

Discovering Capabilities for Community Living and Participation for Older Adults with Autism Spectrum Disorder: A Mixed –Methods Systematic Review Protocol

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Background and aims: Older autistic adults are an under-researched population regarding their community living capabilities by their intrinsic or inherent capacities. This mixed methods systematic review protocol proposed to synthesize the evidence on types of intrinsic capacities older autistic adults report for maintaining, restoring, or augmenting their community living outcomes. **Methods:** We propose to search for published articles from a variety of electronic databases including PsycINFO, Academic Search Complete, Medline, PubMed and manual searches. Articles published in English language journals from January 2010 to January 2025 will be included for review. Inclusion criteria will be articles published between January 2010 and January 2025 in English, and on older autistic adults who are 55 years or older (specific diagnosis, inclusive of Pervasive Developmental Disorder-Otherwise not Specified, Asperger's Syndrome) (see APA, 2013); (2) moderate to high functioning, (3) self-reported their community living capabilities in life situations, (3) known community living arrangement (independent, family and/ assisted). Our exclusion criteria will be older autistic adults; a)with advanced dementia or other aging related cognitive decline; b) proxy or informant reporting, (c) unknown or institutionalized living arrangements. The study will follow the guidelines of Preferred Reporting Items for Systematic Reviews and Meta-Analysis 2020 (PRISMA 2020). For the risk of bias and

quality assessment, review will apply the Mixed Methods Appraisal Tool (MMAT) (Johnson & Onwuegbuzie, 2004). A narrative synthesis approach will be employed to integrate findings from both quantitative and qualitative studies that meet the inclusion criteria..

Results, conclusion and implications. We expect the mixed methods systematic evidence synthesis to provide a nuanced understanding of autistic community living strengths overlooked by the historical bias towards deficit oriented studies. Findings will likely suggest that older autistic adult inclusive community living is more likely with recognition and utilization of their intrinsic capacities with customization to their personal and life situations.. Informed by the systematic review findings, we envisage prospective efficacy, dissemination, and utilization studies on capabilities for the inclusive community living of older autistic adults framed on their intrinsic capacities.

Keywords: *Older autistic adults, intrinsic capacities, life situations, capabilities, community living outcomes*

Introduction

There remains a significant gap in our understanding of the real-world community living and participation priorities of older autistic adults (den Houting, 2020). Even less is known about their capabilities for inclusive community living and participation (Lerner et al., 2020).

Autism is characterized by “persistent deficits in social communication and social interaction across multiple contexts” and “the presence of restricted, repetitive patterns of behavior, interests or activities” (American Psychiatric Association, 2013, p. 31), These characteristics contribute to an elevated risk of social exclusion for autistic individuals.

Importantly, autistics advocate for and prefer a strengths rather than deficit model about their community living wellbeing, seeking to be “accepted or appreciated as an autistic person, with Autism positively recognized and accepted by others and the self as an integral part of

that individual” (Cage et al., 2018, p. 424). This perspective aligns with a growing recognition of the diverse atypical intrinsic capacities of autistic individuals in social skills, attention switching, attention to detail, communication, imagination, and interest in numbers, dates, patterns, and categories of things (World Health Organization (WHO), 2020). The realization of these capacities into functioning is contingent upon the presence of enabling environments and opportunities (Daniels, 2010; Mpofu & Wilson, 2004). Yet, little is known about life situation capabilities of older autistic adults for converting their intrinsic capabilities into community action performances inclusive community living and participation.

Importance of the problem . Presently, autism research increasingly focuses on factors of “direct impact on the daily lives of autistic people and their families, especially related to services and supports, and with underserved populations” (Pellicano, 2018, p. 82). Within this framework, life situation capabilities such as opportunities for positive appraisal, tangible or material support and belongingness support would bridge their intrinsic capacity and actual performance for improved community living (see Figure b.1).

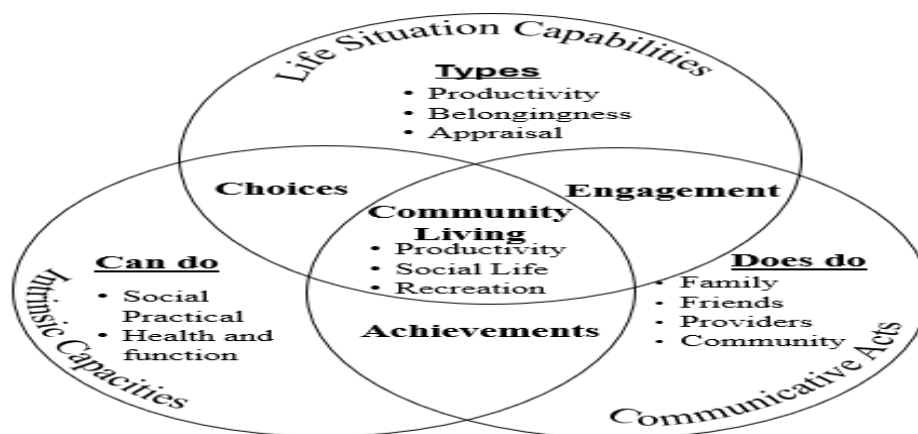


Figure 1. Intersection of capabilities, intrinsic capacities and community actions

As Daniels (2010) argues, what individuals are capable of doing does not automatically translate into what they actually do. Much depends on capabilities as opportunities to be who

they can be with others in their lives. Yet the capabilities of aging autistic adults for realizing their full community inclusion remain unexplored while critically important for translating their intrinsic capacities into community living actions.

The Need. The population of American autistic adults is estimated to reach 770,000 by year 2030. Older autistic adults represent one of the most at-risk groups for exclusion from community living among individuals with disabilities (Jones et al., 2019). This increased vulnerability is partly attributable to their status as a “lost generation”, individuals who grew up during a time when autism was less understood and frequently undiagnosed (Lai & Baron-Cohen, 2015). The World Health Organization (WHO) International Classification of Functioning, Disability and Health (WHO-ICF, 2001) defined participation as a person’s “involvement in life situations” (p. 10).. However, there is a notable lack of research on how the challenges of aging intersect with the lifelong characteristics of autism to shape community living outcomes. As Piven et al. (2011) underscore, little is known about “how the disabilities and dependencies that result from aging interact with those resulting from Autism” (p. 2151). This This systematic review aims to address this gap by advancing scientific knowledge on the life situation capabilities for improving old autistic adults inclusive community living.

The Target Population. The primary target population for this exploratory and discovery research is older autistic adults (age 55 years and above). Autism Spectrum Disorder (ASD) is a high incidence developmental disorder affecting 1 in 31 individuals (Centers for Disease Control and Prevention, 2023). It “manifests in varying levels of severity, affecting development throughout the lifespan” (Chapman 2020, p. 800). More importantly, there is a dearth of information about the life situation capabilities of older autistic adults for community living (Howlin et al, 2013; Stewart et al, 2020). This gap is further compounded by the influence of social determinants, such as age, race/ethnicity, gender, and living

arrangements et cetera, which may mediate how intrinsic capacities are translated into actual community living actions.. For example, in the United States, people of racial/ethnic minority backgrounds, and females are more likely to be diagnosed with Autism in adulthood, compared to their white, male peers (Green et al., 2019; Mandell et al., 2007). Despite these disparities, little is known about how their intrinsic capacities can be leveraged to support inclusive community living.,

Camouflaging. To self-manage their social environments with less need to hide or disguise their true interests and abilities for a productive social life, older autistic adults acquire camouflaging behaviours throughout their life span. As Verhoeff (2015) notes, “autism cannot avoid being related to the cultural norms of a social, empathic and engaged individual” (p.21). However, what is problematic is the bias against autistic behaviours imposing a life long burden on how they can express themselves ‘at different ages and for different genders and cultures” (Williams et al., 2014, p. 225). While older autistic adults have a lived culture over many years transacting both the mainstream culture and their autism community culture, their intrinsic capabilities negotiating these disparate world go unrecognized (Chapman 2021; Milton, 2012). This is despite the emerging evidence to suggest that autism acceptance benefits not only the individual but also their families, and service providers (Cage, 2020; Cage et al., 2017; Da Paz et al., 2018).

The present study. To address this knowledge gap, this study proposes a mixed methods systematic review to; 1). characterize older autistic adults’ intrinsic capabilities for their improved community living and 2). Determine how older autistic adults’ life situations hinder or facilitate use of their intrinsic capabilities for their priority community living outcomes. Findings from this review will provide study directions on priority community living of older autistic adults, translating their intrinsic capabilities into community living choices and actions. Study findings will also provide guidelines for product development,

dissemination, and utilization studies on inclusive community living and participation of older autistic adults.

Method

Research Design

This study adopts a mixed methods systematic review approach to aggregate and synthesize the evidence on types and use of intrinsic capabilities by older autistic adults for their improved community living. A mixed methods systematic review combines qualitative and quantitative approaches to deepen the interpretive synthesis of studies that is possible with either of the approaches alone (Bryman, 2007). Mixed methods systematic reviews have the advantage to apply a well defined procedures for defining what information in a report will constitute a finding and resolve issues related to content (what a finding says), context (what information in a report is most relevant to understanding a finding) and form (how a finding-in-context is to be expressed) (Sandelowski et al., 2012, p. 1429). Moreover, this study follows the guidelines of Preferred Reporting Items for Systematic Reviews and Meta-Analysis 2020 (PRISMA 2020).

Inclusion and exclusion criteria

The included articles will be those that published between January 2010 and January 2025 in English. Searches will implement in a variety of data bases including PsycINFO, Academic Search Complete, Medline, PubMed et cetera. The included articles will be on older autistic adults who are 55 years or older (specific diagnosis, inclusive of Pervasive Developmental Disorder-Otherwise not Specified, Asperger's Syndrome) (see APA, 2013); (2) moderate to high functioning, (3) self-reported their community living capabilities in life situations, (3) known community living arrangement (independent, family and/ assisted). Our **exclusion criteria** will be older autistic adults a)with advanced dementia or other aging

related cognitive decline; 2) proxy or informant reporting, (b) unknown or institutionalized living arrangements.

Search strategy

Key concepts for including studies in this systematic review are: ‘older adults’, ‘autism’ “autistic”, community living, capabilities, moderate to high functioning. Table 1 presents the summary of search terms to be used to extract the studies for inclusion.

Table 1. Search terms

Key Concepts*		Search Terms*	
	Autism Spectrum Disorder	OR	“Autistic” OR “Autistic disorder” OR “Asperger’s Syndrome” “OR “Pervasive Developmental Disorder-Otherwise not Specified” OR “Childhood Degenerative Disorder” OR “Atypical autism””
AND	Older adults	OR	“Older adult” OR elderly OR aging OR geriatric * OR “older people” OR “Aged 65” OR over 65” OR “65 years” OR “65<” OR “65yr OR “65” OR “elderly.” OR senior * OR aged or older elder or geriatric* or “elderly people” OR “older people”
AND	Community living and participation	OR	“Productiveness” OR “Social life” Or “Recreation” OR “Civic activity”, OR “Family life” OR “Friendships” OR “Virtual community” OR “Social networking” OR “social interaction”, OR “social ties” OR “social contact” OR “social connection” OR “Tangible support” OR “Appraisal Support” OR “Belongingness support”
AND	Intrinsic capacities	OR	“Social abilities” OR “Practical abilities” OR “Health and Function” OR “Atypical abilities” “OR “Camouflaging”

AND Life situation

OR “Living arrangements”, OR “Housing”
OR “Employment”, OR “Social Security
Disability Insurance” ,OR
“Transportation” OR
“Health Insurance” OR “Food security”

** This symbol signifies unlimited searches of diverse forms of a word, created by attaching various suffixes.*

Data Selection and Collection Process

The processes of article selection will be conducted in three consecutive steps including title screening, abstract screening, and full article screening in RefWorks. The second listed author (RZ) will employ text extraction techniques by using Python for criteria compliance. The first and third listed authors (EM, CY) authors will verify the final extraction met the criteria. The other co-authors will independently verify if the final extraction met the criteria, and discrepancies will be resolved by consensus.

Search Outcomes. Based on the final section, a PRISMA 2020 flow diagram of included studies will result for the Table of study characteristics (by authors names, publication year and country, participant characteristics (including age and sample size), types of intrinsic capacities, community living, life situations, methods, comparisons, and findings.

Risk of Bias and Quality Assessment

The Mixed Methods Appraisal Tool (MMAT) (Johnson & Onwuegbuzie, 2004) will be employed to verify the risk of bias and quality assessment of the included studies. The MMAT tool is comprised of 5 domains including “qualitative, quantitative randomized controlled trials, quantitative non-randomized, quantitative descriptive, and mixed methods” to appraise the methodological quality of the studies (Hong et al., 2018). The MMAT ensures interpretive coherence and dependability of the included studies (Hong et al., 2018). Each of

the included studies will be appraised for bias on five criteria ranging from low quality (high risk of bias, MMAT 0 score) to high quality (low risk of bias, MMAT 5 score). In addition, The MMAT levels of evidence will be utilized to further appraise each study's research method quality of evidence from level 1 (lowest) and to level 7 (highest). Only the studies that rate as moderate to high quality with low bias will be included for review.

Data Synthesis

A narrative synthesis (Popay et al., 2006) will be employed to identify common findings and themes from multiple studies. Narrative synthesis is particularly suited to mixed method review of studies that seek to integrate findings from quantitative and qualitative studies (Levac et al., 2010). The second listed author (RZ) will conduct the initial thematic analysis in Python coalescing the evidence from the heterogeneous studies. The third listed author (CI) will independently replicate evidence by recurring themes and variables, offering a concise summary of key findings and then analyzing variations across studies. The first listed author will guide the interpretation of findings to the studies' capabilities framework with substantiating these with pertinent quotations from the field. The other co-authors will appraise the validated and collated evidence for confirmation of results.

Results

We expect to result with a mix of studies that employed qualitative interviews and focus group discussion, others of a quantitative nature including cross-sectional design studies, Randomized Controlled Trial (RCT), and studies used mixed methods for the analysis. We shall present the results in three tables: evidence trends across the total sample of all studies, contextual factors, and personal factors.

Discussion and conclusion

To our knowledge, there is no previous mixed methods review trending evidence on intrinsic capacities utility for community living outcomes of older autistic adults by their life situations. Our proposal to use of mixed methods systematic is a particular strengths by the inclusiveness of studies and also prospects for a “syntheses of evidence that will be accessible to and usable by a wider range of consumers” (Sandelowski et al., 2013, p. 1428). Prospectively, this mixed methods review we will provide the evidence for studies to construct a taxonomy of capability priorities of older autistic adults by their age cohorts for their improved community living and participation outcomes by their intrinsic capacities. The study will also provide the much preliminary evidence on how older autistic adults’ personal factors and life situations related their community living to inform intervention studies with this vulnerable populations. Findings will yield guidelines for a holistic framework for older autistic adults utilize their intrinsic capacities to maintain, restore and/or augment their community living outcomes.

In conclusion, this mixed methods systematic review protocol provides an outline and framework for further systematic review that fills the research gap in intrinsic capacities utilization by older autistic adults for their improved community living. We shall discuss the findings for trends in the evidence on intrinsic capacities supported community living at older adulthood with autism, with autism as a different rapidly becoming the new normal discourse important the community health wellbeing of autistic people. Synthesizing the evidence on older autistic adults intrinsic capacities is critical for researchers, stakeholders, practitioners, and policymakers to improve community living services inclusive of older autistic adults. Finding may contribute to the further intrinsic capacity oriented innovations to support the community living outcomes of older autistic adults.

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