

Meaningful Social Inclusion and Mental Well-being among Autistic Adolescents and Emerging Adults: A Community-Based Mixed Methods Study

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Abstract

Background: In the United States autistic people face high rates of co-occurring mental illnesses and premature death due to self-harm. Social inclusion may enhance mental well-being and resilience among autistic people. There is limited research on social inclusion as integration of interpersonal relationships and community participation or the impact of social inclusion on the well-being of autistic people. Additionally, little evidence exists regarding how autistic people prefer to be included in the community or form interpersonal relationships.

Objective: This protocol describes a project to develop a definition of meaningful social inclusion for autistic people, and to understand the relationship between meaningful social inclusion and mental well-being among autistic adolescents and emerging adults.

Methods: The project uses a sequential mixed methods design with a formative phase (Phase 1) that informs a survey phase (Phase 2) and concludes with a process evaluation of the community engagement process (Phase 3). During Phase 1 we will recruit 10 community partners (autistic adults and stakeholders) and conduct sharing sessions to co-create a survey of meaningful social inclusion and well-being. During Phase 2 we will recruit 200 participants (100 autistic adolescents and emerging adults and 100 caregivers) to complete the survey. During Phase 3 the community partners from Phase 1 will complete a survey on their experiences with the project.

Results: Ethics approval was obtained for this project in March 2023. We have recruited community partners and started the Phase 1 focus groups as of September 2023. Phase 2 and Phase 3 have not yet started. We expect to complete this study by March 2025.

Conclusions: This project has practical relevance and could result in concrete recommendations to facilitate meaningful social inclusion aligned with the lived experiences of autistic people, which can improve the quality of life of autistic adolescents and emerging adults.

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Original Manuscript

Meaningful Social Inclusion and Mental Well-being among Autistic Adolescents and Emerging Adults: A Community-Based Mixed Methods Study

Abstract

Background: In the United States autistic people face high rates of co-occurring mental illnesses and premature death due to self-harm, indicators of threats to mental well-being. Social inclusion may enhance mental well-being and resilience among autistic people. According to Simplican's (2015) model of social inclusion for people with intellectual and developmental disabilities, social inclusion is an interaction between community participation and interpersonal relationships. There is limited research on social inclusion as integration of interpersonal relationships and community participation among autistic people, or the impact of social inclusion on the well-being of autistic people. Additionally, little evidence exists regarding how autistic people prefer to be included in the community or form interpersonal relationships.

Objective: The long-term objective of this project is to improve social inclusion factors to support the mental well-being of people with autism. This protocol describes a community-based, mixed methods pilot study to develop a definition of meaningful social inclusion for autistic people, and to understand the relationship between meaningful social inclusion and mental well-being among autistic adolescents and emerging adults.

Methods: The project uses a community-based sequential mixed methods design with a formative phase (Phase 1) that informs a survey phase (Phase 2) and concludes with a process evaluation of the community engagement process (Phase 3). During Phase 1 we will recruit 10 community partners (autistic adults and stakeholders) and conduct sharing sessions to co-create a definition of meaningful social inclusion and a survey of meaningful social inclusion and well-being. During Phase 2 we will recruit 200 participants (100 autistic adolescents and emerging adults and 100 caregivers) to complete the survey. We will examine whether meaningful social inclusion predicts well-being given sociodemographic factors using ordered logistic regression, with well-being categorized as low, medium, and high. During Phase 3 the community partners from Phase 1 will complete a survey on their experiences with the project.

Results: Ethics approval was obtained for this project in March 2023. We have recruited community partners and started the Phase 1 focus groups as of September 2023. Phase 2 and Phase 3 have not yet started. We expect to complete this study by March 2025.

Conclusions: Using a community-based, mixed methods approach we intended to develop a definition of meaningful social inclusion for autistic people and understand the role meaningful social inclusion plays in the well-being of autistic people.

Keywords: autism; social inclusion; well-being; mixed methods; community-based

Overview

Mental well-being is a holistic conceptualization of mental health characterized by lack of symptoms of mental conditions and presence of positive feelings [1]. Compared to non-autistic people, autistic people often experience poor mental well-being [2], reduced quality of life [3], higher rates of suicidality and premature death due to suicide [4–6], and greater rates of mental health conditions [7–9]. World-wide, across decades, and across age groups autistic people have a twofold increase in mental health issues compared to people without autism. For example, rates of mental health issues among the general population in the United States hit an all-time high during the COVID-19 pandemic with an estimated 40% reported mental health challenges [10], while rates of co-occurring mental health issues among autistic adolescents and emerging adults during a 'typical' time period are as high as 82% [11]. The total size of the autistic population is unknown due to women, gender diverse people, and people of color being historically under-diagnosed and adult-diagnosed autistic people not being captured in prevalence rates. Even so, current estimates suggest that 1 in 44

children in the U.S. are diagnosed with autism [12]. The impact of poor mental well-being among people with autism impacts a substantial proportion of the U.S youth population. The burden of poor mental well-being in the autistic community increases with age [13,14] and shortens life expectancy [5].

A complex interplay of internal and external factors may explain disparities in mental well-being between autistic people and non-autistic people. While endogenous factors like genetics and neurology play a role, systemic, compounding stressors exogenous to the autistic person can also influence mental well-being. These modifiable, external factors include experiences like being bullied, masking, and feeling accepted. Autistic people experience higher rates of bullying compared to non-autistic people, and these experiences are linked to a greater risk of mental health issues [15]. Masking (also known as camouflaging) describes the efforts of autistic people to hide autistic traits and avoid negative experiences like bullying. Like bullying, masking is also associated with poorer mental wellbeing [16–19]. Conversely, when autistic people feel accepted they report better mental wellbeing. Higher levels of acceptance by non-autistic people are associated with lower levels of mental distress [20]. Contrary to stereotypes of autistic people, research confirms that interpersonal relationships are important to autistic wellbeing [20], and higher levels of community participation are associated with better mental well-being [21,22].

However, current research suggests that people with autism face individual-level social inclusion barriers [20,23], and are less likely to participate in the community [24] or form interpersonal relationships [25] compared to non-autistic people. Additionally, this literature primarily focuses on how autistic people should change to adapt to communities and other people, rather than on how communities and other people could adapt to include autistic people [26]. Because of not centering on the autistic experience, many of these studies focus on independence rather than autonomy and conformity to neurotypical standards as criterion for social inclusion and enforced normalization. Given the historic emphasis on children [7], it is imperative to focus on the mental well-being of autistic adolescents and emerging adults. Social inclusion may hold the key to implementing sweeping changes to improve mental well-being for autistic adolescents and emerging adults [23,27], particularly as identification with social groups is associated with higher levels of mental well-being among autistic people [1]. Social inclusion and mental well-being are research priorities for the autistic community [28], as is shifting the focus from ‘fixing’ the individual to addressing systemic issues external to the autistic person [29].

To the best of our knowledge, no study has integrated both aspects of social inclusion, included autistic voices, and focused on mental well-being. These two relationship contexts (interpersonal relationships and community participation) are instrumental in promoting adaptive mental and physical health among autistic people. Interpersonal relationships are important to autistic well-being [30], and higher levels of community participation are associated with better mental well-being [21,22]. This project fills a critical need to develop an understanding of meaningful social inclusion that includes both interpersonal relationships and community participation for autistic people and use this to understand the impact of social inclusion on mental well-being. Without an understanding of social inclusion factors shaping mental well-being, we cannot identify and implement effective and efficient community level change to improve well-being and quality of life of autistic people. In the absence of this knowledge, rates of co-occurring mental health conditions and the resulting diminished quality of life and premature deaths will remain high. Filling this gap with our study is critical as this information is necessary for policy and planning to improve mental health parity among autistic people.

Conceptual Framework

There is no agreed upon conceptual framework for social inclusion. However, the ecological model of social inclusion for people with intellectual and developmental disabilities by Simplican and colleagues provides a road map for understanding, measuring, and modifying social inclusion [31]. According to this model, social inclusion is defined as the interaction of interpersonal relationships (family, staff, friends, acquaintances, and partners) and community participation (leisure activities, political and civic activities, employment and education, access to goods and services, and religious and cultural activities).

Study Aims

The long-term objective of this project is to improve social inclusion factors to support the mental well-being of people with autism. Our goal is to address the problem of high rates of poor mental well-being by understanding how social inclusion is associated with this phenomenon. We focus on adolescence and emerging adulthood because this is a key developmental period for autistic people and a challenging time for mental well-being [32,33]. We will meet our goal through two specific aims:

Aim 1. Develop a working definition of meaningful social inclusion for autistic people living in the community that is co-created with the autistic community.

Aim 2. Delineate variation in mental well-being by social inclusion (interpersonal relationships and community participation) among autistic adolescents and emerging adults. Our hypothesis is that higher levels of social inclusion will be associated with higher rates of mental well-being.

Methods

All protocols and materials will follow the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) practice-based guidelines for research co-produced with autistic people [34].

Study Design

The project uses a community-based, sequential mixed methods design with a primary formative phase that will inform a subsequent secondary survey phase [35] a tertiary phase that consists of a process evaluation of the community engagement process. This design has been used successfully to capture community member experiences and influence policy changes [36]. In Phase 1 we will conduct sharing sessions with members of the autistic community to co-create 1) a working definition of meaningful social inclusion and 2) adaptation of a survey of social inclusion and well-being. In Phase 2 we will deploy the co-created survey in the autistic community to gather data on level of social inclusion and mental well-being. In Phase 3 we will evaluate the research processes. Findings from each phase will be integrated using triangulation with the autistic community: we will consider where findings from each part agree (convergence), result in complementary information (complementarity), or disagree (discrepancy).

Phase 1: Formative Research

Sharing sessions will be held virtually through Zoom, recorded, and transcribed for analysis. Sharing sessions will be facilitated through a series of open-ended questions developed to capture the lived experiences of meaningful social inclusion of autistic community members. Community members participating in the sharing sessions will be provided informed consent, a one-page description of the

study, the open-ended questions, the draft survey, and the background of the research team. Multiple meetings will be scheduled to 1. develop an understanding of meaningful social inclusion; 2. select and refine survey items; 3. review analysis results; and 4. determine the best ways to disseminate the results that align with the community's agenda. Over the course of the project, the timing, number, and the format of the meetings will be negotiated with community partners [37].

Phase 2: Adapted Survey of Social Inclusion and Mental Well-being

This aspect of the project follows a cross-sectional survey design in which data are captured at a single point in time. Autistic adults living in the community will report on social inclusion and mental well-being using adaptations of existing survey instruments created with community members during the sharing sessions. Data will be gathered through an anonymous online questionnaire hosted through the Qualtrics platform.

Phase 3: Process Evaluation

Satisfaction with community engagement will be measured by asking community partners at the end of the study to report on their experiences with the community engagement process.

Measures

Our main variables of interest are meaningful social inclusion and mental well-being. We will measure autistic identity and address potentially confounding variables via sociodemographic variables associated with social inclusion and mental well-being. Whenever possible, short form versions of instruments will be used to reduce the burden on participants. Items will also be adapted for completion by caregivers reporting on autistic adolescents and emerging adults in their care. Caregivers will be asked if the autistic adolescent and emerging adults in their care also completed the survey to create a subgroup of caregivers providing proxy responses and caregivers providing additional responses.

Autistic identity will be measured using current guidelines for establishing rigor to generalize to autistic people [38], through self-identification, age at diagnosis, diagnosis status (self vs. community) and the RAADS-14 [39]. This measure will be used for autistic people completing the survey. Caregivers will be asked if they care for an autistic adolescent or emerging adult, whether the autistic adolescent or emerging adult was professionally diagnosed, the current age of the person they provide care for, and the age the person was diagnosed.

Social inclusion will be assessed using adaptations of the Temple University Community Participation measure (TUCP) [40] for community participation and the Friendship Questionnaire for interpersonal relationships [41]. The TUCP contains 26 items that measure independent and self-directed community participation over the last 30 days in the following domains: community activities, employment, education, and volunteering. The TUCP asks 1. for the number of days in the past 30 days that the person engaged in a community activity (0–30), 2. if the activity is important to the person (1 = Yes or 0 = No), and 3. if the activity was done enough, not enough, or too much (–1 = Not enough, 0 = Enough, or 1 = Too much). Although initially created for use with people with complex and chronic mental health conditions, the TUCP has been used to assess community participation among autistic adults [24,42,43].

The Friendship Questionnaire (FQ) contains 35 items that measure multiple aspects of interpersonal relationships, like having best friends (“I have one or two particular best friends”) and characteristics

of friends (“In terms of interests, how similar to your friends do you tend to be?”). The FQ was designed for use with non-autistic and autistic adults [41].

Mental well-being will be captured via the Warwick-Edinburgh Mental Well-being Scale (WEMWBS)[44] and the Depression Anxiety Stress Scales-21 (DASS-21) [45]. The WEMWBS is a 14-item questionnaire measuring positive mental well-being via positive emotions, positive mental health, and psychological functioning. Each item is a positively worded statement (e.g., “I’ve been feeling good about myself”) with a 5-point Likert-type scale (1=None of the time to 5=All the time) indicating how often the statement applied to the person over the past two weeks. An overall score is calculated by totaling the scores for each item. Higher scores indicate higher levels of mental well-being. The WEMWBS has good content and construct validity, face validity, cross-cultural validity, test-retest reliability (intraclass correlation = .83), and internal consistency with Cronbach’s alpha ranging from 0.89-0.93 [44,46]. The WEMWBS has been used extensively to measure mental well-being among autistic adults [1,47]. The DASS-21 contains three self-report scales measuring depression, anxiety and stress. The DASS-21 has been found to function well as a measure of psychological distress among autistic people [48].

Sociodemographic variables include age, gender, race and ethnicity, rurality, income, education, employment status, co-occurring conditions, level of support need, and social functioning using the Social Functioning Questionnaire [49]. Gender, education, race and ethnicity, and co-occurring conditions are items derived from the National Survey on Health and Disability (NSHD). Gender will include options for gender diverse people. Employment status is based on items used in the 2021 Behavioral Risk Factor Surveillance System (BFRSS). Participants will be asked to estimate their household income and will be presented with multiple choice income options. Level of support need will be determined using items representing assistance needed for activities of daily living (ADLs) and instrumental activities of daily living (IADLs).

Rurality will be identified using the self-reported residence zip code of participant’s permanent residence and categorized based on Rural-Urban Commuter Area (RUCA) codes. RUCA codes classify U.S. census tracts on a continuum of rural to urban categories using patterns of daily commuting, population density, and measures of urbanization. Whether a participant originated from a rural community will be determined based on residence in a ZIP code associated with large rural, small rural, or isolated RUCA codes.

Satisfaction with community engagement will be measured by asking community partners who participated in the sharing sessions to complete a Community Engagement Questionnaire [37] describing their experiences with the project: 1. What has been your experience of participating in this research study? 2. How satisfied were you with your contribution to this research study? 3. How could your experience be improved? 4. Is there anything else you would like to add?

Study Participants and Recruitment

Participants will be recruited online through groups like the Autism Foundation of Oklahoma, Autistic Adults of Oklahoma, AutismStillwater.org, AutismOKC.org, tribal organizations, and state department health services caseworkers. Our community partners will leverage their community contacts in each of these groups for recruitment of participants for the study.

The Phase 1 intended participants are autistic adults and caregivers of autistic young people. The participants will be over 18 years old and reside in Oklahoma. For Phase 2 the intended subjects are 1) autistic adolescents (10-18 years) and emerging adults ages (19-25 years) residing in Oklahoma,

fluent in English, who have a community diagnosis of autism or meet the RAADS-14 cutoff for autism and 2) caregivers of autistic adolescents and emerging adults. Phase 3 participants are the same participants from Phase 1. Exclusion criteria include communication impairment and inability to consent.

For Phase 1 and Phase 3 we will recruit up to 10 autistic community partners to participate in the sharing sessions, and each partner will be paid \$400 for their participation. For Phase 2 we will recruit 100 autistic adolescents and emerging adults living in the community and 100 caregivers to complete the adapted survey. The most recent electronic survey deployed by the Autism Foundation of Oklahoma resulted in 270 respondents. Based on this, we believe 200 respondents is feasible. We will not incentivize the survey. Recent online surveys deployed by the research team that were incentivized (i.e., had a gift card raffle) resulted in a high number of bots and scammers completing the survey for monetary gain. This, combined with the relatively high number of participants the Autism Foundation of Oklahoma had on their surveys that were not incentivized, led the research team to drop the use of incentives.

Data Analysis

Phase 1: Formative Research and Phase 3: Process Evaluation

The data from the sharing sessions and community engagement questionnaire will be analyzed and interpreted using iterative inductive and deductive thematic analyses. Data will be developed via verbatim transcription of audio-recordings and analyzed using Dedoose and transformed into concept maps. The transcripts and texts will be reviewed several times and coded based on themes to reduce and display the data and draw conclusions. This process involves 1) familiarizing the research team with the data, 2) coding the data, 3) using the codes to develop initial themes, 4) reviewing the themes as a team, 5) defining the themes, and 6) writing up the results. Inductive codes will be based on emerging codes from the data, and deductive codes will be based on the literature and the open-ended sharing session and process evaluation questions. The credibility of the outcomes will be verified with community members to help ensure we capture the experiences of the community members.

Phase 2: Adapted Survey of Social Inclusion and Mental Well-being

We will examine whether meaningful social inclusion predicts well-being given sociodemographic factors using ordered logistic regression, with well-being categorized as low, medium, and high [50]. Models will be adjusted using participant characteristics to hold influences outside of social inclusion constant.

Power analysis. Qualitative data will be collected until saturation is reached. For quantitative analysis, logistic regression is a nonlinear model and thus probability at the mean and one standard deviation above the mean is necessary for the power analysis. These values are not available in the literature. We will develop these probabilities through this pilot study for use in a larger study. However, in general, a sample size over 100 with cell counts over ten is necessary for logistic regression.

Ethics Approval

Ethics approval for Phase 1 was obtained for this project in March 2023 from the Institutional Review Board of Oklahoma State University (IRB-23-46). Phase 2 and Phase 3 of this protocol will

be reviewed and approved and electronic informed consent or assent, where appropriate, will be attained before beginning any aspect of the study.

Results

We have developed Phase 1 materials, recruited community partners, developed a draft of the survey, and started the Phase 1 focus groups as of September 2023. Phase 2 and Phase 3 have not started yet. We expect to complete this study by March 2025.

Discussion

Expected Outcomes and Potential Impact

The expected outcomes of this protocol include a definition of meaningful social inclusion for autistic people, and an enhanced understanding of the role meaningful social inclusion plays in the well-being of autistic people. The research findings may generate new knowledge on meaningful social inclusion that addresses community level needs, and limited social inclusion among autistic adolescents and emerging adults. This project could advance our understanding of how to improve social inclusion and reduce poor mental well-being among adolescents and emerging adolescents with autism and advance our scientific understanding of facilitating social inclusion and integration of autistic people in communities.

Results will be integrated into the Autism Foundation of Oklahoma's training and awareness programs on, for example, employment, education, and criminal justice. Results also will be used to develop new training and awareness programs focused on social inclusion. The proposed study will provide preliminary data for developing interventions for testing (e.g., modifying the Autism Foundation of Oklahoma's current training program for employers to hire autistic people), and lay the groundwork for larger studies on enhancing quality of life and social inclusion factors like interpersonal relationships and community participation for autistic adolescents and emerging adults.

Potential Difficulties and Limitations.

We assume that social inclusion is associated with better mental well-being. However, it could be that better mental well-being is associated with higher levels of social inclusion – i.e., better mental well-being leads to more social inclusion. This is an issue of endogeneity – when the outcome variable is a predictor and not simply a response (simultaneity bias). We can test for this relationship using the Hausman test for endogeneity, and we also included variables that can be used as statistical instruments should we need to use an instrumental variables analysis to control for endogeneity.

Strength of the Study

Most research on social inclusion and autistic people focuses on exclusion rather than inclusion. This research is typically conducted on autistic children in primary school settings and often excludes the lived experiences of autistic people. This can result in outcomes and recommendations that do not align with the experiences and goals of the autistic community. As such, several strengths of this study lie in our focus on social inclusion rather than exclusion, our centering of the experiences of autistic adolescents and emerging adults, and our use of a community-based mixed methods approach to engage the autistic community. By centering the lived experiences of autistic people, we increase the likelihood that the outcomes of this project will have a meaningful impact on the wellbeing of autistic people.

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Authors' Contributions

DJM and MC designed the study protocol and wrote the manuscript. DN provided content experience. EP and DJ developed the community member engagement materials. DJM, EP, AG, and CL are leading community member engagement and focus groups. DJM, MC, EP, CL, DN, and AM are developing the survey. CL programmed the draft survey. All authors provided input for the study protocol and reviewed the manuscript and will participate in implementing the study protocol.

Conflicts of Interest

None declared.

Abbreviations

AASPIRE: Academic Autism Spectrum Partnership in Research and Education

ADL: activities of daily living

BFRSS: Behavioral Risk Factor Surveillance System

DASS-21: Depression Anxiety Stress Scales-21

FQ: Friendship Questionnaire

IADL: instrumental activities of daily living

NSHD: National Survey of Health and Disability

OCAST: Oklahoma Center for the Advancement of Science and Technology

RAADS-14: Ritvo Autism & Asperger Diagnostic Scale

RUCA: Rural-Urban Commuter Area

TCUP: Temple University Community Participation measure

WEMWBS: Warwick-Edinburgh Mental Well-being Scale

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Supplementary Files

Multimedia Appendixes

Oklahoma Center for the Advancement of Science and Technology grant reviewer comments.
URL: <http://asset.jmir.pub/assets/de477c38108020d7eb253ba9b166b057.pdf>