musicians. *Psychology of Aesthetics, Creativity, and the Arts*, 17(6), 682–693.
<https://doi.org/10.1037/aca0000409>
- Kokotsaki, D., & Hallam, S. (2007). Higher education music students' perceptions of the benefits of participative music making. *Music Education Research*, 9(1), 93–109.
<https://doi.org/10.1080/14613800601127577>
- Komoriya, Y., Aluwi, N. I. A., Ono, Y., Kishikawa, M., Hirano, T., & Sekiguchi, M. (2015). Pleasant music increases cardiac autonomic responses both in young adults with

- autism spectrum disorder and typical development. *Autonomic Neuroscience*, *192*, 81–82. <https://doi.org/10.1016/j.autneu.2015.07.090>
- Korošec, K., Backman Bister, A., & Bojner Horwitz, E. (in press). “A space to be myself”: Music and self-determination in the lives of autistic adults. *Psychology of Music*.
- Korošec, K., Osika, W., & Bojner Horwitz, E. (2022). “It is more important than food sometimes”; Meanings and Functions of Music in the Lives of Autistic Adults Through a Hermeneutic-Phenomenological Lens. *Journal of Autism and Developmental Disorders*, *54*(1), 366–378. <https://doi.org/10.1007/s10803-022-05799-2>
- Krause, A. E., & Davidson, J. W. (2021). A Qualitative Exploration of Aged-Care Residents’ Everyday Music Listening Practices and How These May Support Psychosocial Well-Being. *Frontiers in Psychology*, *12*, Article 585557. <https://doi.org/10.3389/fpsyg.2021.585557>
- Krause, A. E., North, A. C., & Davidson, J. W. (2019). Using Self-Determination Theory to Examine Musical Participation and Well-Being. *Frontiers in Psychology*, *10*, Article 405. <https://doi.org/10.3389/fpsyg.2019.00405>
- Küpers, E., van Dijk, M., McPherson, G., & van Geert, P. (2014). A dynamic model that links skill acquisition with self-determination in instrumental music lessons. *Musicae Scientiae*, *18*(1), 17–34. <https://doi.org/10.1177/1029864913499181>
- Kuttner, P. J. (2015). Educating for cultural citizenship: Reframing the goals of arts education. *Curriculum Inquiry*, *45*(1), 69–92. <https://doi.org/10.1080/03626784.2014.980940>
- Lai, M.-C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *The Lancet. Psychiatry*, *6*(10), 819–829. [https://doi.org/10.1016/S2215-0366\(19\)30289-5](https://doi.org/10.1016/S2215-0366(19)30289-5)
- Lamers, S. M. A., Westerhof, G. J., Bohlmeijer, E. T., ten Klooster, P. M., & Keyes, C. L. M. (2011). Evaluating the psychometric properties of the mental health Continuum-Short Form (MHC-SF). *Journal of Clinical Psychology*, *67*(1), 99–110. <https://doi.org/10.1002/jclp.20741>
- Legg, C., & Hookway, C. (2021). Pragmatism. In E. N. Zalta (Ed.), *Stanford Encyclopedia of Philosophy*. The Metaphysics Research Lab, Department of Philosophy, Stanford University. <https://plato.sydney.edu.au/entries/pragmatism/>
- Levstek, M., & Banerjee, R. (2021). A Model of Psychological Mechanisms of Inclusive Music-Making: Empowerment of Marginalized Young People. *Music & Science*, *4*, 1–8. <https://doi.org/10.1177/20592043211059752>
- Lewis, L. F. (2017). A Mixed Methods Study of Barriers to Formal Diagnosis of Autism Spectrum Disorder in Adults. *Journal of Autism and Developmental Disorders*, *47*(8), 2410–2424. <https://doi.org/10.1007/s10803-017-3168-3>
- Longo, Y., Gunz, A., Curtis, G. J., & Farsides, T. (2016). Measuring Need Satisfaction and Frustration in Educational and Work Contexts: The Need Satisfaction and Frustration

- Scale (NSFS). *Journal of Happiness Studies*, 17(1), 295–317.
<https://doi.org/10.1007/s10902-014-9595-3>
- Lundin Remnélius, K. (2023). *Female autism phenotypes: Sex/gender differences in functioning, camouflaging, and eating problems* [Doctoral thesis, Karolinska Institutet, Dept of Women's and Children's Health].
<http://openarchive.ki.se/xmlui/handle/10616/48554>
- MacLennan, K., O'Brien, S., & Tavassoli, T. (2021). In Our Own Words: The Complex Sensory Experiences of Autistic Adults. *Journal of Autism and Developmental Disorders*, 52, 3061–3075. <https://doi.org/10.1007/s10803-021-05186-3>
- MacLeod, A. (2019). Interpretative Phenomenological Analysis (IPA) as a tool for participatory research within Critical Autism Studies: A systematic review. *Research in Autism Spectrum Disorders*, 64, 49–62. <https://doi.org/10.1016/j.rasd.2019.04.005>
- Mamashli, F., Khan, S., Bharadwaj, H., Michmizos, K., Ganesan, S., Garell, K.-L. A., Ali Hashmi, J., Herbert, M. R., Hämäläinen, M., & Kenet, T. (2017). Auditory processing in noise is associated with complex patterns of disrupted functional connectivity in autism spectrum disorder. *Autism Research*, 10(4), 631–647. <https://doi.org/10.1002/aur.1714>
- Marquez-Garcia, A. V., Magnuson, J., Morris, J., Iarocci, G., Doesburg, S., & Moreno, S. (2022). Music Therapy in Autism Spectrum Disorder: A Systematic Review. *Review Journal of Autism and Developmental Disorders*, 9(1), 91–107.
<https://doi.org/10.1007/s40489-021-00246-x>
- Martini, M. I., Kuja-Halkola, R., Butwicka, A., Du Rietz, E., D'Onofrio, B. M., Happé, F., Kanina, A., Larsson, H., Lundström, S., Martin, J., Rosenqvist, M. A., Lichtenstein, P., & Taylor, M. J. (2022). Sex Differences in Mental Health Problems and Psychiatric Hospitalization in Autistic Young Adults. *JAMA Psychiatry*, 79(12), 1188–1198.
<https://doi.org/10.1001/jamapsychiatry.2022.3475>
- Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism Research*, 11(8), 1138–1147.
<https://doi.org/10.1002/aur.1965>
- Mayer-Benarous, H., Benarous, X., Vonthron, F., & Cohen, D. (2021). Music Therapy for Children With Autistic Spectrum Disorder and/or Other Neurodevelopmental Disorders: A Systematic Review. *Frontiers in Psychiatry*, 12, Article 643234.
<https://doi.org/10.3389/fpsy.2021.643234>
- McConachie, H., Mason, D., Parr, J. R., Garland, D., Wilson, C., & Rodgers, J. (2018). Enhancing the Validity of a Quality of Life Measure for Autistic People. *Journal of Autism and Developmental Disorders*, 48(5), 1596–1611.
<https://doi.org/10.1007/s10803-017-3402-z>
- McConachie, H., Wilson, C., Mason, D., Garland, D., Parr, J. R., Rattazzi, A., Rodgers, J., Skevington, S., Uljarevic, M., & Magiati, I. (2020). What Is Important in Measuring Quality of Life? Reflections by Autistic Adults in Four Countries. *Autism in Adulthood*, 2(1), 4–12. <https://doi.org/10.1089/aut.2019.0008>

- McCrary, J. M., Altenmüller, E., Kretschmer, C., & Scholz, D. S. (2022). Association of Music Interventions With Health-Related Quality of Life: A Systematic Review and Meta-analysis. *JAMA Network Open*, *5*(3), Article e223236. <https://doi.org/10.1001/jamanetworkopen.2022.3236>
- McDonald, T. A. M. (2020). Autism Identity and the “Lost Generation”: Structural Validation of the Autism Spectrum Identity Scale and Comparison of Diagnosed and Self-Diagnosed Adults on the Autism Spectrum. *Autism in Adulthood*, *2*(1), 13–23. <https://doi.org/10.1089/aut.2019.0069>
- McLean, K. J., Haas, M., Koenig, J., Horvath, M., Vigil, M., Werner, N. E., & Bishop, L. (2024). “I’m dealing with a health care system that doesn’t get it”: Barriers and facilitators to inclusive healthcare for autistic adults. *Autism*, *28*(6), 1382–1393. <https://doi.org/10.1177/13623613241236380>
- Microsoft. (2024). *Microsoft Excel for Mac* (Version 16.86) [Computer software]. Microsoft.
- Milton, D. (2012). On the ontological status of autism: The ‘double empathy problem’. *Disability & Society*, *27*(6), 883–887. <https://doi.org/10.1080/O9687599.2012.710008>
- Milton, D., & Green, J. (2024). Theorising autism. *Autism*, *28*(4), 795–797. <https://doi.org/10.1177/13623613241235786>
- Milton, D., Gurbuz, E., & López, B. (2022). The ‘double empathy problem’: Ten years on. *Autism*, *26*(8), 1901–1903. <https://doi.org/10.1177/13623613221129123>
- Morgan, D. L. (2014). Pragmatism as a Paradigm for Social Research. *Qualitative Inquiry*, *20*(8), 1045–1053. <https://doi.org/10.1177/1077800413513733>
- Mottron, L., & Bzdok, D. (2020). Autism spectrum heterogeneity: Fact or artifact? *Molecular Psychiatry*, *25*(12), 3178–3185. <https://doi.org/10.1038/s41380-020-0748-y>
- Mottron, L., Peretz, I., & Menard, E. (2000). Local and Global Processing of Music in High-functioning Persons with Autism: Beyond Central Coherence? *Journal of Child Psychology and Psychiatry*, *41*(8), 1057–1065. <https://doi.org/10.1111/1469-7610.00693>
- Musgrave, G. (2022). Music and wellbeing vs. musicians’ wellbeing: Examining the paradox of music-making positively impacting wellbeing, but musicians suffering from poor mental health. *Cultural Trends*, *127*, 1–16. <https://doi.org/10.1080/O9548963.2022.2058354>
- Mvududu, N. H., & Sink, C. A. (2013). Factor Analysis in Counseling Research and Practice. *Counseling Outcome Research and Evaluation*, *4*(2), 75–98. <https://doi.org/10.1177/2150137813494766>
- National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1979). *The Belmont report: Ethical principles and guidelines for the protection of human subjects of research*. U.S. Department of Health and Human Services. <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html>

- Natri, H. M., Chapman, C. R., Heraty, S., Dwyer, P., Walker, N., Kapp, S. K., Dron, H. A., Martinez-Agosto, J. A., Mikkola, L., & Doherty, M. (2023). Ethical challenges in autism genomics: Recommendations for researchers. *European Journal of Medical Genetics*, 66(9), Article 104810. <https://doi.org/10.1016/j.ejmg.2023.104810>
- Nguyen, K. T., Xiao, J., Chan, D. N. S., Zhang, M., & Chan, C. W. H. (2022). Effects of music intervention on anxiety, depression, and quality of life of cancer patients receiving chemotherapy: A systematic review and meta-analysis. *Supportive Care in Cancer*, 30(7), 5615–5626. <https://doi.org/10.1007/s00520-022-06881-2>
- Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., Weiner, M., Maslak, J., Hunter, M., & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*, 23(8), 2007–2019. <https://doi.org/10.1177/1362361319830523>
- Nilsson, M., Handest, P., Nylander, L., Pedersen, L., Carlsson, J., & Arnfred, S. (2019). Arguments for a Phenomenologically Informed Clinical Approach to Autism Spectrum Disorder. *Psychopathology*, 52(3), 153–160. <https://doi.org/10.1159/000500294>
- Nordoff, P. (1964). Music therapy and personality change in autistic children. *Journal of the American Institute of Homeopathy*, 57, 305–310.
- Nordoff, P., & Robbins, C. (1965). Improvised music for autistic children. *Music Journal*, 23(8), 39.
- Ntoumanis, N., & Moller, A. C. (2023). Facilitating Health Behavior Change: A Self-Determination Theory Perspective. In R. M. Ryan (Ed.), *The Oxford Handbook of Self-Determination Theory* (pp. 777–800). Oxford University Press. <https://doi.org/10.1093/oxfordhb/9780197600047.013.39>
- Nunnally, J. C., & Bernstein, I. H. (1994). *Psychometric Theory* (3rd Edition). McGraw-Hill Companies Inc.
- Ochs, E., & Solomon, O. (2010). Autistic Sociality. *Ethos*, 38(1), 69–92. <https://doi.org/10.1111/j.1548-1352.2009.01082.x>
- Pakulski, J. (1997). Cultural citizenship. *Citizenship Studies*, 1(1), 73–86. <https://doi.org/10.1080/13621029708420648>
- Pantazakos, T. (2019). Treatment for whom? Towards a phenomenological resolution of controversy within autism treatment. *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences*, 77, Article 101176. <https://doi.org/10.1016/j.shpsc.2019.04.001>
- Peat, J., & Barton, B. (2005). *Medical Statistics: A Guide to Data Analysis and Critical Appraisal*. John Wiley & Sons, Incorporated. <http://ebookcentral.proquest.com/lib/ki/detail.action?docID=351271>
- Pellicano, E., Lawson, W., Hall, G., Mahony, J., Lilley, R., Heyworth, M., Clapham, H., & Yudell, M. (2022). “I Knew She’d Get It, and Get Me”: Participants’ Perspectives of a Participatory Autism Research Project. *Autism in Adulthood*, 4(2), 120–129. <https://doi.org/10.1089/aut.2021.0039>

- Pellicano, L., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism, 18*(7), 756–770. <https://doi.org/10.1177/1362361314529627>
- Pellicano, L., Fatima, U., Hall, G., Heyworth, M., Lawson, W., Lilley, R., Mahony, J., & Stears, M. (2022). A capabilities approach to understanding and supporting autistic adulthood. *Nature Reviews Psychology, 1*(11), 624–639. <https://doi.org/10.1038/s44159-022-00099-z>
- Pellicano, L., Mandy, W., Bölte, S., Stahmer, A., Lounds Taylor, J., & Mandell, D. S. (2018). A new era for autism research, and for our journal. *Autism, 22*(2), 82–83. <https://doi.org/10.1177/1362361317748556>
- Perkins, R., Mason-Bertrand, A., Fancourt, D., Baxter, L., & Williamon, A. (2020). How Participatory Music Engagement Supports Mental Well-being: A Meta-Ethnography. *Qualitative Health Research, 30*(12), 1924–1940. <https://doi.org/10.1177/1049732320944142>
- Perkins, R., Mason-Bertrand, A., Tymoszuk, U., Spiro, N., Gee, K., & Williamon, A. (2021). Arts engagement supports social connectedness in adulthood: Findings from the HEartS Survey. *BMC Public Health, 21*(1), 1208. <https://doi.org/10.1186/s12889-021-11233-6>
- Pickard, B., Thompson, G., Metell, M., Roginsky, E., & Elefant, C. (2020). “It’s Not What’s Done, But Why It’s Done”: Music Therapists’ Understanding of Normalisation, Maximisation and the Neurodiversity Movement. *Voices: A World Forum for Music Therapy, 20*(3), Article 3. <https://doi.org/10.15845/voices.v20i3.3110>
- Pickard, H., Pellicano, E., den Houting, J., & Crane, L. (2022). Participatory autism research: Early career and established researchers’ views and experiences. *Autism, 26*(1), 75–87. <https://doi.org/10.1177/13623613211019594>
- Pukki, H., Bettin, J., Outlaw, A. G., Hennessy, J., Brook, K., Dekker, M., Doherty, M., Shaw, S. C. K., Bervoets, J., Rudolph, S., Corneloup, T., Derwent, K., Lee, O., Rojas, Y. G., Lawson, W., Gutierrez, M. V., Petek, K., Tsiakkirou, M., Suoninen, A., ... Yoon, wn-ho. (2022). Autistic Perspectives on the Future of Clinical Autism Research. *Autism in Adulthood, 4*(2), 93–101. <https://doi.org/10.1089/aut.2022.0017>
- Qian, X., Shogren, K., Odejimi, O. A., & Little, T. (2022). Differences in Self-Determination Across Disability Categories: Findings From National Longitudinal Transition Study 2012. *Journal of Disability Policy Studies, 32*(4), 245–256. <https://doi.org/10.1177/1044207320964396>
- QSR International Pty Ltd. (2020). *NVivo* (Version released in March 2020) [Computer software]. QSR International Pty Ltd. <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>
- Quintin, E.-M. (2019). Music-Evoked Reward and Emotion: Relative Strengths and Response to Intervention of People With ASD. *Frontiers in Neural Circuits, 13*, Article 49. <https://doi.org/10.3389/fncir.2019.00049>
- Quintin, E.-M., Bhatara, A., Poissant, H., Fombonne, E., & Levitin, D. J. (2013). Processing of musical structure by high-functioning adolescents with autism spectrum disorders.

- Child Neuropsychology*, 19(3), 250–275.
<https://doi.org/10.1080/09297049.2011.653540>
- Reio, T. G., & Shuck, B. (2015). Exploratory Factor Analysis: Implications for Theory, Research, and Practice. *Advances in Developing Human Resources*, 17(1), 12–25.
<https://doi.org/10.1177/1523422314559804>
- Reschke–Hernández, A. E. (2011). History of music therapy treatment interventions for children with autism. *Journal of Music Therapy*, 48(2), 169–207.
<https://doi.org/10.1093/jmt/48.2.169>
- Roche, L., Adams, D., & Clark, M. (2021). Research priorities of the autism community: A systematic review of key stakeholder perspectives. *Autism*, 25(2), 336–348.
<https://doi.org/10.1177/1362361320967790>
- Rødgaard, E.–M., Jensen, K., Miskowiak, K. W., & Mottron, L. (2021). Autism comorbidities show elevated female-to-male odds ratios and are associated with the age of first autism diagnosis. *Acta Psychiatrica Scandinavica*, 144(5), 475–486.
<https://doi.org/10.1111/acps.13345>
- Rosas, A., Helgesen, J., & Goodman, D. (2022). *The Strength of Diversity: Human Rights and Pluralist Democracy*. Martinus Nijhoff Publishers.
- Roth, G., Assor, A., Niemiec, C. P., Ryan, R. M., & Deci, E. L. (2009). The emotional and academic consequences of parental conditional regard: Comparing conditional positive regard, conditional negative regard, and autonomy support as parenting practices. *Developmental Psychology*, 45, 1119–1142. <https://doi.org/10.1037/a0015272>
- Ryan, J., Brown, H. M., Borden, A., Devlin, C., Kedmy, A., Lee, A., Nicholas, D. B., Kingsley, B., & Thompson–Hodgetts, S. (2024). Being able to be myself: Understanding autonomy and autonomy–support from the perspectives of autistic adults with intellectual disabilities. *Autism*, 0(0), 1–13. <https://doi.org/10.1177/13623613241254432>
- Ryan, R. M. (2023). *The Oxford Handbook of Self-Determination Theory*. Oxford University Press. <https://doi.org/10.1093/oxfordhb/9780197600047.001.0001>
- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55(1), 68–78.
<https://doi.org/10.1037/0003-066X.55.1.68>
- Ryan, R. M., & Deci, E. L. (2020). Intrinsic and extrinsic motivation from a self-determination theory perspective: Definitions, theory, practices, and future directions. *Contemporary Educational Psychology*, 61, Article 101860.
<https://doi.org/10.1016/j.cedpsych.2020.101860>
- Ryan, R. M., & Vansteenkiste, M. (2023). Self-Determination Theory: Metatheory, Methods, and Meaning. In R. M. Ryan (Ed.), *The Oxford Handbook of Self-Determination Theory* (pp. 3–30). Oxford University Press.
<https://doi.org/10.1093/oxfordhb/9780197600047.013.2>

- Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57(6), 1069–1081. <https://doi.org/10.1037/0022-3514.57.6.1069>
- Saarikallio, S. (2012). Development and Validation of the Brief Music in Mood Regulation Scale (B-MMR). *Music Perception: An Interdisciplinary Journal*, 30, 97–105. <https://doi.org/10.1525/mp.2012.30.1.97>
- Saarikallio, S. (2019). Access–Awareness–Agency (AAA) Model of Music–Based Social–Emotional Competence (MuSEC). *Music & Science*, 2, 1–16. <https://doi.org/10.1177/2059204318815421>
- Saarikallio, S., Maksimainen, J. P., & Randall, William. M. (2019). Relaxed and connected: Insights into the emotional–motivational constituents of musical pleasure. *Psychology of Music*, 47(5), 644–662. <https://doi.org/10.1177/0305735618778768>
- Salari, N., Rasoulpoor, S., Rasoulpoor, S., Shohaimi, S., Jafarpour, S., Abdoli, N., Khaledi-Paveh, B., & Mohammadi, M. (2022). The global prevalence of autism spectrum disorder: A comprehensive systematic review and meta-analysis. *Italian Journal of Pediatrics*, 48(1), 112. <https://doi.org/10.1186/s13052-022-01310-w>
- Savage, P. E., Loui, P., Tarr, B., Schachner, A., Glowacki, L., Mithen, S., & Fitch, W. T. (2021). Music as a coevolved system for social bonding. *Behavioral and Brain Sciences*, 44, 23–39. <https://doi.org/10.1017/S0140525X20000333>
- Shalit, L., Elefant, C., & Roginsky, E. (2024). Exploring music in the everyday lives of autistic women: An Interpretative Phenomenological Analysis. *Nordic Journal of Music Therapy*, 33(5), 1–20. <https://doi.org/10.1080/08098131.2024.2396105>
- Sheppard, A., & Broughton, M. C. (2020). Promoting wellbeing and health through active participation in music and dance: A systematic review. *International Journal of Qualitative Studies on Health and Well-Being*, 15(1), 1–19. <https://doi.org/10.1080/17482631.2020.1732526>
- Siddiqui, W., & Sharp, R. R. (2021). Beyond the Belmont Report. *The American Journal of Bioethics*, 21(10), 1–4. <https://doi.org/10.1080/15265161.2021.1972649>
- Silverman, M. J., Gooding, L. F., & Yinger, O. (2020). It's...Complicated: A Theoretical Model of Music–Induced Harm. *Journal of Music Therapy*, 57(3), 251–281. <https://doi.org/10.1093/jmt/thaa008>
- Small, C. (1999). Musicking—The meanings of performing and listening. A lecture. *Music Education Research*, 1(1), 9–22. <https://doi.org/10.1080/146138099001010102>
- Soskey, L. N., Allen, P. D., & Bennetto, L. (2017). Auditory spatial attention to speech and complex non-speech sounds in children with autism spectrum disorder. *Autism Research*, 10(8), 1405–1416. <https://doi.org/10.1002/aur.1790>
- Spearman, C. (1987). The proof and measurement of association between two things. By C. Spearman, 1904. *The American Journal of Psychology*, 100(3–4), 441–471.

- Stanutz, S., Wapnick, J., & Burack, J. A. (2014). Pitch discrimination and melodic memory in children with autism spectrum disorders. *Autism, 18*(2), 137–147. <https://doi.org/10.1177/1362361312462905>
- Straus, J. (2014). Music Therapy and Autism: A View from Disability Studies. *Voices: A World Forum for Music Therapy, 14*(3). <https://doi.org/10.15845/voices.v14i3.785>
- Strehle, R. (2023). A critical investigation of self-determination theory in the context of a music conservatoire: Basic needs satisfaction, autonomy support, and motivation of BMus and MMus Performance students [Doctoral thesis, The University of St Andrews]. <https://doi.org/10.17630/sta/418>
- Talantseva, O. I., Romanova, R. S., Shurdova, E. M., Dolgorukova, T. A., Sologub, P. S., Titova, O. S., Kleeva, D. F., & Grigorenko, E. L. (2023). The global prevalence of autism spectrum disorder: A three-level meta-analysis. *Frontiers in Psychiatry, 14*, Article 1071181. <https://doi.org/10.3389/fpsy.2023.1071181>
- Tang, Q., Huang, Z., Zhou, H., & Ye, P. (2020). Effects of music therapy on depression: A meta-analysis of randomized controlled trials. *PLOS ONE, 15*(11), Article e0240862. <https://doi.org/10.1371/journal.pone.0240862>
- Tarr, B., Launay, J., & Dunbar, R. I. M. (2014). Music and social bonding: ‘self-other’ merging and neurohormonal mechanisms. *Frontiers in Psychology, 5*, Article 1096. <https://doi.org/10.3389/fpsyg.2014.01096>
- Tavakol, M., & Wetzell, A. (2020). Factor Analysis: A means for theory and instrument development in support of construct validity. *International Journal of Medical Education, 11*, 245–247. <https://doi.org/10.5116/ijme.5f96.Of4a>
- Tecchio, F., Benassi, F., Zappasodi, F., Gialloreti, L. E., Palermo, M., Seri, S., & Rossini, P. M. (2003). Auditory sensory processing in autism: A magnetoencephalographic study. *Biological Psychiatry, 54*(6), 647–654. [https://doi.org/10.1016/S0006-3223\(03\)00295-6](https://doi.org/10.1016/S0006-3223(03)00295-6)
- The Autism Self-advocacy Network. (2009, January 9). About Autism—Autistic Self Advocacy Network. <https://Autisticadvocacy.Org/>. <https://autisticadvocacy.org/about-asan/about-autism/>
- The Autistic Self Advocacy Network. (2022). For Whose Benefit?: Evidence, Ethics, and Effectiveness of Autism Interventions—Autistic Self Advocacy Network. <https://autisticadvocacy.org/policy/briefs/intervention-ethics/>
- Theorell, T., Kowalski, J., & Bojner Horwitz, E. (2019). Music listening as distraction from everyday worries. *Nordic Journal of Arts, Culture and Health, 1*(1), 35–46. <https://doi.org/10.18261/issn.2535-7913-2019-01-04>
- Theorell, T., Kowalski, J., Theorell, A. M. L., & Horwitz, E. B. (2023). Choir Singers Without Rehearsals and Concerts? A Questionnaire Study on Perceived Losses From Restricting Choral Singing During the Covid-19 Pandemic. *Journal of Voice, 37*(1), 1–9. <https://doi.org/10.1016/j.jvoice.2020.11.006>

- Thompson, G. A., Raine, M., Hayward, S., & Kilpatrick, H. (2020). Gathering community perspectives to inform the design of autism-friendly music-making workshops for wellbeing. *International Journal of Wellbeing*, *10*(5), Article 5.
<https://doi.org/10.5502/ijw.v10i5.1497>
- Thompson, P. (2000). Re-using Qualitative Research Data: A Personal Account. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *1*(3), Article 3.
<https://doi.org/10.17169/fqs-1.3.1044>
- Thompson-Hodgetts, S., Ryan, J., Coombs, E., Brown, H. M., Xavier, A., Devlin, C., Lee, A., Kedmy, A., & Borden, A. (2023). Toward understanding and enhancing self-determination: A qualitative exploration with autistic adults without co-occurring intellectual disability. *Frontiers in Psychiatry*, *14*, Article 1250391.
<https://doi.org/10.3389/fpsy.2023.1250391>
- Tomas, V., Kingsnorth, S., Anagnostou, E., Kirsh, B., & Lindsay, S. (2023). "I Wish This Tool Was Available to Me Sooner": Piloting a Workplace Autism Disclosure Decision-Aid Tool for Autistic Youth and Young Adults. *Autism in Adulthood*, *6*(3).
<https://doi.org/10.1089/aut.2023.0054>
- Uddholm, M., & Backman Bister, A. (2019, November 12). Vem får vara med och skapa normerna för vad musik är?: Ett rundabordsamtal om estetiska uttrycksformer i arbete med intellektuell funktionsnedsättning [Panel discussion]. Aesthetic Experiences In Education, Stockholms Musikpedagogiska Institut (SMI), Stockholm, Sweden. <https://www.ucviden.dk/en/publications/vem-f%C3%A5r-vara-med-och-skapa-normerna-f%C3%B6r-vad-musik-%C3%A4r-ett-rundabor>
- United Nations Convention on the Rights of Persons with Disabilities (CRPD), § Article 30 – Participation in cultural life, recreation, leisure and sport (2006).
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-30-participation-in-cultural-life-recreation-leisure-and-sport.html>
- Urban, M., & Urban, K. (2023). Orientation Toward Intrinsic Motivation Mediates the Relationship Between Metacognition and Creativity. *The Journal of Creative Behavior*, *57*(1), 6–16. <https://doi.org/10.1002/jocb.558>
- Vansteenkiste, M., Soenens, B., & Ryan, R. M. (2023). Basic Psychological Needs Theory: A Conceptual and Empirical Review of Key Criteria. In R. M. Ryan (Ed.), *The Oxford Handbook of Self-Determination Theory* (p. 84–123). Oxford University Press.
<https://doi.org/10.1093/oxfordhb/9780197600047.013.5>
- Váradi, J. (2022). A Review of the Literature on the Relationship of Music Education to the Development of Socio-Emotional Learning. *Sage Open*, *12*(1), Article 21582440211068501. <https://doi.org/10.1177/21582440211068501>
- Venter, F., Morelli, J., & Erasmus, E. (2023). Understanding the lived music listening experiences of adults on the autism spectrum. *Psychology of Music*, *51*(3), 971–985.
<https://doi.org/10.1177/03057356221126201>

- Verhoeff, B. (2013). Autism in flux: A history of the concept from Leo Kanner to DSM-5. *History of Psychiatry*, 24(4), 442–458. <https://doi.org/10.1177/0957154X13500584>
- Viding, C. G., Osika, W., Theorell, T., Kowalski, J., Hallqvist, J., & Bojner Horwitz, E. (2015). “The Culture palette”- a randomized intervention study for women with burnout symptoms in Sweden. *British Journal of Medical Practitioners*, 8(2), Article a813.
- Walker, N. (2021). *Neuroqueer heresies: Notes on the neurodiversity paradigm, autistic empowerment, and postnormal possibilities*. Autonomous Press.
- Wehmeyer, M. L. (2023). Self-Determination Theory and the Education of Learners with Disabilities. In R. M. Ryan (Ed.), *The Oxford Handbook of Self-Determination Theory* (p. 684–698). Oxford University Press.
<https://doi.org/10.1093/oxfordhb/9780197600047.013.34>
- Weiss, J. A., & Burnham Riosa, P. (2015). Thriving in Youth with Autism Spectrum Disorder and Intellectual Disability. *Journal of Autism and Developmental Disorders*, 45(8), 2474–2486. <https://doi.org/10.1007/s10803-015-2412-y>
- White, K., Flanagan, T. D., & Nadig, A. (2018). Examining the Relationship Between Self-Determination and Quality of Life in Young Adults with Autism Spectrum Disorder. *Journal of Developmental and Physical Disabilities*, 30(6), 735–754.
<https://doi.org/10.1007/s10882-018-9616-y>
- Wilkenfeld, D. A., & McCarthy, A. M. (2020). Ethical Concerns with Applied Behavior Analysis for Autism Spectrum “Disorder”. *Kennedy Institute of Ethics Journal*, 30(1), 31–69. <https://doi.org/10.1353/ken.2020.0000>.
- World Health Organization. (1977). *Manual of the international statistical classification of diseases, injuries, and causes of death*. World Health Organization.
- World Health Organization. (2005). *Handbook for good clinical research practice (GCP): Guidance for implementation*. World Health Organization.
<https://iris.who.int/handle/10665/43392>
- Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Research*, 15(5), 778–790. <https://doi.org/10.1002/aur.2696>
- Zoom Video Communications, Inc. (2024). *Zoom Workplace for Mac* (Version Version 6.1.6 (37851)) [Computer software]. Zoom Video Communications, Inc.
https://zoom.us/download#client_4meeting

10 Appendices

10.1 Appendix A: Information for the participants of Study I

Vad handlar projektet om?

Det har utvecklats en hel del insatser och aktiviteter för att förbättra välmående och livskvalitet för barn med autism/Aspergers syndrom, men för vuxna finns det inte lika många sådana insatser och aktiviteter. Det saknas dessutom kunskap om hur vi kan använda musik för att förbättra vardagen för vuxna med autism/Aspergers syndrom. Vi håller därför på att utveckla ett koncept med musikaktiviteter i grupp, för personer med autism/Aspergers syndrom, med syftet att förbättra livskvalitet och välbefinnande. För att förbereda och utveckla musikaktiviteterna måste vi först lära oss vad som är viktigt för att livskvalitet skall kunna utvecklas, och hur musik kan användas för att stimulera välbefinnande. För att få svar på dessa frågor vänder vi oss till dig som har erfarenhet av detta och som vill hjälpa oss att utveckla aktiviteter där musik kan spela en viktig roll.

Forskningshuvudman för projektet är Karolinska Institutet.

Hur går studien till?

Studien bygger på insamling av data genom två intervjuer.

- 1) Vi genomför en online intervju (via Zoom). Du behöver ingen speciell programvara eller konto på din dator. Du behöver bara klicka på en länk som vi skickar till dig. Länken öppnar upp ett videosamtal mellan dig och intervjuaren. Du bestämmer själv vilken tid som passar dig bäst (bokning via telefon eller e-post till Kaja, se nedan). Du kommer få svara på några korta allmänna frågor om din ålder och därefter frågor kopplat till dina intressen, såsom till exempel vad du gör dagligen för att må bra, vad som stressar dig och om du spelar eller lyssnar på musik. Intervjun tar mellan 30 och 60 minuter.
- 2) Efter ett par veckor bjuder vi in dig igen till den andra intervjun med samma intervjuare. Intervjun tar max 30 minuter) och de kommer också att ske digitalt (via Zoom). Intervjuaren kommer då att ställa några uppföljande frågor kopplat till den första intervjun.

Möjliga följder och risker med att delta i studien

Eftersom intervjuaren kommer att fråga dig om dina dagliga utmaningar och om vad som kan tänkas stressa dig i olika situationer så kan detta påverka dig på olika sätt. Det kan till exempel väcka negativa känslor hos dig eller framkalla negativa minnen av något slag. Intervjuaren är utbildad för att stödja dig i denna process. Du kan när som helst be om hjälp om du behöver förtydliga någon fråga eller om du behöver annan hjälp. Du kan även avstå från att svara på de frågor som du tycker är för personliga eller som du upplever är för svåra. Efter intervjun har du möjlighet att prata med intervjuaren om hur du mår och hur du har upplevt intervjun. Du kan även kontakta den ansvariga för studien, Kaja Korošec, som är utbildad psykolog.

Vad händer med mina uppgifter?

Projektet kommer att samla in och registrera information om dig.

Informationen vi kommer att behandla och använda i forskningsprojektet är dels hämtad från frågeformuläret och dels från de två intervjuerna som gjorts med dig. Intervjuerna kommer att spelas in på en video- och ljudfil. Syftet med behandlingen av personuppgifterna är av allmänt intresse och följer dataskyddsförordningen.

Dina svar och dina resultat kommer att behandlas så att inte obehöriga kan ta del av dem. Ansvarig för dina personuppgifter är som sagt Karolinska Institutet. Enligt EU:s dataskyddsförordning har du rätt att kostnadsfritt få ta del av de uppgifter om dig som hanteras i studien, och vid behov få eventuella fel rättade. Du kan också begära att uppgifter om dig raderas samt att behandlingen av dina personuppgifter begränsas. Rätten till radering och till begränsning av behandling av personuppgifter gäller dock inte när uppgifterna är nödvändiga för den aktuella forskningen. Om du vill ta del av uppgifterna ska du kontakta Kaja Korošec (e-post: kaja.korosec@kmh.se). Dataskyddsombud Mats Gustavsson nås på telefonnummer X (e-post: dataskyddsombud@ki.se). Om du är missnöjd med hur dina personuppgifter behandlas har du rätt att lämna in klagomål till Integritetsskyddsmyndigheten, som är tillsynsmyndighet.

Hur får jag information om resultatet av studien?

Du som deltar i studien kan när som helst efter genomförd studie få tillgång till dina resultat. Studiens resultat kommer även att publiceras i vetenskapliga tidskrifter. Du som forskningsperson behöver inte ta del av resultat om du inte vill. Projektet hanterar även eventuella oförutsedda fynd från studien med högsta konfidentialitet.

Försäkring och ersättning

Forskningsprojektet är försäkrat genom Kungl. Musikhögskolan. Du som forskningsperson kommer inte att erhålla någon ersättning för ditt deltagande.

Deltagandet är frivilligt

Ditt deltagande är frivilligt och du kan när som helst välja att avbryta deltagandet. Om du väljer att inte delta eller vill avbryta ditt deltagande behöver du inte uppge varför, och det kommer inte heller att påverka din framtida eventuella vård eller behandling. Om du vill avbryta ditt deltagande ska du kontakta den ansvariga för studien Kaja Korošec (se nedan).

Ansvariga för studien

Ansvarig för studien är doktorand **Kaja Korošec**, e-post: kaja.korosec@ki.se; mobilnummer: /. Adress: Kungl. Musikhögskolan, Valhallavägen 105, Box 277 11, SE-115 91 Stockholm.

Huvudansvarig forskare/handledare är Professor **Eva Bojner Horwitz**, PhD, e-post: eva.bojner-horwitz@kmh.se; mobilnummer: /; Adress: Institutionen för musik, pedagogik och samhälle, Kungl. Musikhögskolan, Valhallavägen 105, Box 277 11, SE-115 91 Stockholm

Råd och hänvisningar till vidare professionell hjälp

Cecilia Brusewitz, e-post: kansliet@attention.se; Adress: Riksförbundet Attention, The Park, Magnus Ladulåsgatan 1, 118 65 Stockholm

10.2 Appendix B: Interview guide for Study I

Suggested question prompts

Area 1: Music, well-being and quality of life.

Overarching question: How is music relevant to autistic adults' well-being?

1. How do you take care of your well-being?
2. What is your favourite thing to do? What do you enjoy most?
3. How do you look at music as a way to take care of yourself? In what way can music make you feel better?
4. What about your body? How does it respond to music? What is happening in your body when you listen or play music?
5. What is it about music that makes you want to listen to it – what does it do for you?

Area 2: Music, stress and everyday challenges.

Overarching question: In which situation is music a stressor or does negatively affect their well-being?

1. What makes your life more stressful or difficult on a day-to-day basis?
2. Are there any challenges you face, that non-autistic people find particularly difficult to understand? Which are those?
3. What about music – can music sometimes be stressful to you? When, in which situations? In what way? What do you do then?

Area 3: Music, resilience and support.

Overarching question: How is music involved in coping with stress?

1. How do you cope with everyday challenges? How do you make it easier or less stressful?
2. Do you feel like there is something missing in the services available to you? (especially related to music and art)
3. If there was an activity available, where you could play and listen to music with a musician and a handful of other autistic adults, how would you think about this?

10.3 Appendix C: Information for the participants of Study III

Vad handlar projektet om?

I Sverige tillgängliggörs olika musikaktiviteter för personer med autismdiagnos men för närvarande vet vi mycket lite om *hur* dessa musikaktiviteter är kopplade till välbefinnande. Genom att undersöka detta närmare så kommer vi i framtiden kunna förbättra musikaktivitetens kvalitet.

I denna studie utvecklar vi ett frågeformulär som utvärderar hur människor använder musik för att främja sitt välbefinnande. Vi samlar in feedback för att se om frågorna är tydliga och relevanta för hur autistiska vuxna upplever musik kopplat till välbefinnande. För att delta i studien behöver du inte kunna spela något instrument, sjunga eller ha någon vana av att gå på konsert. Även om du inte lyssnar på musik så är dina svar viktiga för oss.

Forskningshuvudman för projektet är Karolinska Institutet. Med forskningshuvudman menas den organisation som är ansvarig för projektet. Ansökan är godkänd av Etikprövningsmyndigheten, diarienummer för prövningen hos Etikprövningsmyndigheten är 2021-01121.

Hur går studien till?

Om du bestämmer dig för att delta kommer du att bli ombedd att fylla i en uppsättning frågeformulär (6 sidor) som tar dig ca. 20 minuter. Frågorna kommer att handla om musik, och ditt välbefinnande. Dina svar kommer att analyseras på gruppnivå.

Möjliga följder och risker med att delta i studien

Frågorna handlar om ditt välbefinnande. Om du är missnöjd med något så skulle det kunna få dig att känna dig orolig. Du kan avsluta när du vill. Om du börjar känna dig trött så kan du ta en paus och fortsätta senare.

Vad händer med mina uppgifter?

Projektet kommer att samla in och registrera information om dig.

Informationen vi kommer att behandla och använda i forskningsprojektet är dels hämtad från frågeformuläret och dels från de två intervjuerna som gjorts med dig. Intervjuerna kommer att spelas in på en video- och ljudfil. Syftet med behandlingen av personuppgifterna är av allmänt intresse och följer dataskyddsförordningen.

Dina svar och dina resultat kommer att behandlas så att inte obehöriga kan ta del av dem. Ansvarig för dina personuppgifter är som sagt Karolinska Institutet. Enligt EU:s dataskyddsförordning har du rätt att kostnadsfritt få ta del av de uppgifter om dig som hanteras i studien, och vid behov få eventuella fel rättade. Du kan också begära att uppgifter om dig raderas samt att behandlingen av dina personuppgifter begränsas. Rätten till radering och till begränsning av behandling av personuppgifter gäller dock inte när uppgifterna är nödvändiga för den aktuella forskningen. Om du vill ta del av uppgifterna ska du kontakta Kaja Korošec (e-post: kaja.korosec@kmh.se)). Dataskyddsombud Mats Gustavsson nås på telefonnummer 08-524 864 73 (e-post: dataskyddsombud@ki.se). Om du är missnöjd med hur dina personuppgifter behandlas har du rätt att lämna in klagomål till Integritetsskyddsmyndigheten, som är tillsynsmyndighet.

Hur får jag information om resultatet av studien?

Du som deltar i studien kan när som helst efter genomförd studie få tillgång till dina resultat (kontakta kaja.korosec@ki.se). Studiens resultat kommer även att publiceras i vetenskapliga tidskrifter. Du som forskningsperson behöver inte ta del av resultat om du inte vill.

Försäkring och ersättning

Forskningsprojektet är försäkrat genom Kungl. Musikhögskolan. Du som forskningsperson kommer inte att erhålla någon ersättning för ditt deltagande.

Deltagandet är frivilligt

Ditt deltagande är frivilligt och du kan när som helst välja att avbryta deltagandet. Om du väljer att inte delta eller vill avbryta ditt deltagande behöver du inte uppge varför, och det kommer inte heller att påverka din framtida eventuella vård eller behandling. Om du vill avbryta ditt deltagande ska du kontakta den ansvariga för studien, Kaja Korošec (kaja.korosec@ki.se).

Ansvariga för studien

Ansvarig för studien är doktorand **Kaja Korošec**, e-post: kaja.korosec@ki.se; mobilnummer: /. Adress: Kungl. Musikhögskolan, Valhallavägen 105, Box 277 11, SE-115 91 Stockholm.

Huvudansvarig forskare/handledare är Professor **Eva Bojner Horwitz**, PhD, e-post: eva.bojner-horwitz@kmh.se; mobilnummer: /; Adress: Institutionen för musik, pedagogik och samhälle, Kungl. Musikhögskolan, Valhallavägen 105, Box 277 11, SE-115 91 Stockholm

Råd och hänvisningar till vidare professionell hjälp

Cecilia Brusewitz, e-post: kansliet@attention.se; Adress: Riksförbundet Attention, The Park, Magnus Ladulåsgatan 1, 118 65 Stockholm

10.4 Appendix D: Questionnaire battery from Study III

Musik, autism och välmående

Bästa deltagare,

I Sverige tillgängliggörs olika musikaktiviteter för personer med autismdiagnos men vi vet inte tillräckligt mycket om *hur* dessa musikaktiviteter är kopplade till välbefinnande. Genom att undersöka detta närmare så kommer vi kunna förbättra musikaktiviteternas kvalitet.

I den här studien kommer vi att ställa frågor om välmående och hur du använder dig av musik.

För att delta i studien behöver du inte kunna spela något instrument, sjunga eller ha någon vana av att gå på konsert. Även om du inte lyssnar på musik så är dina svar viktiga för oss.

Information och kontaktuppgifter hittar du i ett separat blad som du gärna får behålla. Om du har frågor skriv till [kaja.korosec@ki.se].

Om du bestämmer dig för att delta så gör du så här:

1. Skriv under ditt samtycke på den här sidan.
2. Fyll i enkäten.
3. Lägg enkäten i kuvertet och lämna i din närmsta postlåda.

Om du i stället vill svara på frågorna digitalt så kan du göra det via denna länk:

https://survey.ki.se/musik_och_valmaende_studie/?qr=1&size=5&ecc=1



Med vänliga hälsningar,

Kaja Korošec, doktorand

prof. Eva Bojner Horwitz, huvudansvarig forskare

Samtycke till att delta i studien

Jag har fått skriftlig information om studien och har haft möjlighet att ställa frågor.

Jag får behålla den skriftliga informationen.

- Jag samtycker till att delta i studien "Musik, autism och välbefinnande".
- Jag samtycker till att uppgifter om mig behandlas på det sätt som beskrivs i forskningspersonsinformation.

Plats och datum	Underskrift
	Namnförtydligande

Frågorna nedan handlar om varför du lyssnar på musik.

1 = Stämmer inte alls

4 = Stämmer ganska bra

2 = Stämmer ganska dåligt

5 = Stämmer helt

3 = Stämmer varken bra eller dåligt

	Sätt ett kryss i den ruta som beskriver hur mycket nedanstående stämmer för dig:	1	2	3	4	5
1.	Jag brukar sätta på bakgrundsmusik för att göra stämningen trevligare.					
2.	När jag är hemma och ingen annan är i närheten, gillar jag att ha lite musik i bakgrunden.					
3.	Jag lyssnar på musik för att göra städning och annat hushållsarbete trevligare.					
4.	Jag lyssnar på musik för att piggnas till efter en jobbig dag.					
5.	När jag är utmattad lyssnar jag på musik för att piggnas till.					
6.	När jag är trött vilar jag genom att lyssna på musik.					
7.	Musiken har givit mig starka upplevelser.					
8.	Jag vill känna musiken i hela kroppen.					
9.	Jag känner mig fantastisk när jag lägger ner hela min själ i musiken.					
10.	För mig är musik ett sätt att glömma mina bekymmer.					
11.	När stressande tankar fortsätter att gå runt och runt i mitt huvud, börjar jag lyssna på musik för att hålla tankarna ifrån mig.					
12.	När jag mår dåligt försöker jag få mig själv på bättre humör genom att ägna mig åt någon trevlig musikrelaterad aktivitet.					
13.	När jag är riktigt arg känner jag för att lyssna på aggressiv musik.					
14.	När allt känns svårt hjälper det mig att lyssna på musik som uttrycker mina svåra känslor.					
15.	När jag är arg på någon lyssnar jag på musik som uttrycker min ilska.					
16.	Musik hjälper mig att förstå mina känslor.					
17.	Musik har hjälpt mig att ta mig igenom svåra upplevelser.					
18.	När jag är bekymrad över något, hjälper musik mig att klargöra mina känslor.					
19.	När allt känns svårt förstår och tröstar musiken mig.					
20.	När jag känner mig ledsen kan musiken trösta mig.					
21.	Jag lyssnar på musik för att få tröst när jag blir överväldigad av problem.					

(Saarikallio, 2012)

Frågorna nedan handlar om ditt välmående. Sätt ett kryss i den ruta som representerar hur ofta du upplevt och/eller känt nedanstående under den senaste månaden:

- 1 = Aldrig
 2 = En eller två gånger
 3 = Ungefär en gång i veckan
 4 = Ungefär två till tre gånger i veckan
 5 = Nästan alla dagar
 6 = Alla dagar

	Under <u>den senaste månaden</u>, hur ofta kände du ...	1	2	3	4	5	6
1.	lycka, glädje						
2.	ett intresse för livet						
3.	dig nöjd/tillfreds						
4.	att du har något viktigt att bidra till samhället						
5.	att du tillhör en gemenskap (tex en <i>grupp människor</i> eller ditt grannskap)						
6.	att vårt samhälle håller på att bli en bättre plats för människor som dig						
7.	att människor i grunden är goda						
8.	att det sätt som samhället fungerar på är logiskt för dig						
9.	att du gillar det mesta av din personlighet						
10.	att du klarar av att ta ansvar för ditt dagliga liv bra						
11.	att du har varma och tillitsfulla relationer med andra						
12.	att du upplevt saker som fått dig att växa som människa						
13.	att du har självförtroende vad gäller dina egna tankar och åsikter, och att du vågar uttrycka dem						
14.	att du är på väg någonstans i livet och att livet har en mening						

(C. Keyes et al., 2008)

- 1 = Mycket sällan
 2 = Ganska sällan
 3 = Ibland
 4 = Ganska ofta
 5 = Mycket ofta

	Under <u>den senaste månaden</u>, hur ofta kände du ...	1	2	3	4	5
15.	press att göra saker på ett annat sätt än hur du tycker att det ska utföras					
16.	dig fri att själv prioritera vad du ska göra					
17.	dig ensam när du varit med andra människor					
18.	att människor i din omgivning verkligen brytt sig om dig					
19.	att du inte lyckats med det du tagit dig för					
20.	att du har kunnat genomföra även mycket krävande uppgifter					

(Longo et al., 2016)

Följande frågor handlar om hur du använder musik och hur viktig den är. Med att "använda musik" menar vi allt från att lyssna på musik hemma, gå på konsert, dansa till musik, komponera, spela, sjunga eller på annat sätt ägna dig åt musik utifrån dina egna val.

Hur ofta använder du musik för att ...

- 1 – Aldrig eller nästan aldrig
- 2 – En eller några gånger om året
- 3 – En eller två gånger per månad
- 4 – Ungefär en till två gånger i veckan
- 5 – Nästan varje dag

Hur viktig är musik för dig för att ...

- 1 – Inte alls viktig
- 2 – Lite viktig
- 3 – Viktig
- 4 – Ganska viktig
- 5 – Väldigt viktig

		Hur ofta använder du musik för att ...					Hur viktig är musik för dig för att ...				
		1	2	3	4	5	1	2	3	4	5
1.	vara mer i kontakt med mina känslor										
2.	hantera känslor										
3.	framkalla positiva känslor										
4.	uppleva känslomässig katarsis (känsla av förnyelse, av rening)										
5.	uppleva bättre psykisk eller fysisk hälsa										
6.	känna mig mer avslappnad										
7.	utveckla mina färdigheter										
8.	känna att jag har uppnått något										
9.	få en känsla av mening										
10.	hjälpa mig att planera eller göra nya aktiviteter										
11.	bygga upp mitt självförtroende										
12.	utveckla min identitet										
13.	skapa en känsla av trygghet										
14.	få tid bara för mig själv										
15.	distrahera mig från problem eller bekymmer										
16.	bli uppslukad av den										
17.	känna gemenskap med andra människor										
18.	få en känsla av kontakt/samhörighet med mitt arv eller förflutna										
19.	bidra till ett bättre samhälle										
20.	uppleva en känsla av tillhörighet										
21.	känna socialt stöd										
22.	berika mitt sociala liv generellt										

PaMEW questionnaire

Frågorna nedan handlar om hur du hanterar dina känslor.

1 = Stämmer inte alls

4 = Stämmer ganska bra

2 = Stämmer ganska dåligt

5 = Stämmer helt

3 = Stämmer varken bra eller dåligt

	Sätt ett kryss i den ruta som representerar <u>hur väl</u> dessa påståenden beskriver hur du hanterar olika situationer.	1	2	3	4	5
1.	I situationer jag känner mig stressad eller orolig är det viktigt för mig att försöka förstå varför jag känner så.					
2.	När jag känner mig stressad eller orolig försöker jag förstå orsakerna.					
3.	Känslor av stress eller ångest hjälper mig att förstå viktiga saker om mig själv.					
4.	Att prata om mina känslor av ångest eller stress har hjälpt mig.					
5.	Känslor av ångest eller stress har hjälpt mig att förstå något om den situation jag var i.					
6.	I situationer där jag känner ångest eller stress försöker jag förstå vad detta indikerar om mig och min situation.					
7.	Jag försöker att inte uttrycka (visa) min stress eller ångest.					
8.	När jag känner mig stressad eller orolig döljer jag det, så att andra inte märker det.					
9.	Jag försöker ignorera känslor av stress eller ångest.					
10.	I alla situationer föredrar jag att inte uttrycka min stress eller ångest.					
11.	Jag visar inte min stress eller ångest för andra.					
12.	Jag försöker att inte referera till de känslor av stress eller ångest jag känner hos mig själv.					
13.	Det är svårt för mig att kontrollera min ångest eller stress och de dyker upp på sätt som jag inte gillar.					
14.	När jag är stressad eller orolig känner jag i allmänhet att jag har liten kontroll över mitt beteende.					
15.	Jag betar mig ofta på ett stressigt eller oroligt sätt, även om jag inte vill bete mig så.					
16.	När jag är orolig eller stressad visar jag min ångest även i situationer som inte är lämpliga för det.					
17.	Min funktionsförmåga (prestationsförmåga) minskar avsevärt när jag känner mig stressad eller orolig.					
18.	När jag är rädd eller känner mig orolig kan jag inte koncentrera mig på andra saker jag måste göra.					

(Roth et al., 2009)

<p>1. Hur viktig är musik i ditt liv?</p> <p><input type="checkbox"/> Inte alls viktig</p> <p><input type="checkbox"/> Lite viktig</p> <p><input type="checkbox"/> Viktig</p> <p><input type="checkbox"/> Ganska viktig</p> <p><input type="checkbox"/> Våldigt viktig</p>
<p>2. Hur många timmar ägnar du åt att lyssna på musik? Ange om du menar per dag, per vecka, per månad eller per år.</p> <p><i>Vänligen räkna tiden som du väljer att lyssna på musik (antingen som huvudaktivitet eller i bakgrunden när du gör något annat). Räkna inte med musik du råkar utsättas för, till exempel i en butik eller när en familjemedlem lyssnar på musik.</i></p> <p><input type="checkbox"/> Jag lyssnar på musik ungefär _____ timmar per _____.</p> <p><input type="checkbox"/> Jag väljer inte att lyssna på musik</p>
<p>3. Hur många år av formell musikutbildning (teori) har du?</p> <p><input type="checkbox"/> Inga</p> <p><input type="checkbox"/> _____ år</p>
<p>4. Hur mycket kan du om musikens struktur och teori?</p> <p><input type="checkbox"/> Ingenting</p> <p><input type="checkbox"/> Lite</p> <p><input type="checkbox"/> Ganska lite</p> <p><input type="checkbox"/> Ganska mycket</p> <p><input type="checkbox"/> Mycket</p>
<p>5. Hur många år av formell musikutbildning (praktik) har du?</p> <p><input type="checkbox"/> Inga</p> <p><input type="checkbox"/> _____ år</p>
<p>6. Hur ofta ägnar du dig åt professionellt musikskapande (t.ex. sjunger, spelar ett instrument, komponerar)?</p> <p><input type="checkbox"/> Aldrig</p> <p><input type="checkbox"/> Några gånger om året, eller mindre</p> <p><input type="checkbox"/> En eller två gånger i månaden</p> <p><input type="checkbox"/> En eller två gånger i veckan</p> <p><input type="checkbox"/> Nästan varje dag eller varje dag</p>
<p>7. Hur ofta övar du ett instrument eller sång?</p> <p><input type="checkbox"/> Aldrig</p> <p><input type="checkbox"/> Några gånger om året, eller mindre</p> <p><input type="checkbox"/> En eller två gånger i månaden</p> <p><input type="checkbox"/> En eller två gånger i veckan</p> <p><input type="checkbox"/> Nästan varje dag eller varje dag</p>

(Chin et al., 2018)

8. Hur ofta ägnar du dig åt musikskapande som hobby eller som amatör?

- Aldrig
- Några gånger om året, eller mindre
- En eller två gånger i månaden
- En eller två gånger i veckan

Nästan varje eller varje dag

9. Ditt kön: _____

10. Din ålder: _____ år

11. Vilken är din huvudsakliga sysselsättning?

Obs! Kryssa bara ett alternativ.

- Arbetar heltid
- Arbetar deltid
- Tjänstledig/Barnledig
- Studerar
- Ålderspensionär
- Sjuk-/aktivitetsersättning (förtidspension)
- Arbetssökande
- Hemmaman/fru
- Annat: _____

12. Vilken är din högsta avslutade utbildning?

Obs! Kryssa bara ett alternativ.

- Grundskola eller motsvarande
- Gymnasieexamen eller motsvarande
- Eftergymnasial utbildning, ej högskola/universitet
- Studier vid högskola/universitet
- Examen från högskola/universitet

13. Vilka neuropsykiatriska diagnoser har du?

Du får kryssa flera alternativ.

- Autism, Autismspektrumtillstånd
- ADHD form: _____
- Andra diagnoser: _____
- Jag vill inte svara
- Jag väntar på neuropsykiatrisk utredning
- Jag identifierar mig eller är självdiagnostiserad som _____

14. Har du några problem med din hörsel?

- Ja, (skriv vilka) _____.
- Nej

15. Vill du lägga till något om musik och ditt välmående? Skriv gärna ner dina tankar här:

16. Tycker du att frågorna var tydliga?

Var frågorna relevanta för hur du upplever kopplingen mellan musik och ditt välmående?

Finns det några frågor som du tycker borde omformuleras? Om ja, vilka?

Tack för att du svarade på enkäten!

10.5 Appendix E: Correlations, eigenvalues, and scree plot from Study III

Table A1: Correlations between items of PaMEW rated on importance

items	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	
1	..																						
2	.72**	..																					
3	.61**	.54**	..																				
4	.47**	.44**	.50**	..																			
5	.56**	.59**	.58**	.56**	..																		
6	.42**	.35**	.33*	.27*	.42**	..																	
7	.41**	.28*	.28*	.44**	.33**	.26*	..																
8	.31*	0.21	.32*	.56**	.37**	.36**	.69**	.81**	..														
9	.58**	.39**	.49**	.57**	.50**	.36**	.36**	.78**	.40**	..													
10	.43**	.34**	.32*	0.22	.33*	.38**	.40**	.37**	.40**	.50**	..												
11	.47**	.37**	.44**	.38**	.44**	.33**	.46**	.59**	.66**	.61**	.34**	..											
12	.43**	.32*	.42**	.42**	.39**	.33**	.66**	.65**	.61**	.34**	.70**	.49**	..										
13	.44**	.46**	.40**	0.17	.26*	.49**	.37**	.47**	.59**	.31*	.51**	.49**	.36**	.65**	..								
14	.40**	.37**	.41**	0.22	.29*	.37**	.32*	.42**	.58**	.47**	.49**	.36**	.58**	.39**	.39**	..							
15	.48**	.51**	.44**	0.23	.34**	.45**	0.21	.21	.39**	.39**	.38**	.36**	.58**	.31*	.51**	.51**	..						
16	.56**	.50**	.46**	.43**	.37**	.39**	.26*	.29*	.53**	0.24	.34**	.27*	.45**	.31*	.51**	.36**	0.23	0.19	..				
17	.36**	.31*	.33*	.48**	.47**	0.24	.47**	.57**	.51**	.30*	.41**	.54**	.37**	.36**	.36**	0.23	0.1953**	..		
18	.47**	0.24	0.19	.31*	.31*	0.17	.39**	.44**	.41**	.32*	.48**	.41**	.28*	.27*	.29*	0.12	.29*57**	.61**	..	
19	.37**	0.19	0.19	.41**	0.19	0.07	.57**	.59**	.57**	0.24	.36**	.39**	.29*	.28*	0.15	0.19	0.1957**	.40**	.42**	..
20	.49**	.52**	.44**	.32*	.55**	0.25	.37**	.35**	.52**	.27*	.42**	.43**	.49**	.44**	.45**	.47**	.58**	.47**55**	.67**	..
21	.42**	.42**	.35**	.45**	.44**	0.13	.39**	.46**	.59**	.39**	.45**	.36**	.49**	.54**	.49**	.36**	.50**	.50**35**	.55**	.67**
22	.39**	.28*	.27*	.39**	.38**	0.05	.55**	.53**	.51**	.35**	.45**	.49**	0.23	.35**	0.14	0.10	.78**	.48**	.64**	.58**	.57**

Note. The table shows Spearman's rank correlation coefficients.

** Correlation is significant at the 0.01 level (2-tailed)

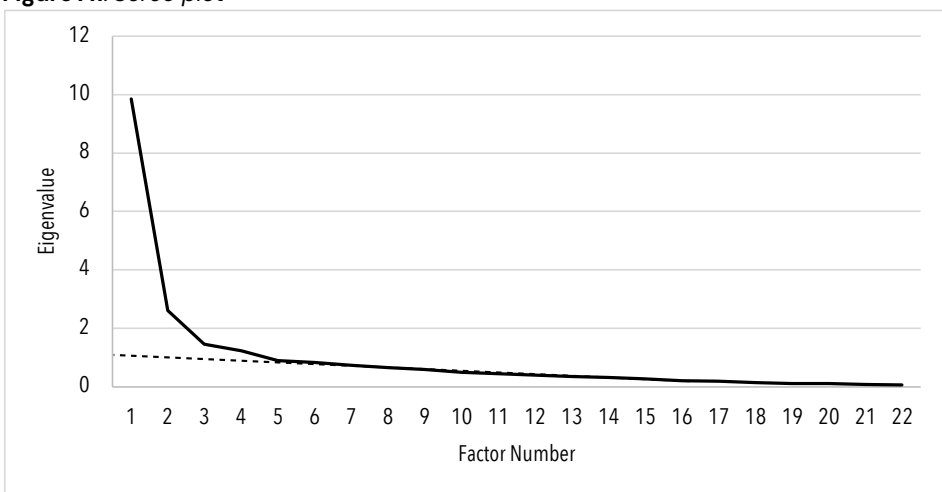
* Correlation is significant at the 0.05 level (2-tailed)

Table A2: Eigenvalues and explained variance

Factor	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total
1	9.861	44.824	44.824	9.507	43.213	43.213	7.363
2	2.602	11.826	56.650	2.255	10.250	53.463	6.720
3	1.460	6.638	63.288	1.166	5.299	58.762	6.666
4	1.234	5.611	68.899	.844	3.835	62.598	4.961
5	.899	4.085	72.984				
6	.823	3.739	76.723				
7	.733	3.333	80.056				
8	.647	2.943	82.999				
9	.587	2.670	85.669				
10	.495	2.249	87.919				
11	.449	2.040	89.959				
12	.400	1.816	91.775				
13	.346	1.575	93.350				
14	.315	1.431	94.781				
15	.271	1.231	96.012				
16	.207	.942	96.954				
17	.187	.848	97.802				
18	.137	.624	98.425				
19	.113	.513	98.939				
20	.105	.478	99.417				
21	.074	.338	99.754				
22	.054	.246	100.000				

Note. Exploratory factor analysis of PaMEW items rated on importance. Extraction Method: Principal Axis Factoring.

Figure A1: Scree plot



Note. The straight dashed line was added to help see the shift in the slope of the scree plot.

