# Healthy Aging and Older Adults with Autism: A Scoping Review

Mary Stringfellow, MSW Candidate

School of Social Work, The University of Texas at Arlington

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Supervising Committee

Dr. Noelle Fields, Supervising Professor

Dr. Keith Anderson

Dr. Kathy Lee

#### Abstract

Autism Spectrum Disorder (ASD) is a lifelong diagnosis. While numerous studies have examined the effects of this disorder throughout childhood, not many have considered older adulthood and the differences between the neurotypical population. Likewise there is an abundance of literature regarding healthy aging. Yet the literature is sparse regarding the intersections of older adulthood and ASD. The purpose of this scoping review was to examine the state of literature regarding older adults with ASD and healthy aging, utilizing the framework conceived by Arksey and O'Malley: identify the research question; identify the relevant studies, study selection; chart the data; and collate, summarize and report the results. The specific domains of healthy aging considered include: physical health, mobility, mental health, cognition and memory, and social connectedness. Results showed that for articles published in English for the past ten years, not much exists concerning older adults with ASD and healthy aging. The most studied aspects of healthy aging for this population include: social connectedness and cognition and memory. This study elucidates the need for additional research.

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# Healthy Aging and Older Adults with Autism: A Scoping Review Chapter 1

#### Introduction

Globally, one in 270 people is thought to have an Autism Spectrum Disorder (ASD) (Autism Spectrum Disorders, 2021). ASD is a collection of disorders characterized as a developmental condition that includes problems in communication and behavior, and social situations, which can vary in presentation and extent (National Center on Birth Defects and Developmental Disabilities, 2020). While a majority of research pertains to children with ASD, there are fewer of adults. The majority of these studies pertain to changes experienced by those with an ASD diagnosis throughout the various life stages. There are also a number of studies that consider differences and similarities between older adults with an ASD and those without.

The research into what supports are needed to help those in older adulthood living with ASD, is even smaller. Research regarding older adults with ASD, from a healthy aging perspective is lacking. This scoping review identified existing research into the intersection of Autism, older adulthood and healthy aging. It also discussed the method of study for this scoping review.

# **Autism Spectrum Disorder**

The word "Autism" was first used in the early 1900s by a German physician, Eugene Bleuler, to describe a particular state of schizophrenia in which the afflicted child did not dwell in reality but existed in his or her own solitary fantastical world (Evans, 2013). It was thought to be a disease of the mind and "was the result of childhood psychoses or psychodynamic disturbances of parent-child relationships" (Mintz, 2016, para. 1). In the 1960s, practitioners began to view Autism in a different light and no longer believed that the patient's fantasy life

dominated reality in his or her mind, but indeed quite the opposite (Evans, 2013). Autism was then thought to be a developmental problem characterized by issues with communication and social integration which surfaced during childhood (Evans, 2013). In 1980, Autism was included in the Diagnostic and Statistical Manual or DSM-3, for the first time under the umbrella main classification of 'pervasive developmental disorders' instead of the 'childhood schizophrenia' which was completely eliminated (American Psychiatric Association, 1980; Evans, 2013).

Since its inclusion in the DSM, what exactly constitutes a diagnosis of Autism has undergone many iterations. The latest, DSM-5, specifies that to in order to justify a diagnosis of ASD, one must persistently have deficiencies in the following three areas of "social communication", including: "social-emotional reciprocity", "nonverbal communicative behaviors used for social interaction", and "developing, maintaining, and understand relationships" (National Center on Birth Defects and Developmental Disabilities & Centers for Disease Control and Prevention, 2020, para. 2). In addition, one must also show deficiencies in two of the following four areas: "stereotyped or repetitive motor movements, use of objects, or speech"; "insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior"; "highly restricted, fixated interests that are abnormal in intensity or focus"; and/or "hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment" (National Center on Birth Defects and Developmental Disabilities & Centers for Disease Control and Prevention, 2020, para. 3).

Early on, despite the belief that this condition was considered a disease of the mind, psychoanalysis was mostly ineffective and more often than not, the patient was relegated to an institutional life unless he or she was considered 'high functioning' (Thompson, 2013).

However, in the late 1960's and early 1970's, some suspected that this condition may instead be

biological in nature (Thompson, 2013). At the same time, some researchers began to discover that a new intervention, behavioral therapy, when applied at an early age, was effective in helping these children to learn (Thompson, 2013). This new understanding paved the way for a change in beliefs, thus, research grew considerably (Thompson, 2013).

Currently the United States Department of Health and Human Services has identified ASD as "a critical public health issue that deeply impacts millions of Americans" (Digital Communications Division, 2017, para. 1). A number of acts were passed to create and support research and provide supports throughout HHS (Digital Communications Division, 2017). A number of programs were also created to help providers and families to identify ASD in children (Digital Communications Division, 2017). Almost all of these are exclusively geared towards children and adolescents.

Within the past decade, research concerning other life stages of those living with an ASD, has increased. Regarding older adults with an ASD, studies have shown a number of findings regarding life expectancy, and changes in mental and physical health, and cognition. One important consideration is that adults on the spectrum typically have a shorter average lifespan (Hirvikoski et al., 2016). This reduction is attributed to increased number of accidents due to gait and other mobility problems as well as higher incidences of comorbidities (Smith DaWalt et al., 2019). Older adults with an ASD, typically have more comorbidities than those without (Smith DaWalt et al., 2019). Research has shown that the older adult ASD population has higher rates of heart disease, lung conditions, epilepsy, Parkinson's, and low bone density (Smith DaWalt et al., 2019). As in other life stages, the older adult with an ASD has more instances of depression and anxiety when compared to the general population (Hand et al., 2020). While this

information is important in understanding the needs of an older adult with an ASD, there is noticeable lack of data regarding healthy aging and those with this disorder.

# **Healthy Aging**

Research into aging as a major area of interest among various industries or disciplines is fairly recent. In 1900, the combined average life expectancy in the United States for all persons was only 47.3 years (Nchs data visualization gallery - mortality trends in the united states, 2020). By 1930, it had increased to 59.7 years (Nchs data visualization gallery - mortality trends in the united states, 2020). Many factors contributed to this increase in longevity, such as "improvements in public health and social determinants of health" as well as advances in medicine (Lindsay et al., 2014, para. 1). Advances in public safety include: vaccinations, food and water quality, auto industry safety standards, worker safety, etc. (Center for Disease Control and Prevention, 1999). In 2018, the average life expectancy in the United States was just under 79 years of age (Xu et al, 2020). As people began to live longer lives, researchers began to focus on quality of life. As a result, healthy aging has become a widely researched topic.

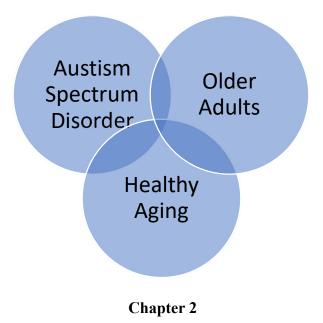
Healthy aging, as defined by the World Health Organization (2020), "is the process of developing and maintaining the functional ability that enables wellbeing in older age" (para. 3). The World Health Organization (2020) equates function ability to: "meet their basic needs"; "learn, grow and make decisions"; "be mobile"; "build and maintain relationships"; and "contribute to society" (para. 4). The World Health Organization also takes into consideration one's environment and how it interacts with one's capabilities (Ageing: Healthy Ageing and Functional Ability, 2020). The World Health Organization considers environment as one's: community, society, domicile, social policies, etc. (Ageing: Healthy Ageing and Functional Ability, 2020). Other factors which influence one's capability include diversity and inequality,

the World Health Organization maintains (Ageing: Healthy Ageing and Functional Ability, 2020). While Rowe and Kahn's concept of successful aging has been studied for almost three decades, the World Health Organization's healthy aging framework takes into account the unique strengths and needs of persons with disabilities whereas Kahn and Rowe's model excludes them (Ageing: Healthy Ageing and Functional Ability, 2020; Rowe & Kahn, 1997). Applying this healthy aging framework to older adults who have an ASD is unique because it may help identify gaps in existing supports and services that are needed to bolster these persons' well-being throughout later life. This is also important in that research has shown that persons with an ASD overall have a shorter life expectancy (Hivikoski et al., 2016).

Yet, there is limited research regarding ASD from this perspective. All persons, regardless of any conditions or disabilities, have the right to healthy aging. This gap in literature must also be addressed as it is important to gain an understanding of what is needed to not only help today's older adults with an ASD but to prepare for the much larger, and younger cohorts as they transition into older adulthood. This knowledge is particularly relevant to the field of social work, as it will assist the profession in advocating on behalf of this population to get those needed services and to provide those relevant supports as well. Thus, the purpose of this study is to examine the intersection of ASD, older adults and healthy aging (see Figure 1). The proposed thesis is to conduct a scoping review to identify the breadth and depth of research regarding older adults with an ASD and healthy aging. Following the methodological guidance for conducting a Joanna Briggs Institute (JBI) scoping review, the "PCC" pneumonic (population, concept, and context) was used to construct the primary research question (Peters et al., 2020):

What is the current state of literature regarding healthy aging among older adults who have an ASD?

Figure 1 Purpose of the study: Intersection of Autism Spectrum Disorder, older adults, and healthy aging



# **Background Literature**

Life expectancy for those with an ASD is much shorter than those who are neurotypical (Guan & Li, 2017). Guan and Li's (2017) research showed that the average age of death for those with an ASD was just over 36 years' of age. This number is startling when compared to the average age of death of the general population for that same period, was approximately 72 years' of age (Guan & Li, 2017). Yet, research regarding older adults with an ASD is limited. Within the available research, studies vary in terms of gender, age, education, age of first diagnosis of Autism, and the presence of an intellectual disability or lack thereof. The sample sizes also vary widely. One limitation in the extant research is that the assessment tools regarding executive function, memory, etc, often vary across studies, which can produce a variance in or conflicting results in outcomes. Moreover, according to Robinson (2019), "we do not know the size of our adult autistic population, and we do not know if the outcome data we have is broadly applicable,

or only applies to the subset profiled by the studies" (p. 271). In spite of these limitations, there is a need to more closely examine the available research on older adults with Autism.

In order to better understand the intersection of healthy aging and Autism and following the World Health Organization's framework, this chapter focused on five key areas: physical health, mobility, mental health, cognition/memory, and social connectivity among older adults with an ASD.

#### **Physical Health**

According to the World Health Organization, one aspect important to healthy aging is one's physical capacities or health (Ageing: Healthy Ageing and Functional Ability, 2020). When compared to the neurotypical older adult, persons on the autism spectrum have more physical health challenges. For example, a recent study comparing a sub-sample of Medicare clients with a diagnosis of an ASD (n = 4,700) against a larger sample of the same age cohort (n = 4,700) = 47,000) found that in almost every area measured, the adults on the autism spectrum fared much worse on physical health outcomes than those without Autism. Those on the spectrum were 18.9 times more likely to have epilepsy (Hand et al., 2020). A systematic review conducted by Patra (2016) related to ASD in the older adult population indicated that the comorbidity of epilepsy may lead to an increase in probability of a premature death (Patra, 2016). Hand's study also indicated that those on the spectrum were 5.2 times more likely to have gastrointestinal issues and are more likely to have heart disease and high blood pressure than those without Autism (Hand et al., 2020). Additionally, there was a higher prevalence of asthma and other respiratory illnesses and infections among persons with Autism (Hand et al., 2020). In Patra's review, older adults with an ASD were also more likely to suffer from low bone density (Patra, 2016).

#### **Mobility**

The World Health Organization also identifies that one's mobility or ability to walk is included in the one's functional ability (Ageing: Healthy Ageing and Functional Ability, 2020). In Hand et al.'s (2020) study, results indicated that those on the spectrum were 6.1 times more likely to suffer from Parkinson's disease. Parkinson's disease is known to affect one's mobility, and as one ages, its affects are amplified (Matinolli et al., 2009).

In a literature review, Bhat et al. (2011) found that people with an ASD are more likely to have problems with motor impairments, including balance and mobility. Another study found that adults with an ASD with ages ranging from 40 to 65 years' old, performed poorly in comparison to a similarly aged group regarding assessments in motor skills functions (Linke et al., 2020).

#### **Mental Health**

Another important aspect to healthy aging is one's psychological status. In general, people with an ASD typically have higher instances of mental illness, including depression, hostility, and anxiety (Lever & Geurts, 2016), as well as higher rates in mood and anxiety disorders, personality disorders, and psychotic disorders (Hand, 2020). Older adults with Autism reportedly have more suicide attempts than those without and may encounter more risk factors for psychological suffering, as a result of ongoing issues with socialization and occupations, the loss of support as a result of the deaths of familial caregivers, etc. (Oakes, 2020). However, one study showed that as persons with an ASD transition throughout the various life stages, there are no significant changes in anxiety or depression (Uljarević et al., 2019). Additionally, older persons with Autism had lower instances of substance abuse than those without (Hand, 2020).

# **Memory and Cognition**

Another factor of healthy aging is one's cognition and memory. Two studies had very similar results in regards to memory and intelligence. However, a third study, a bit older than the first two, showed conflicting results. In their study, Tse and colleagues (2019) found no significant difference in working memory between the ASD and control groups. Similarly, Spek and colleagues (2017), found the same result. However, Geurts & Vissers (2011) found that the group with Autism did not perform as well as the control group in respects to working memory. Research by Tse et al. (2019) also showed no discernable difference on "auditory memory, visual memory, immediate memory and delayed memory" (p. 4129). Geurts & Vissers' (2011) study found similar results.

Regarding intelligence, research suggests that there was no discernible difference between the ASD group versus the control group in verbal comprehension and perceptual reasoning or perceptual organization (Spek et al., 2017; Tse et al., 2019). Moreover, persons with ASD perform as well in processing speeds in comparison to the control groups (Spek et al., 2017; Tse et al., 2019). However, Geurts & Vissers (2011), found no major difference in results of processing speed between the two groups. Another study found that overall, there was no difference between the autistic and control groups in processing speed, but the autistic group did require more time to finish complex tasks (Davids et al., 2016). This study postulated that older adults with an ASD may have more issues with executive functions than those without (Davids et al., 2016).

#### **Social Connectivity**

The World Health Organization also considers social connectivity, such as the ability to develop and or maintain friendships, important to healthy aging (Ageing: Healthy Ageing and

Functional Ability, 2020). A well-known characteristic of any ASD, is difficulty in social situations (Autism Spectrum Disorders, 2021). Issues with social interactions can make developing and maintaining relationships problematic. One study explored the effects of aging on social cognition, empathy and alexithymia (issues with identifying one's feelings), between adults and older adults with an ASD and their respective age control groups (Zıvralı Yarar et al., 2020). The authors found that no significant difference in their assessment of the older adult group with an ASD and its respective control group with respects to social cognition (Zıvralı Yarar et al., 2020). However, both control groups did vary significantly – the younger control group scored higher than the older control group (Zıvralı Yarar et al., 2020). In respects to the alexithymia assessment, both age groups with an ASD had higher scores than their respective control groups, with the younger adult group with an ASD had more issues with identifying their feelings when compared to the older group (Zıvralı Yarar et al., 2020). Both groups with an ASD also scored lower in respects to self-reported empathy than the two control groups (Zıvralı Yarar et al., 2020).

In summary, research regarding older adults with Autism suggests that these individuals may face more challenges in the areas of physical health, mobility, mental health, cognition and memory, and social connectivity, when compared to other older adults without an ASD. These findings raise many important questions about healthy aging. What changes, if any, are needed to make an impact with this population regarding physical and or mental health, mobility, cognition and memory, and social connectivity? Are providers adequately trained in working with the autistic population in how best to address any of these issues? Are existing programs fashioned in such a way that it could reach and influence this population? Moreover, what

remains unknown are what resources and supports are needed for older persons with Autism as it relates to healthy aging.

#### **Chapter 3: Methods**

# **Study Design**

The chosen method for this proposed study was a scoping review. A scoping review is defined as "a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge" (Colquhoun et al., 2014, pp. 1292, 1294). A scoping review is preferable to a systematic review when the subject has not been thoroughly examined (Pham et al., 2014). Reasons to conduct a scoping review include: to capture research on a given topic; act as a preliminary to ascertain whether a systematic review of a particular subject is warranted; to capture, synthesize and communicate existing research; and to determine what is presently lacking in said research (Colquhoun et al., 2014). Unlike systematic reviews, studies in scoping reviews are not appraised for quality (Arksey & O'Malley, 2005).

The proposed study examined the current state of literature regarding older adults with Autism and healthy aging as well as examined key concepts pertaining to the intersection of older adulthood, ASD and healthy aging. While older adulthood is often defined as 65 years and over, for this study older adulthood was operationalized as a person aged 54 years and older. Studies indicate that the average lifespan for someone with an ASD is much shorter than someone who does not. In Hivikoski et al.'s study (2016), the mean age of death for the group of those with an ASD, was 54. The scoping review followed the five framework stages as outlined by Arksey and O'Malley (2005): "stage 1: identifying the research question"; "stage 2:

identifying the relevant studies", "stage 3: study selection"; "stage 4: charting the data"; and "stage 5: collating, summarizing and reporting the results" (Colquhoun et al., 2014, p. 22). As this study was an analysis of extant published literature, no approval was required from the university's institutional review board to conduct this scoping review.

The research team, led by graduate level thesis student, Mary Kris Stringfellow, utilized the PRISMA-ScR framework and checklist (Tricco et al., 2018) in reporting the methodology for the proposed review (See Appendix I). The proposed scoping review included all scholarly (e.g. peer-reviewed) research studies published beginning on January 1, 2010 through May 31, 2021. Only studies published in English were included in the scoping review.

# **Search Strategy**

The scoping review included the following databases: Academic Search Complete,

AgeLine, APA PsycArticles, APA PsychInfo, Global Health, Health Source: Nursing/Academic

Edition, MEDLINE, and Social Work Abstracts..

The research question, what is the current state of literature regarding healthy aging among older adults who have an ASD, provided the foundation for the research strategy. As recommended by JBI, the Population/Concept/Context framework was used (Peters et al., 2020). The population search terms included: (older AND autism) OR (older AND asd) OR (older AND autism) OR (older AND autism) OR (older AND autism) OR (elder\* AND asperger\*) OR (elder\* AND asd) OR (elder\* AND autistic) OR (elder\* AND autism) OR (elder\* AND autism) OR (geriatric\* AND asd) OR (geriatric\* AND autism) OR (geriatric\* AND asperger\*) OR (\*aging AND asd) OR (\*aging AND autism) OR (\*aging AND asperger\*) OR (\*aging AND autistic).

The concept search terms included: wellbeing OR "quality of life" OR qol OR well-being OR "well being" OR wellness OR happiness OR "life satisfaction" OR "healthy aging" OR "healthy aging" OR "successful aging" OR "successful ageing" OR "positive aging" OR "positive ageing" OR "active ageing" OR "active aging" OR ageing.

The context search terms included: (mental health) OR (physical health) OR (relationships) OR (community) OR (connect\*) OR (relationships) OR ("social belonging") OR (sense of belonging) OR (sense of community) OR (cognition) OR (Memory) OR (depression) OR (anxiety) OR (suicide) OR (health).

## **Study Selection**

In order to eliminate studies that did not address the study's research question, two reviewers (Stringfellow and Fields) applied inclusion and criteria to all of the articles yielded from the database and reference list searches (Arksey & O'Malley, 2005). The a priori inclusion criteria were as follows: 1) peer-reviewed articles written in English; 2) studies that included at least one domain of healthy aging; and 3) studies that included older adults over the age of 53 with a diagnosis of an ASD. The peer-reviewed articles were limited to those published in English, due to lack of funding that is necessary for translation services.

After the initial review of the results, (Stringfellow and Fields), created and applied or excluded additional search terms (Tricco et al., 2018) and the inclusion criteria was refined iteratively through the search process. A deadline of June 1, 2021, acted as the cut-off date for the review of any further studies (Tricco et al., 2018).

## **Data Management**

This study utilized Covidence as the primary screening and data extraction tool for the scoping review. This software allowed the researchers to import citations, search for and

highlight specified words, house articles, incorporate reviewers' notes that were used for exclusion or to discuss any disagreements, and provided flexibility when extracting data (Covidence, n.d.). Several universities use Covidence, including Tulane, Stanford, Yale and Texas A&M (Covidence, n.d.).

#### **Selection of Sources of Evidence**

In this step, two researchers (Stringfellow and Fields) independently reviewed the articles in Covidence at the title and abstract screening phase. The reviewers then convened to discuss any conflicts. Once consensus was reached, these articles were excluded in Covidence. The same two reviewers then conducted a full-text review of the included studies in Covidence. The reviewers then convened to discuss any conflicts until consensus was reached. Charting the Data

According to Arksey and O'Malley, charting is a "technique for synthesizing and interpreting qualitative data by sifting, charting, and sorting material according to key issues and themes" (p. 26). The research team was broadly looking for domains of healthy aging related to ASD as well as what formal and informal interventions, resources, or supports, that have been identified both within the community or institutional settings to facilitate healthy aging in regards to an older adult with an ASD. The lead researcher (Stringfellow) developed a charting form (Tricco et al., 2018) that included: authors, year of publication, study location, population and sample size, methods, aim/purpose, domain/s of health aging, measures and outcomes, study recommendations, as well as services and supports that facilitate healthy aging, see Tables 1 through 6.

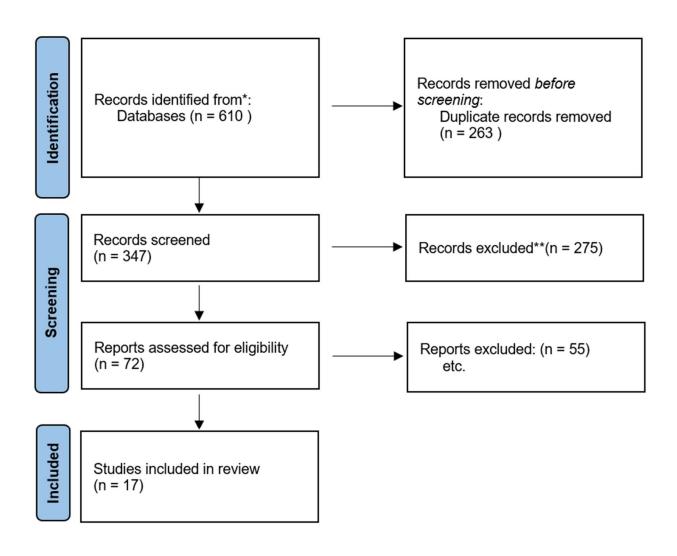
## Collating, Summarizing, and Reporting the Results

Following Arksey and O'Malley (2005), the scooping review presents the findings in two ways: 1) the production of tables and chart map; and 2) a narrative organizing the literature

thematically as it relates to the domains that facilitate healthy aging among older adults with an autism diagnosis. A PRISMA chart is also included (See figure 2). The scoping review concludes with a discussion and implications for social work practice, research, and policy.

Figure 2

PRISMA Flowchart



(Adapted from Moher et al., 2009)

#### **Chapter 4: Results**

Initial search results from the various databases included 610 articles. Overall, 263 duplicates were removed (Covidence identified 259 while an additional four were discovered during the title and abstract screening process). Furthermore, 275 articles were deemed irrelevant based upon inclusion and exclusion criteria, including studies in which the subjects did not have a formal ASD diagnosis, wrong population – such as no older adults were included or those studies in which results pertaining only to the older adult participants were not conveyed, was a book review, dissertation, or literature review, or not published in English. During the title and abstract screening process, two members each reviewed the articles and when there was a conflict, met later to discuss and resolve as a final step in this stage of the process. An additional 55 articles were eliminated during the full text review stage, leaving 17 articles as our sample. Figure 2 provides a visual overview of the entire process, utilizing the PRISMA flowchart.

# **General Characteristics of the Sample**

Roughly 24% of the articles was published before 2016. Approximately 53% of the sample was published in 2019 and 2020. These studies took place in the United States (41%), the United Kingdom (29%), the Netherlands (18%), and Australia (12%). The studies published in 2019 and 2020 took place either in the United States (56%) or the United Kingdom (44%). Fifteen studies utilized quantitative methods, one used mixed methods, and one used qualitative methods. Nine studies (53%) were focused on a better understanding of the differences in the healthy aging domains between those with an ASD diagnosis and those considered neurotypical. Six studies (35%) compared and contrasted how both populations change in assessments in these domains of healthy aging at various life ages. Two studies (6%) contained participants with an

ASD diagnosis only. Sample sizes ranged from 24 participants to 529,5403 participants. Table 1 provides an overview.

**Table 1**PRISMA Flowchart

Title	Lead Author	Yr of Publication	Location	Population	Sample n	Methods	Aim
Age-related differences in cognition across the adult lifespan in autism spectrum disorder	Anne G. Lever	2015	Netherlands	Adults with ASD	ASD = 118 NT = 118 TOTAL = 236	Quant.	Confirm previous results re episodic memory and generativity, examine ToM for older adults with ASD
Atypical working memory decline across the adult lifespan in autism spectrum disorder	Anne G. Lever	2015	Netherlands	Adults with ASD	ASD = 111 NT = 164 TOTAL =275	Quant.	Study effect of age on working memory for adults with ASD and explore differences between the NT population
Impaired motor skills and atypical functional connectivity of the sensorimotor system in 40- to 65-year-old adults with autism spectrum disorders	Annika Carola Linke	2020	USA	Adults with ASD	ASD = 17 NT = 19 TOTAL =36	Quant.	To study sensorimotor networks in adults with ASD
Predictors of quality of life for autistic adults	David Mason	2018	UK	Adults with ASD	ASD = 370 NT = UK Gen Population	Quant.	Study QoL of adults with ASD, identify predictors to use to inform interventions

**Table 1 Cont.**PRISMA Flowchart

Title	Lead Author	Yr of Publication	Location	Population	Sample n	Methods	Aim
Quality of life for older autistic people: The impact of mental health difficulties	David Mason	2019	UK	Adults with ASD	ASD = 69	Mixed	Understand QoL and determine predictive factors for adults with ASD
Social cognition in autism spectrum disorder across the adult lifespan: Influence of age and sex on reading the mind in the eyes task in a cross-sectional sample	Broc A. Pagni	2020	USA	Adults with ASD	ASD = 95 NT = 82 TOTAL = 177	Quant.	Study the effects of age and sex between adults with ASD and NT
Comparing Intellectual and Memory Abilities of Older Autistic Adults with Typically Developing Older Adults Using WAIS-IV and WMS-IV	Venus W. S. Tse	2019	UK	Adults with ASD	ASD = 28 NT = 29 TOTAL = 57	Quant.	Guage intellectual abilities in adults aged 50+ with and without ASD

Table 1 Contd

# PRISMA Flowchart

Title	Lead Author	Yr of Publication	Location	Population	Sample n	Methods	Aim
Age group differences in executive network functional connectivity and relationships with social behavior in men with autism spectrum	Melissa J. M. Walsh	2019	USA	Adults with ASD	ASD = 49 NT = 36 TOTAL = 85	Quant.	To ascertain agerelated declines in executive functioning and the executive brain network in normal aging for those with ASD and without
Correlates of daily functioning in older adults with autism spectrum disorder	Elizabeth A. Wise	2019	USA	Adults with ASD	ASD = 74	Quant.	To identify correlates of functioning and illustrate the types of supports that older adults with ASD require
Age-related effects on social cognition in adults with autism spectrum disorder: A possible protective effect on theory of mind	Esra Zıvralı Yarar	2020	UK	Adults with ASD	ASD = 58 NT = 39 TOTAL = 97	Quant.	To investigate age-related effects on social cognition by comparing younger and older ASD and TD adults

Table 1 Contd

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Title	Lead Author	Yr of Publication	Location	Population	Sample n	Methods	Aim
Executive Function and Functional and Structural Brain Differences in Middle-Age Adults With Autism Spectrum Disorder Prevalence of	B Braden	2017	USA	Aging adults with ASD	ASD = 16 NT = 17 TOTAL = 33	Quant.	To determine how adults with ASD compared to NT adults in executive functioning, verbal memory, and local visual search
mental health conditions, sensory impairments and physical disability in people with co-occurring intellectual disabilities and autism compared with other people: a crosssectional total population	Kirsty Dunn	2020	UK	Adults with ASD	ASD/ID = 5,709 GEN POP	Quant.	To research rates of issues with mental health, sensory impairments and physical disability in the ASD with ID compared with the general population
study in Scotland Elderly with Autism: Executive Functions and Memory.	Hilda Geurts	2011	Netherlands	Older adults with high functioning ASD	ASD = 23 NT = 23 TOTAL 46	Quant.	To determine which cognitive deficits are present in older adults with HFA

**Table 1 Contd**PRISMA Flowchart

Title	Lead Author	Yr of Publication	Location	Population	Sample n	Methods	Aim
Prevalence of physical and mental health conditions in Medicare- enrolled, autistic older adults	Brittany N. Hand	2019	USA	Older adults with ASD	ASD = 4,685 NT = 46,850 TOTAL = 51,535	Quant.	To examine the prevalence of physical and mental health conditions in older adults with ASD
Aging Well on the Autism Spectrum: An Examination of the Dominant Model of Successful Aging	Ye Hwang	2018	Australia	Adults with ASD	ASD = 92 NT = 60 TOTAL = 152	Quant.	To investigate the proportion of autistic adults involved in a longitudinal study who are AW according to Rowe and Kahn's (1987, 1997) model
Aging well on the autism spectrum: the perspectives of autistic adults and carers	Ye Hwang	2017	Australia	Adults with ASD	ASD = 15 CARERS = 9 TOTAL = 24	Qual.	To explore the meaning of Aging Well from perspective of ASD adults and their carers
Health-related quality of life and its determinants among adults with autism	Rahul Khanna	2014	USA	Adults with ASD	ASD = 291 GEN POP	Quant.	To determine Health Related Quality of Life (HRQOL) among adults with autism

(Braden et al., 2017; Dunn et al., 2020; Geurts & Vissers, 2011; Hand et al., 2019; Hwang et al., 2018; Hwang et al., 2017; Khanna et al., 2014; (Lever & Geurts, 2015; Lever et al., 2015; (Linke et al., 2020; Mason et al., 2018; Mason et al., 2019; Pagni et al., 2020; Tse et al., 2019; Walsh et al., 2019; Wise et al., 2019; Zivrali Yarar et al., 2020).

## **Autism Spectrum Disorder Characteristics**

A majority of the studies included participants of all levels of functioning, levels one through three. Level one is characterized as "requiring support" or high functioning (what was formerly diagnosed as Asperger's syndrome) (American Psychiatric Association, 2013). Level two is defined as "requiring substantial support," and level three translates to "requiring very substantial support" (American Psychiatric Association, 2013). Approximately 47% (8) of the articles included all levels of Autism. In comparison, 53% (9) included either level one or level three or a combination of levels one and two. The Autism spectrum method of diagnosis was verified via some version of the Autism Diagnostic Observation Schedule (ADOS) (41%), formal diagnosis based on DSM or ICD-10 (29%), self-reported giving the year and provider's name who diagnosed them (12%), their participation in an ongoing longitudinal study, the Adult Autism Spectrum Cohort-UK (ASC-UK) (12%), or other including Autism Spectrum Quotient (AQ) (6%) and verified census data (6%). In some studies, more than one method was used to confirm ASD diagnosis.

## **Age Characteristics**

A majority of these studies included participants from multiple age groups to examine changes throughout the life course. Some sample populations were comprised of participants of all ages such as children as well as adults (12%), or young adults as well as older adults (47%). Some studies had age parameters inclusive of those who were aged 40 (18%) or aged 50 (18%).

In two studies older adults were only aged 64 or 65 (12%). Finally, only one study included adults aged 65+ (6%).

# **Domains of Healthy Aging**

Only three of the studies specifically mention healthy aging, more often 'quality of life'. For this scoping review, the following domains were examined as part of healthy aging: physical health, mobility, mental health, cognition/memory and social connectedness. 47% of these studies considered only one domain, 24% studied two domains, while 18% measured three domains and 12% assessed four domains. No study considered all five domains.

## **Physical Health**

Several methods were used in these studies to assess physical health: Medicare claims data, Scotland census data from 2011, data from the World Health Organization Disability Assessment Schedule 2.0, details from the Medical Outcomes Study Short-Form Health Survey version 2, and information from the ASC-UK registration questionnaire along with the WHOQoL-BRE. See Table 2 for a summary of results by physical health.

The Medical Outcomes Study Short-Form Health Survey version 2 provides scores across eight areas that was grouped into two summary scores, "physical component summary (PCS) and mental component summary (MCS)" (Khanna et al., 2014, p. 159). ASD adults in the age bracket, 55 – 64, had a PCS of 48.31 (Khanna et al., 2014). While slightly lower than ASD adults in age brackets 18 – 24 (51.13) and 35 – 44 (50.87), their PCS score of 48.3 was higher or showed a more positive quality of life than the control population's PCS score (46.9) (Khanna et al., 2014). Another article provided those results from the review of claims data, but were in favor of the neurotypical control population as opposed to those with ASD, in all factors that comprised physical health, including, metabolic disorders, menopausal disorders, cancer,

nervous system diseases, circulatory issues, etc. (Hand et al., 2019). Likewise, another study showed that in the domain of "avoidance of disease and disability", ASD participants (23%) had a more negative outcome when compared to the neurotypical population studied (20%) (Hwang et al., 2018, p. 7). In one study which compared older adults with ASD and IDD to those without, the ASD/IDD group had more illnesses and physical disabilities ((Dunn et al., 2020). In Mason et al.'s study (2018), overall, the ASD group (49) performed poorly when compared to the UK population (76), but age bands 41 – 60 (slightly over 50) and 61+ (approximately 50), performed better than 28 – 40 age group (approximately 47). There was no data that compared the neurotypical population to ASD by age groups (Mason et al., 2018).

Two other studies provided information regarding other variables that were shown to have an adverse effect on physical health ratings (Mason et al., 2019; Wise et al., 2019). One study found that depression and or anxiety was associated with lower quality of life ratings in physical health for older adults with ASD (Mason et al., 2019). While the other article found that physical health was positively associated with activities of daily living (Wise et al., 2019).

# **Mobility**

To determine mobility abilities, three methods were used. WHOQoL-BREF (Harper, 1998) included a score which comprised how well the respondent was "able to get around" (Mason et al., 2019, p. 16). While the Bruininks Motor Ability Test (BMAT; Bruininks and Bruininks, 2005) was used to measure motor skills, dexterity, balance, etc. (Linke et al., 2020). The Australian Longitudinal Study of Adults with Autism (ALSAA) questionnaire was used to determine functions related to mobility including distance walked and ability to climb a flight of stairs (Hwang et al., 2018). See Table 3 for mobility related results.

**Table 2**Results - Domains of Healthy Aging – Physical Health

Article	Author	Year	Physical Health			
Article	Author	r ear	Method/Test	Results	Support	
Prevalence of mental health conditions, sensory impairments and physical disability in people with co-occurring intellectual disabilities and autism compared with other people: a crosssectional total population study in Scotland	Kirsty Dunn	2020	Information taken from 2011 Census data	NT+	Train Providers	
Prevalence of physical and mental health conditions in Medicare-enrolled, autistic older adults.	Brittany N. Hand	2019	Medicare Claims data	Most Phys Health = NT+ (Except for menopausal disorders, MS, back conditions) = ASD+	Train Providers	
Aging Well on the Autism Spectrum: An Examination of the Dominant Model of Successful Aging.	Ye Hwang	2018	Data from the ALSAA pertinent to Rowe and Kahn's Model of Aging	Rowe and NS		
Health-related quality of life and its determinants among adults with autism	quality of life and its determinants among tism Rahul Khanna 2014 Short-Form Health v. physical comp		Medical Outcomes Study Short-Form Health Survey v. physical component summary (PCS)	ASD age group 55 - 64 - PCS v NT Pop = ASD+	Socal support and engagement	
Predictors of quality of life for autistic adults	David Mason	2018	ASC-UK registration questionnaire; WHOQoL-BRE	NT+	Longitudinal Studies	
Quality of life for older autistic people: The impact of mental health difficulties	David Mason	2019	ASC-UK registration questionnaire; WHOQoL-BRE	Depression and Anxiety = poorer physical health	Individualized Provisions	
Correlates of daily functioning in older adults with autism spectrum disorder	Elizabeth A Wise	9	GMHR	GMHR was a significant predictor of independence	Longitudinal Studies	

(Braden et al., 2017; Dunn et al., 2020; Geurts & Vissers, 2011; Hand et al., 2019; Hwang et al., 2018; Hwang et al., 2017; Khanna et al., 2014; (Lever & Geurts, 2015; Lever et al., 2015; (Linke et al., 2020; Mason et al., 2018; Mason et al., 2019; Pagni et al., 2020; Tse et al., 2019; Walsh et al., 2019; Wise et al., 2019; Zivralı Yarar et al., 2020)

showed that in the domain of "avoidance of disease and disability", ASD participants (23%) had a more negative outcome when compared to the neurotypical population studied (20%) (Hwang et al., 2018, p. 7). In one study which compared older adults with ASD and IDD to those without, the ASD/IDD group had more illnesses and physical disabilities ((Dunn et al., 2020). In Mason et al.'s study (2018), overall, the ASD group (49) performed poorly when compared to the UK population (76), but age bands 41 – 60 (slightly over 50) and 61+ (approximately 50), performed better than 28 – 40 age group (approximately 47). There was no data that compared the neurotypical population to ASD by age groups (Mason et al., 2018).

Two other studies provided information regarding other variables that were shown to have an adverse effect on physical health ratings (Mason et al., 2019; Wise et al., 2019). One study found that depression and or anxiety was associated with lower quality of life ratings in physical health for older adults with ASD (Mason et al., 2019). While the other article found that physical health was positively associated with activities of daily living (Wise et al., 2019).

Hwang and associates (2018) found that older adults with ASD were not nearly as mobile as the control population. In addition, one study found that older adults suffering from depression and or anxiety, were more likely to have issues with physical health, which included mobility (Mason et al., 2019). However, another study found that the ASD and control samples had not discernable difference in scores in 'balance and mobility' (Linke et al., 2020) See table 3 for the results for mobility.

**Table 3**Results - Domains of Healthy Aging – Mobility

Article	Author	Year		Mobility	
Article	Autnor	y ear	Method/Tests	Results	Supports
Aging Well on the Autism Spectrum: An Examination of the Dominant Model of Successful Aging.	Ye Hwang	2018	Data from the ALSAA pertinent to Rowe and Kahn's Model of Aging	NT+	Research best practices for interventional earlier in life
Impaired motor skills and atypical functional connectivity of the sensorimotor system in 40- to 65-year-old adults with autism spectrum disorders.	Annika Carola Linke	2020	BMAT	BMAT standard score and subscales for manual dexterity, coordination, strength, flexibility = NT+ Subscales of fine motor skills, balance and mobility = NS	Longitudinal Studies
Quality of life for older autistic people: The impact of mental health difficulties	David Mason	2019	ASC-UK registration questionnaire; WHOQoL-BRE	Depression and Anxiety = poorer physical health	Individualized Provisions
NT+ = Neurotypic Significant Differe		ormed Better ASD	+ = ASD Population	Performed Better	NS = No

(Braden et al., 2017; Dunn et al., 2020; Geurts & Vissers, 2011; Hand et al., 2019; Hwang et al., 2018;

Hwang et al., 2017; Khanna et al., 2014; (Lever & Geurts, 2015; Lever et al., 2015; (Linke et al., 2020; Mason et al., 2018; Mason et al., 2019; Pagni et al., 2020; Tse et al., 2019; Walsh et al., 2019; Wise et al., 2019; Zıvralı Yarar et al., 2020)

#### **Mental Health**

There were several different approaches to measure mental health. The most recent census data (2011) from Scotland was used, and the Medical Outcomes Study Short-Form Health Survey version 2 (SF-12v2; Ware, Kosinski, & Keller, 1996), charting data, as well as Medicare claims data (Dunn et al., 2020; Hand et al., 2019; Khanna et al., 2014; Wise et al., 2019). Two

other studies used both ASC-UK registration questionnaire and the WHOQoL-BRE (Mason et al., 2018; Mason et al., 2019). The qualitative study used interview questions to capture participant experiences with mental health. See Table 4 for a summary of results.

One study found that in mood, anxiety, personality, attention deficit, sleep, or psychotic disorders as well as the potential to self-harm, older adults with ASD performed worse than the neurotypical control population (Hand et al., 2019). Of note, older adults with ASD were more likely, ten times or greater, to suffer from personality disorders, psychotic disorders, attention deficit disorders and self-harm (Hand et al., 2019). Khanna and associates (2014) found that persons with ASD in the 55 – 64 age bracket had a worse MCS score from the Medical Outcomes Study Short-Form Health Survey version 2 when compared to the sampled neurotypical population. However, this age bracket had a higher score than all other age brackets of those with ASD (Khanna et al., 2014). One research study also showed that, the entire ASD population (44.38) sampled had a much lower score mean psychological score when compared to the neurotypical population (67.82) (Mason et al., 2018). This same study showed that age brackets 61+ (approximately 49) and 41-60 (roughly 44), had the second and third highest psychological scores of the ASD population sampled (Mason et al., 2018). One study showed that when an older adult with ASD had a clinical diagnosis or were within range in either depression or anxiety, it had an adverse effect on the older adult's quality of life psychological rating (Mason et al., 2019). Wise and colleagues (2019) found that mental health did not have a strong correlate with activities of daily living.

The qualitative study explored what is considered aging well for those with an ASD diagnosis. This study found that "of particular prominence was the importance of resilience and

**Table 4**Results - Domains of Healthy Aging – Mental Health

Article	Author	V	Physical Health			
Article	Author	Year	Method/Test	Results	Support	
Prevalence of mental health conditions, sensory impairments and physical disability in people with co-occurring intellectual disabilities and autism compared with other people: a crosssectional total population study in Scotland	Kirsty Dunn	2020	Information taken from 2011 Census data	NT+	Train Providers	
Prevalence of physical and mental health conditions in Medicare-enrolled, autistic older adults.	Brittany N. Hand	2019	Medicare Claims data	Most Conditions NT+, Substance Abuse Only = ASD+	Train Providers	
Aging well on the autism spectrum: the perspectives of autistic adults and carers	Ye Hwang	2017	Interviews	Pschological Health identified as an important factor of aging well.	Additonal Research and New Model for Aging Well	
Health-related quality of life and its determinants among adults with autism	Rahul Khanna	2014	Medical Outcomes Study Short-Form Health Survey version 2 - 2 summary scores: mental component summary (MCS)	ASD age group 55 - 64 - MCS v Overall NT Pop = NT+	Socal support and engagement	
Predictors of quality of life for autistic adults	David Mason	2018	ASC-UK registration questionnaire; WHOQoL-BRE	NT+	Longitudinal Studies	
Quality of life for older autistic people: The impact of mental health difficulties	David Mason	2019	ASC-UK registration questionnaire; WHOQoL-BRE	Depression and Anxiety = poorer mental health	Individualized Provisions	
Correlates of daily functioning in older adults with autism spectrum disorder	Elizabeth A Wise	2019	Review charts	not associated with ADL	Longitudinal Studies	

(Braden et al., 2017; Dunn et al., 2020; Geurts & Vissers, 2011; Hand et al., 2019; Hwang et al., 2018; Hwang et al., 2017; Khanna et al., 2014; (Lever & Geurts, 2015; Lever et al., 2015; (Linke et al., 2020; Mason et al., 2018; Mason et al., 2019; Pagni et al., 2020; Tse et al., 2019; Walsh et al., 2019; Wise et al., 2019; Zıvralı Yarar et al., 2020)

coping, being optimistic and having positive attitudes" (Hwang et al., 2017, p. 2037). Through the interview process, researchers ascertained that mood disorders adversely impacted aging well (Hwang et al., 2017).

#### **Cognition/Memory**

Several of the studies (eight) evaluated the domain of Cognition/Memory. Some used the same tests to evaluate cognition and memory such as Medicare claims data, chart data and information from the World Health Organization Disability Assessment Schedule 2.0, that were used to assess other domains (Hand et al., 2019; Hwang et al., 2018; Wise et al., 2019). In addition, several other instruments were utilized. See Table 5 for results.

The Wisconsin Card Sorting test (WCST) or a modified version, known as The Modified Card Sorting Test (MCST), were used by two studies (Braden et al., 2017; Geurts & Vissers, 2011). WCST was chosen to assess domains of executive function (Braden et al., 2017). Geurts & Vissers (2011) chose a modified version, MCST, as they determined that the WCST was not an appropriate tool to evaluate older adults (Geurts & Vissers, 2011). They used this test to assess cognitive flexibility (Geurts & Vissers, 2011). Results from these studies showed that older adults with ASD made more errors than their neurotypical counterparts but age was not shown to be a driver for these variances (Braden et al., 2017; Geurts & Vissers, 2011).

Multiple studies assessed verbal memory via the Rey Auditory Verbal Learning Task (RAVLT) (Braden et al., 2017; Geurts & Vissers, 2011; Lever & Geurts, 2015). One researcher noted that many studies have employed this test in older adult populations to gauge this domain

of cognition (Geurts & Vissers, 2011). Results were consistent across all articles. One article found that among the ASD and control populations, aged 40 – 64, results were similar – suggesting that in verbal memory, older adults with ASD do not experience a faster decline than the neurotypical population (Braden et al., 2017). Likewise, Geurts & Vissers (2011) and Lever & Geurts (2015) reported that both populations experience a decline with age in verbal memory, but there was no difference between the two groups. One study compared older adults with high functioning ASD and neurotypical controls, ages ranging from 51 – 83; while the other compared adults with an ASD and neurotypical controls, aged 20 to 70 (Geurts & Vissers, 2011; Lever & Geurts, 2015).

Two studies used the Verbal n-Back Task to measure working memory (Braden et al., 2017; Lever et al., 2015). This tool has been used to study memory in the neurotypical older adult population as well as adults diagnosed with ASD (Braden et al., 2017). Both studies found that in terms of the number of correct responses, there was not a significant difference between the ASD and neurotypical population, but both groups did see a decline when age was considered (Braden et al., 2017; Lever et al., 2015). However, one study found that working memory performance seemingly increased in older adults with ASD when considering the oldest of the older adults (Lever et al., 2015). Both studies also found that although the number of correct responses were not significant between the two populations, overall, the ASD group had a slower response time (Braden et al., 2017; Lever et al., 2015).

Three studies used Wechsler Adult Intelligence Scale (WAIS) to assess intellectual ability but used different versions and only subtests of the tool (Geurts & Vissers, 2011; Lever et al., 2015; Tse et al., 2019). Geurts & Vissers (2011) used a subtest to measure processing speed.

**Table 5**Results - Domains of Healthy Aging - Cognition/Memory

	4 .1	**	Physical Health		
Article	Author	Year Method/Test Results		Results	Support
"Executive Function and Functional and Structural Brain Differences in Middle-Age Adults With Autism Spectrum Disorder"	B. Braden	2017	Functional MRI; WCST; RAVLT; the N-back Task; EFT	(RAVLT,EFT) = S, (WCST) = NT+; N-back Task = NS	None Reported
Elderly with Autism: Executive Functions and Memory.	Hilda Geurts	2011	DART; WAIS-III; SART; MCST; TMT; ToL-DX; COWAT; RAVLT; The subtest Spatial Span from the WMS-III	DART; WAIS-III; SART; MCST; TMT; ToL-DX; COWAT; RAVLT = NS; Spatial Span from the WMS-III = NT+	None Reported
Prevalence of physical and mental health conditions in Medicare-enrolled, autistic older adults.	Brittany N. Hand	2019	Medicare claims data	Cognitive Disorders = NT+	Cognitive Disorders = NT+
Aging Well on the Autism Spectrum: An Examination of the Dominant Model of Successful Aging.	Ye Hwang	2018	Data from the ALSAA pertinent to Rowe and Kahn's Model of Aging	NT+	None Reported
Age-related differences in cognition across the adult lifespan in autism spectrum disorder	Anne G. Lever	2015	WMS-III; RAVLT; COWAT; the Word Naming subtest of the GIT; CFQ	The ASD group more cognitive failures on the CFQ = NT+	None Reported
Atypical working memory decline across the adult lifespan in autism spectrum disorder?	Anne G. Lever	2015	N-back	NS	None Reported
Comparing Intellectual and Memory Abilities of Older Autistic Adults with Typically Developing Older Adults Using WAIS-IV and WMS-IV	Venus W. S. Tse	2019	WAIS-IV (Intelligence); WMS (Memory)	Most = NS, Processing Speed and Visual Working Memory= NT+	Additional Research
Correlates of daily functioning in older adults with autism spectrum disorder	Elizabeth A Wise	2019	Review charts	not associated with ADL	Longitudinal Studies
NT+= Neurotypical Population Performed Better $ASD+=$ $ASD$	D Population Per	formed Bett	ter NS = No Significant Di	fference	

(Braden et al., 2017; Dunn et al., 2020; Geurts & Vissers, 2011; Hand et al., 2019; Hwang et al., 2018; Hwang et al., 2017; Khanna et al., 2014; (Lever & Geurts, 2015; Lever et al., 2015; (Linke et al., 2020; Mason et al., 2018; Mason et al., 2019; Pagni et al., 2020; Tse et al., 2019; Walsh et al., 2019; Wise et al., 2019; Zivrali Yarar et al., 2020)

While Tse and colleagues (2019) collected data from ten subtests to measure build multiple indices, including "(i) Verbal Comprehension Index (VCI), (ii) Perceptual Reasoning Index (PRI), (iii) Working Memory Index (WMI), (iv) Processing Speed Index (PSI), (v) General Ability Index (GAI), and (vi) Full-Scale IQ (FSIQ)" as well as GAI and FSIQ (p. 4125). In respects to processing speed, Geurts & Vissers (2011) did not find age to be a factor for the difference in scores for the neurotypical and ASD older adult samples. However, Tse and associates (2019) did find age to be a factor between the two scores, but they did utilize the fourth edition as opposed to the third. Tse and associates (2019) conveyed that the third edition was less sensitive in ascertaining nuances in processing speed. In all other WAIS measures they found no significant difference between the two populations (Tse et al., 2019). The third study used two subtests of the WAIS, along with the Mini-Mental State Exam (MMSE) and Mini International Neuropsychiatric Interview (MINI) to gauge intelligence but for exclusionary purposes only (Lever et al., 2015).

A number of studies assessed memory via the Wechsler Memory Scale (WMS) or from a number of its subtests (Geurts & Vissers, 2011; Lever & Geurts, 2015; Tse et al., 2019). Geurts & Vissers (2011) used two subtests to test visual and working memory, Visual Reproduction and Spatial Span respectively. Both tests have been used to assess memory performance in neurotypical older adults. Results showed that in visual memory, age seemed to have more of a negative impact for adults with ASD (Geurts & Vissers, 2011). In respects to working memory, while differences in performance was evident between the two groups, age did not seem to be a

factor (Geurts & Vissers, 2011). Lever & Geurts (2015) also used the Visual Reproduction subtest to assess visual memory. In this study, they found that the control population experienced a more pronounced decline in relation to age (Lever & Geurts, 2015). However, the age ranges were completely different between the two. Lever & Geurts (2015) sampled people between the ages of 20 and 79 years while Geurts & Vissers (2011) considered adults between the ages of 51 and 83. Tse and associates (2019) used a more recent version of WMS, the fourth edition, in its entirety. Results showed that in a majority of these memory measures except for visual working memory, performance did not significantly differ between the two older adult populations, those with ASD and those without (Tse et al., 2019). In respects to visual working memory, older adults with ASD did not perform as well (Tse et al., 2019). The age range for the sample of this study was aged 50 and greater.

Geurts & Vissers (2011) and Lever & Geurts (2015) both also used Controlled Word Association Task (COWAT) to assess verbal fluency, specifically phonemic. For the COWAT, subjects are asked to provide words starting with a certain letter, like 'n' (Geurts & Vissers, 2011). Geurts & Vissers (2011) found that while the control population had more correct responses than those with ASD, age had a more significant effect on the control as opposed to those with ASD. Levers & Geurts (2015) result's conflict. While the older adult ASD population did not perform as well as the control, age did not affect one population more than the other (Levers & Geurts, 2015).

A few measures were utilized by only one study. Geurts & Vissers (2011) used the Dutch Adult Reading Test (DART) to assess verbal intelligence. They used the Sustained Attention to Response Test (SART) to measure attention between the two groups (Geurts & Vissers, 2011). They used the Trail Making Test (TMT) to gauge cognitive flexibility. Past studies have shown

older adults or an ASD diagnosis can adversely effect one's performance in this measure (Geurts & Vissers, 2011). They used the Tower of London of the Drexel University (ToL-DX) to determine planning capacity (Geurts & Vissers, 2011). In past studies, this assessment has shown poorer performance associated with age (Geurts & Vissers, 2011). It has also been a dependable tool to measure issues for the executive function of planning in the ASD population (Geurts & Vissers, 2011). The authors found no significant differences that could be attributed to age in the performance of these tests in either population, neurotypical and ASD (Geurts & Vissers, 2011).

Lever & Geurts (2015) also used a number of assessments not found in any of the other studies. They utilized a subtest of the Groninger Intelligence Test (GIT), Word Naming, to assess semantic fluency. Semantic fluency is a measure of executive function (Lever & Geurts, 2015) and this test requires the subject to provide unique names from a specific category, such as types of fruit, within a specified time (Lever & Geurts, 2015). They also used the Cognitive Failures Questionnaire (CFQ) to assess memory and attention (Lever & Geurts, 2015). This survey is a "25-item self-report questionnaire used to assess the experience of memory errors, committing blunders, and distractibility in everyday situations" (Lever & Geurts, 2015, p. 669). While the neurotypical population performed better than the ASD population in both tools, age did not seem to have a greater effect on one population over the other (Lever & Geurts, 2015).

A number of studies used only one measure to assess cognition and or memory. Braden and associates (2017) used the Embedded Figures Task (EFT) to measure local visual search. They found no difference in performance between ASD and neurotypical samples (Braden et al., 2017). Hwang and colleagues (2018) used data collected from the World Health Organization Disability Assessment Schedule 2.0 to ascertain cognitive function, specifically "participants needed to report no difficulty in concentrating on something for 10 min and in learning a new

task" (p. 5). They found that older adults with ASD had a much lower percentage in positive responses when compared to the sampled neurotypical older adults (Hwang et al., 2018). Another study utilized Medicare claims data to comment on cognition issues in older adults with ASD (Hand et al., 2019). They found that this population "may be over eight times more likely to experience cognitive conditions such as delirium, dementia, and amnesia" (Hand et al., 2019, p. 760).

#### **Social Connectedness**

Nine studies were related to the domain of social connectedness. Many utilized tests to assess Theory of Mind (ToM). ToM "is the ability to reason about mental states, such as beliefs, desires, and intentions, and to understand how mental states feature in everyday explanations and predictions of people's behaviour" (Apperly, 2012, p. 826). Lever & Geurts (2015) used a shortened form of the Faux Pas test to assess the samples' ToM. ToM, while known to be deficient in people with ASD, has also been known to decrease as a result of the aging process (Lever & Geurts, 2015). As the authors hypothesized, the control population performed better in the Faux Pas test (Levers & Geurts, 2015). However, when results were limited to those in the sample aged 50 and older, the ASD sample performed similarly as the control population (Levers & Geurts, 2015). Pagni and associates (2020) also utilized a task to measure ToM to gauge social connectedness. They used the Reading the Mind in the Eyes (RME) task to assess participants aged 18 to 71, both ASD and neurotypical (Pagni et al., 2020). While overall the neurotypical population performed better than the ASD sample, this changed when considering aging and sex (Pagni et al., 2020). According to their results, performance of females with ASD begin to improve in their scores with age (Pagni et al., 2020). Yaryar and associates (2020) also assessed ToM but used multiple instruments to assess, including RME, the Frith-Happé Triangles Test,

the Strange Situations Film Task, and the new ToM Cartoon Stories Task (ToM-CSt). They combined these results into a composite score and found that the control population performed better than the ASD population but when age was included as a variable, the difference in performance is nonexistent (Yaryar et al., 2020). See Table 6 for a summary of results.

Other methods were used to assess social connectedness. Data obtained from Australian Longitudinal Study of Adults with Autism (ALSAA) questionnaire, specifically that both the following were satisfied: connecting with loved ones or friends at least monthly and having or doing one or more of the following: a job, attending school, acting as a caregiver, or doing volunteer work (Hwang et al., 2018). The older adult ASD sample (42%) did not score as well as the neurotypical sample (78%) (Hang et al., 2018). Another study used the Multidimensional Scale of Perceived Social Support (MSPSS) to assess the older ASD adult's perceived social support (Khanna et al., 2014). They found a moderate correlation between social support and mental as well as physical quality of life (Khanna et al., 2014). Two studies used the one of the same tools: the WHOQoL-BREF (Mason et al., 2018; Mason et al., 2019). Mason and associates (2018) found that the control population sample had higher social quality of life when compared the ASD population sample (Mason et al., 2018). They also found that when the ASD population was stratified by age, age and social quality of life had an inverse relationship (Mason et al., 2018). They did not report on different scores by age for the control population. Mason and colleagues (2019) found that clinical depression and clinical anxiety contributed to lower quality of life scores for their ASD sample, aged 55 years and older (Mason et al., 2019). Walsh and associates (2019) assessed social behavior via the self-report Social Responsiveness Scale-2 (SRS-2). Results overall did not vary by age for the ASD sample but in respects to the SRS-2 Social Cognition Subscale, the older ASD group performed better than the younger ASD

**Table 6**Results - Domains of Healthy Aging - Social Connectedness

Article	Author	Year	Ph	Physical Health		
Article	Aumor	Y ear	Method/Test	Results	Support	
Aging Well on the Autism Spectrum: An Examination of the Dominant Model of Successful Aging.	Ye Hwang	2018	Data from the ALSAA pertinent to Rowe and Kahn's Model of Aging	NT+	None Reported	
Aging well on the autism spectrum: the perspectives of autistic adults and carers	Ye Hwang	2017	Interviews	Social and relationships were important to aging well	Additonal Research and New Model for Aging Well	
Health-related quality of life and its determinants among adults with autism	Rahul Khanna	2014	MSPSS	Social support vital to mental health	Socal support and engagement	
Age-related differences in cognition across the adult lifespan in autism spectrum disorder	Anne G. Lever	2015	Abbreviated version of the Faux Pas test	NT+	None Reported	
Predictors of quality of life for autistic adults	David Mason	2018	The SRS	NT+	Longitudinal Studies	
Quality of life for older autistic people: The impact of mental health difficulties	David Mason	2019	ASC-UK registration questionnaire; WHOQoL-BRE	Depression and Anxiety = poorer mental health	Individualized Provisions	
Social cognition in autism spectrum disorder across the adult lifespan: Influence of age and sex on reading the mind in the eyes task in a cross-sectional sample	Broc A. Pagni	2020	RME	NT+ (also ASD+ - females only)	None Reported	
Age group differences in executive network functional connectivity and relationships with social behavior in men with autism spectrum disorder	Melissa J. M. Walsh	2019	SRS-2; ToL	NS (age not broken out for NT)	None Reported	
Age-related effects on social cognition in adults with autism spectrum disorder: A possible protective effect on theory of mind  NT+ = Neurotypical Population Performed Better ASD+ = ASI	Esra Zıvralı Yarar	2020	RMET; the Frith-Happé Triangles Test; the Strange Situations Film Task; ToM Cartoon Stories Task ter NS = No Significant Di	NT+	None Reported	

group (Walsh et al., 2019).

(Braden et al., 2017; Dunn et al., 2020; Geurts & Vissers, 2011; Hand et al., 2019; Hwang et al., 2018; Hwang et al., 2017; Khanna et al., 2014; (Lever & Geurts, 2015; Lever et al., 2015; (Linke et al., 2020; Mason et al., 2018; Mason et al., 2019; Pagni et al., 2020; Tse et al., 2019; Walsh et al., 2019; Wise et al., 2019; Zivralı Yarar et al., 2020)

## **Chapter 5: Discussion**

The purpose of this scoping review was to ascertain the current state of literature in respects to older adults with ASD and healthy aging. Inclusion criteria included adults with ASD over the age of 54, any of the domains of healthy aging: physical health, mobility, mental health, cognition/memory and social connectedness, a publication date within the past ten years, and written in English. As a result, 17 research articles were identified.

Overall, the studies included samples with various age ranges. For studies concerning changes throughout the life course, a wide variety in respects to age were included, such as all ages or 18 – 70 years. Regarding studies concerning the differences in the older adult population, for those with ASD and those who are considered neurotypical, the age range was more focused, for instance ages 65 and older. Some studies provided information regarding multiple domains while others focused on just one aspect. While one qualitative study gave insight into what aging well means to those with ASD, no quantitative studies reported results for every domain of healthy aging. For example, Hwang and associates (2018) considered aging well from Rowe and Kahn's model of successful aging: including avoidance of disease and disability, physical and mental functioning (cognitive), and active engagement with life, by examining differences between two populations, those with ASD and neurotypical adults, aged 40 and older. Other than querying the participants regarding whether they suffer from anxiety or depression, psychological functioning was not considered (Hwang et al., 2018). Likewise, Mason

and colleagues (2018), studied predictors of quality of life as defined by the World Health Organization, for physical, psychological, social and the environment, for the older adult ASD population (Mason et al., 2018). Mobility was mentioned only once within the entire article with no results provided (Mason et al., 2018).

Of the five domains considered for this scoping review, social connectedness and cognition and memory were by far the most represented in the studies. Mobility was less researched – only three of the 17 studies provided results concerning this domain. Given that social behavior is a hallmark of ASD, the focus on social connectedness seems justified. Moreover, memory and cognition are of great importance for gerontological/geriatric research which may explain the focus on this domain in the ASD literature.

# **Physical Health**

Seven of the seventeen articles provided information regarding the physical health of the older adult ASD population. Overall, results indicated that they are not as physical healthy as neurotypical older adults (Dunn et al., 2020; Hand et al., 2019; Mason et al., 2018; Mason et al., 2019; Wise et al., 2019). Even though one study found conflicting results, the authors noted that a potential reason for this is that those who have more severe ASD may not necessarily understand their own physical wellbeing (Khanna et al., 2014). Participants completed a questionnaire that queried their own ratings in various health related categories (Khanna et al., 2014). However, another study, in its review of Medicare claims data, found the neurotypical population outperformed the ASD older adult sample in all areas pertaining to physical health (Hand et al., 2019). While self-report data is important, diagnostic data provides more insight into one's actual physical functioning. These results are not surprising as it has been well documented that those with ASD have more comorbidities than the neurotypical population

(Croen et al., 2015). It is important that healthcare providers learn to identify medical problems for the ASD population, as those with ASD may not be able to communicate issues or symptoms they experience. Early intervention too would be key to help a person with ASD, to prevent the progression of symptoms into a full-blown illness such as type 2 diabetes (Dunn et al., 2020).

Mobility

Three studies examined mobility for the older adult ASD population and overall, results indicated that an older adult with ASD had more functional mobility issues than a neurotypical older adult (Hwang et al., 2018; Linke et al., 2020; Mason et al., 2019). However, one study indicated that there was not a significant difference between the two groups (Linke et al., 2020). Balance and motor skills, which are necessary for mobility, are known to be deficient in the ASD population (Hilton et al., 2011; Stins & Emck, 2018). Research regarding older adults with ASD and mobility is lacking.

## **Mental Health**

Seven of the seventeen studies considered mental health. Regarding this domain, all studies that provided ratings for mental health, indicated that older adults with ASD had significantly lower scores (poor results) when compared to the neurotypical population. (Dunn et al., 2020; Hand et al., 2019; Khanna et al., 2014; Mason et al., 2018; Mason et al., 2019). In respects to self-harm risk, the older adult ASD population is substantially more at risk than the neurotypical population (Hand et al., 2019). Providers need to have adequate training in the ability to identify mental health problems in the older adult ASD population.

## **Cognition and Memory**

Eight of the selected studies discussed cognition and memory, of which seven provided results regarding performance in this area. Multiple domains were measured including: attention,

inhibition, fluency, flexibility, memory, and learning. In most tests administered, the neurotypical population outperformed those in same with ASD, but age was not a factor in performance. However, there were a few studies where age did influence the performance of one population over the other. In respects to visual memory, Geurts & Vissers, (2011) found that age was a factor for those with ASD. While Lever & Geurts (2015) found age to have a more prominent effect on the neurotypical group. Age ranges of the studies may explain the conflicting results. Lever & Geurts (2015) studied adults aged 20 to 79 years and Geurts & Vissers (2011) sampled adults aged 51 to 83 years. One could interpret this to mean that while over the life course, age has more of a negative effect on the neurotypical population; in older adulthood, age has more of an adverse effect for those with ASD. In verbal fluency results were also inconsistent. Geurts & Vissers (2011) found that age had more of a negative impact on the neurotypical, while Lever & Geurts (2015) found that age was not a more prominent factor for either population. Studies also had conflicting results regarding processing speeds. Tse and colleagues (2019) used a more updated version of the instrument used and found that age was more of an issue for the ASD than neurotypical. However, Geurts & Vissers (2011) used an older version of the same test – one that was found to be less sensitive to processing speeds than the more recent version. They found that age was not a factor in performance for both populations (Geurts & Vissers, 2011). Overall, it would appear that in terms of memory and cognition, the older adult ASD population may not perform as well as the neurotypical, but age does not adversely affect them more than the neurotypical. The instruments used to assess cognition and memory were created for the neurotypical population. They may be biased towards this group and not adequately capture the functioning of those with ASD.

#### **Social Connectedness**

A majority of these studies provided details regarding social connectedness. This domain was more prominently featured than any other. For those studies comparing scores between the two populations of those with ASD and those without, the neurotypical population performed better until older adulthood was reached, when the difference between the two seemed to disappear (Levers & Geurts, 2015; Pagni et al., 2020; Yaryar et al., 2020). All of those studies measured ToM (Levers & Geurts, 2015; Pagni et al., 2020; Yaryar et al., 2020). However, it is important to note that Pagni & colleagues (2020) found this pattern to be true but only for the female older adult population with ASD. One study showed that in respects to elements of social connectedness, the older adult neurotypical population had higher positive instances (Hwang et al., 2018). These results were unsurprising. Strong relationships and social ties have been linked to longevity (Holt-Lunstad et al., 2017).

# **Supports and Services Identified**

For problem areas identified in the domains of healthy aging, some of the authors suggested supports to assist deficiencies in the older adult ASD population. Regarding health, Dunn and associates (2020) suggested that medical personnel and staff need additional training in working with the older adults who have ASD and an intellectual disability, to be able to adequately evaluate, diagnose and determine appropriate courses of action in light of this population's difficulties with communication and cognition. Hand and associates (2019) as well as Hwang and colleagues (2017) also indicated that providers and their staff need tools specific to this population to better assess and manage the multiple health concerns that are characteristic to this population. They also stated that their findings could be used to create or adjust programs and supports for this population's specific set of needs (Hand et al., 2019). Hwang and

colleagues (2018) conveyed that early intervention for the development in skillsets pertaining function and daily living, before the age of 30, will continue to be a priority for this population and that research should continue in identifying other factors that can mitigate poor performance or functioning. A number of the authors stated that social activities and participation remain important throughout the life course and should be age appropriate (Hwang et al., 2018; Khanna et al., 2014). Many articles discussed the importance of continued research in the aging ASD population (Hand et al., 2019; Hwang et al., 2018; Hwang et al., 2017; Lever & Geurts, 2015; Lever et al., 2015; Linke et al., 2020; Pagni et al., 2020; Tse et al., 2019; Walsh et al., 2019; Wise et al., 2019). A number of authors also noted that changes are needed in models of aging (Hwang et al., 2018; Mason et al., 2019) or move away from the stance of preventing decline to maintaining one's personal assets as well as developing new ones throughout the aging process (Hwang et al., 2018).

## Limitations

There are a few limitations to this study to consider. First, there is a potential that relevant sources may have been omitted due to the scoping review's inclusion and exclusion criteria. However, this is a potential limitation for any scoping review (Peters et al., 2020). In order to minimize the risk of inadvertently omitting studies, a social science librarian assisted the lead author (Stringfellow) with a broad search strategy (e.g. databases, search terms) to capture the relevant literature. Second, only articles published in English were included. Third, the scoping review does not consider the quality of the studies. However, the purpose of the study was to broadly understand the available research related to healthy aging and persons with ASD which is appropriate for scoping reviews.

## **Implications for Practice and Research**

#### **Practice**

In respects to social work practice, this review has several important implications. As prevalence of ASD across the life course increase, it is likely that social workers will be providing services and supports to persons with ASD (Haney, 2017). Across settings (e.g. healthcare, home and community-based services, behavioral health) social workers are wellprepared to engage in practice that aims to "promote full and meaningful inclusion in society, as well as social and economic justice, for individuals on the autism spectrum" (Bishop-Fitzpatrick et al., 2018, p. 1). For example, in healthcare settings, social workers can remain with their ASD clients throughout their visit with the provider, thus spending more time emphasizing social engagement. With proper training, social workers may observe strengths and opportunities that a provider might miss in only working with a client for 30 minutes at a time. For older persons who are undiagnosed, the social worker could also alert the provider that additional testing may be necessary to help adequately diagnose ASD and thus more accurately target supports that may be needed. Coordination of services and benefits is also common role for social workers in healthcare settings (Reckrey et al., 2014). Older adults in general, often need assistance in this area, particularly when discharging from the hospital (Eaton, 2018).

This review has shown that the older adult ASD population will most likely need more assistance than the older adult neurotypical population, in areas of mobility, physical health, and mental health. The social worker can identify supports in these areas specific to those with ASD. Agencies that provide services to the older adult population should train at least one social worker if not more, to assist those clients with ASD. Again, the social worker would be trained

to assist these clients more effectively. As therapists, social workers who specialize in gerontology, would also need to have training to identify potentially undiagnosed clientele. ASD has symptoms that are similar to other disorders, such as ADHD, and are often misdiagnosed. Proper diagnosis is imperative to support mental health needs.

#### Research

This review has many implications for research. While healthy aging or aging well is an important area of study, the literature rarely, if ever, touches upon the needs of the ASD older adult population. Regarding what little research is available, measurements used to assess those with ASD may not be appropriate. Valid and reliable instruments are necessary in measuring memory and cognitive functioning/ability for persons with ASD. Longitudinal studies are also crucial. Comparing cohorts in respects to age-based performance is useful, however, change over time may better capture the dynamic aspects of growing older with ASD. Moreover, identifying what supports are needed today for the older ASD adult, the issues themselves could change for later generations who have had the benefit of emerging therapies (Walsh et al., 2019). In regards to age ranges for various life stages, studies lack a common definition of what these constitutes "older age" for people with ASD, hence the various age ranges found in the selected studies. One main reason for these inconsistencies pertain to mortality rate. Numerous studies have found that people with ASD have a much higher mortality rate when compared to the neurotypical population (Hirvikoski et al., 2016; Mouridsen et al., 2008).

Finally, while additional research is necessary in all domains, much more is needed related mobility. Not just physical mobility but mobility in one's environment. While some mobility issues may be similar across the aging population, those with ASD typically have more challenges.

# Conclusion

The purpose of this scoping review was to elucidate the current state of research regarding the older adult ASD population and healthy aging. While research exists, much more is needed to accurately assess this population in the five domains of physical health, mobility, mental health, cognition and memory, and social connectedness. Mapping of the data for this research has provided information into those areas and what is needed in times to come.

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# Appendix

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED
TITLE			ON PAGE #
Title	1	Identify the report as a scoping review.	1
ABSTRACT	-	, and the second of the second	
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	2
NTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	7 - 16
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	7 - 16
METHODS			1
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	N/A
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	16 - 17
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	17
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	17 - 19
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	19
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	20 - 21
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Click here to enter text.
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Click here to enter text.
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	20 - 21
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	21
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	20 - 22
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Click here to enter text.
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	21 - 45
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	21
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	45 - 50
Limitations	20	Discuss the limitations of the scoping review process.	50
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SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #		
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	53		
FUNDING					
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	N/A		

*From:* Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.