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TITLE: Older Age Autism Research: A rapidly growing field, but still a long way to go

RUNNING TITLE: TRENDS IN OLDER AGE AUTISM RESEARCH

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Keywords: older age, aging, autism, autistic people

Abstract

Background There is a paucity of research involving older autistic people, as highlighted in a number of systematic reviews. However, it is less clear whether this is changing, and what the trends might be in research on autism in later life.

Method We conducted a broad review of the literature by examining the number of results from a search in three databases (PubMed, Embase, PsychINFO) across four age groups: childhood, adolescence, adulthood, and older age. We also examined the abstracts of all the included papers for the older age group and categorised them under broad themes.

Results Our database search identified 145 unique papers on autism in older age, with an additional 67 found by the authors (hence, the total number of papers in this review is 212). Since 2012, we found a 392% increase in research with older autistic people, versus 196% increase for childhood/early life, 253% for adolescence, and 264% for adult research. We identify 2012 as a point at which, year-on-year, older age autism research started increasing, with the most commonly researched areas being cognition, the brain, and genetics. However, older adult research only accounted for 0.4% of published autism studies over the past decade.

Conclusion This increase reflects a positive change in the research landscape, although research with children continues to dominate. We also note the difficulty of identifying papers relevant to older age autism research, and propose that a new keyword could be created to increase the visibility and accessibility of research in this steadily growing area.

Keywords: older age, aging, autism, autistic people

Community Brief

Why is this topic important?

Autistic children grow into autistic adults, and autistic adults grow old. However, there is very little research about older autistic people. This is important so we know how to support older autistic people.

What is the purpose of this article?

We wanted to examine how autism research activity has changed over time with respect to four life stages: infancy, childhood and adolescence, adulthood, and older age. We then more closely looked at older age autism research to point out important gaps where more research is needed.

What did the authors do?

We conducted a broad review of the literature on autism and described what life stages are studied in published research. We looked at how the amount of research on different life stages has changed over time. We further examined studies focused on older age and summarized the topics covered. *What did you find about this topic?*

Our review estimates only 0.4% of autism-related publications over the past decade are about older autistic people. We identify 2012 as a turning point, since when the number of studies has markedly increased year-on-year. Encouragingly, the percentage increase in autism research over the past decade is greater for older age research (392% rise) than childhood/early life (196%), adolescence (253%), or adulthood research (264%).

What do the authors recommend?

We suggest that there are many research areas that need addressing. Specifically, more research is needed on social isolation and the practicalities of living arrangements for older autistic people, as well as more studies including older autistic adults with intellectual disability.

How will these findings help autistic adults now or in the future?

We do not think our findings will immediately benefit the lives of autistic people. However, we do hope to draw attention to topics where research is needed to improve the lives of autistic older people. We also suggest that a new keyword could be created that researchers could include in their papers to help autistic people and those interested in autism and aging find relevant writings.

Introduction

"*Although much [research] is carried out with respect to young individuals with ASD, there is an urgent need to address the needs of the current population of older individuals with ASD*".[1] Mukaetova-Ladinska et al's 2012 paper drew attention to the scarcity of aging research with older autistic people after examining the literature between 1946

and 2011. In the intervening years what has changed in this respect? We decided to mark another decade in autism research by re-examining this question.

Several reviews have pointed out the dearth of research with older autistic participants.[2–5] In America, as of 2019, approximately 35.5% of the population (c.117.0 million people[6]) were aged 50 years or older[1], and the proportion is similar in the United Kingdom (37.7%, c.25.2 million people[7]). A UK population survey reported an autism prevalence of around 1% in adults[8], suggesting that there could be many millions of people aged over 50 who would meet diagnostic criteria, although most are not diagnosed (the "lost generation"[9]). Clearly, it is a pressing concern to identify the state of autism research with older samples of autistic adults.

Research attention is slowly encompassing older autistic people, but as yet, there is no evidence to show how quickly interest in this area is growing. Thus, the aim of this perspective is to track the rates of autism publications, indexed in three databases. We update the search strategy of Mukaetova-Ladinska and colleagues (described in Figure 1 of that paper) to assess, in 2021, how autism research is distributed across the age categories of childhood, adolescence, adulthood, and older age. Moreover, we identify the rate of publication of autism research with older autistic participants. Finally, we draw attention to broad categories of the search records according to the topic of each study (e.g.. cognitive, genetic, etc.). Whilst previous aging reviews have tended to be systematic, we opted for a broad review of the literature to gain an overview of the state of autism aging research and trends over time.[10] This enabled us to chart how publication trends have changed over time, and provide a qualitative schema for organising older autism research.

Positionality

One of the first authors, DM, is a late-diagnosed autistic adult, with a Bachelor's degree in Health, and a Master's degree in Psychology. Currently, DM is completing a PhD to examine issues of outcome and quality of life for older autistic people. DM's research interests are the quality of life of autistic people and aging as an autistic person. GRS has a Bachelor's degree in Psychology, a Master's degree in Genes, Environment and Development in Psychology and Psychiatry (GEDPP), and a PhD on ageing and autism. His research interests focus on the health, wellbeing, and cognition of middle-aged and older autistic (and high autistic trait) adults. SJC has a Bachelor's degree in Applied Psychology, a Master's degree in GEDPP, and is currently undertaking a PhD. Her PhD and research interests focus on mental health and quality of life in autistic adults with a particular emphasis on how these outcomes might be different for other neurodivergent adults (e.g. ADHD) or those who are neurodivergent in multiple ways (e.g. Autistic with ADHD). FH has worked in autism research for over 30 years, following an undergraduate degree in Experimental Psychology and a PhD on autism. She is the primary PhD supervisor for DM, GRS and SJC. All the

[1] We selected 50 years here because it has been reported that cognitive aging can be observed at this age in several domains.[47]

authors share a neurodiversity perspective that recognises that the different way in which autistic people process the world can be disabling in a society designed by and for non-autistic people.

Method

Search strategy

First, we designed a search based on Mukaetova-Ladinska et al's (2012) search strategy. We opted to search not only Pubmed, as Mukaetova-Ladinska and colleagues did, but also Embase and PsychINFO to capture as broad a range of research topics as possible. All searches (childhood & early life, adolescence, adulthood, and older age) for each of the three databases (Pubmed, PsychInfo, Embase) were exported to Endnote[2] and results were deduplicated. Both first authors created an a-priori set of themes to use to code each study based on common research topics in the autism and ageing literatures. These themes were then refined and finalised through group discussions with the third and fourth authors. Each first author then independently coded the abstracts according to the themes. Once initial coding was completed, these authors discussed the coded abstracts to reach 100% agreement.

Our first strategy replicated Mukaetova-Ladinska and colleagues' initial search terms, plus some additional terms. The autism terms were autism*, autism spectrum disorder, autistic*, autistic disorder, autistic symptoms, Asperger*, and PDD-NOS. The aging terms varied by age group. We used terms for: 1) infancy (toddler, infant, infancy) and childhood (child*, children); 2) adolescence (adolescence, adolescent*, teen*); 3) adulthood (adult*, young adult*); and 4) older age (old age*, older age, older adult, elder*, senior, late* adulthood). See Supplementary Material 1 for a comparison between the present search terms, and the search terms used by Mukatova-Ladinska et al. See Supplementary Material 2 for an example search strategy using AND/OR terms. Searches were restricted to the title and abstract only.

This initial search strategy brought numerous false positive results in the older age search; for example, including the search term "senior" returned abstracts about "high school seniors", or "senior management". As we wanted to maximise true positive hits but minimise these false positives, we refined our search strategy. To do so, we used the same approach as above, but added the following terms (using the NOT function); child*, infan*, youth, school, senior manag*. The NOT function aims to exclude irrelevant hits (and when combined with the '*' wildcard, to exclude permutations of irrelevant hits); the aim of this was to exclude false positives such as "older children". This is referred to as our "stringent search" below.

[2] We did this for each of the age-band searches. However, we only thematically coded the results for the older age group, as this was an aim of the paper.

To ensure the completeness of our search, we identified review papers that our search strategy retrieved, and checked the reference list for any relevant papers. In this way, and based on our own knowledge of the literature, we added in any papers that were relevant but not returned by the search strategy.

Finally, abstracts from the stringent older adult search were categorized into an a-priori set of research topics. DM and GRS coded the abstracts individually, and then agreed on the final categorization. These research topics were derived from common autism research areas and the authors' knowledge of the literature. Abstracts were deemed relevant and given a category if they included a clear reference to autism in older age or included autistic people aged 50 years and older. An irrelevant category was created to account for abstracts that included no reference to autism in older age. Abstracts with multiple themes were coded into their primary topic area. See Supplementary Material 3 for the abstract screening flow diagram.

Results

A final total of 212 unique papers were identified by our stringent older adult search criteria. The database search yielded a total of 145 unique papers across the three search engines used, with an additional 67 papers being added by the authors after checking reference lists of relevant review articles and/or based on their knowledge of the literature (see Figure 1 for a full breakdown of the search strategy for each age group). Table 1 shows the number of results by database and age group. Figure 2 shows the average database N of results, by age group, published before and after 2012 for the stringent search strategy. See Supplementary Material 3 for full database N breakdown.

[Table 1 about here]

[Figure 1 about here]

Is there a trend over time?

We identified a sharp increase in the number of autism-related publications since 2010. Specifically, for autism older age papers, we found that the number of publications rose from an average of 1 paper per year in the years prior to 2012 (i.e., before Mukaetova-Ladinska et al's review), to an average of 14 papers per year over the 9 years since. When comparing the average number of papers on older adults identified in our stringent search of the three databases (N=187) papers, a total of 136 were published in, or after, 2012. See Figure 2 for a visualisation of this trend. When considering the percentage increase in the number of publications since 2012 (averaged across the three databases in the search), childhood and early life research has increased by 196%, with a 253% increase for adolescence research, 264% for adult research, and finally 392% older age research (identified through the stringent search). Yet, despite an almost four-fold increase, the older age research (identified through the stringent search) only accounts for 0.4% of the new publications since 2012, with childhood and early life research accounting for 67%, 13% by adolescence research, and 20% by adulthood research. Finally, we examined the changes in number of

publications per year, for each age band (childhood adolescence, adulthood, and stringent older age search). The trend is depicted in Figure 3. We can see a steady increase in abstracts for each age band across time (the increase in older age is obscured by the scale of the graph – see inset panel of Figure 3). Encouragingly, 2010 seems to mark an increase in older age autism research, with around four times as many publications in 2020 as in 2010.

[Figure 2 about here]

[Figure 3 about here]

What research is being conducted with older autistic adults?

Table 2 shows the number of papers found that fell into our different topic categories. Studies that examine general health (N=17, 8.0% of all papers in the stringent search), genetics/molecular aspects (N=16, 7.5%), and cognition (N=15, 7.1%) were most common. A large number of review articles was also found (N=16, 7.5%). Several studies examined autistic traits (N=11, 5.2%), with slightly fewer focusing on support needs (N=9, 4.2%) or quality of life (N=8, 3.8%). Few studies examined sensory processing (N=5, 2.4%). We also have a miscellaneous category of studies that could not readily be assimilated into the a-priori themes (N=9, 4.2%)., including for example a paper exploring age-related differences in restrictive repetitive behaviours, as well as case study accounts. Our study identified a number of first-person accounts and community-member advocacy writings (e.g. Michael, 2016) which we coded into the Letter to the Editor section (N=6, 2.8%). We also identified a number of qualitative papers; however, rather than list these as a discrete category (with diverse coverage) we listed them in the relevant category by topic (e.g. Hickey et al., 2018 is listed under support services). Finally, we did have a large irrelevant category, which included papers with no clear reference to autism in older age, such as papers related to advanced parental age and autism, criminal justice and mental health, and non-autistic older adult health and cognition (N=68, 32.1%). Please see Supplementary Material 4 for a full list of the papers within each category of Table 2.

[Table 2 about here]

A note on keywords

Our search demonstrated how hard it is to specifically locate research papers on autism and aging. As indicated above, our initial search strategy included a large number of false positives that were clearly irrelevant. We refined the search strategy to try and remove some of those false positives, yet still a large number of irrelevant papers were retrieved. We examined the use of keywords in the 145 unique paper abstracts returned by the stringent search that were categorised as relevant. A total of 60 abstracts did not have keywords indexed by the search engine. The remaining 85 used a wide range of keywords. There were nine unique references to autism: ‘Autism Spectrum Disorder(s)’, ‘Autistic Spectrum Disorder’ and ‘ASD’ (n=48); ‘Autism’ (n=25); ‘Broad Autism Phenotype’ or ‘BAP’ (n=12); ‘Autism traits’ (n=3); ‘neurodevelopmental disorder’ (n=3); and ‘autistic identity’ (n=1). Eighteen unique age-

related terms were used. The most common were ‘aging’ or ‘ageing’ (n=43); ‘older adult(s)’ and ‘old(er) age’ (n=19); ‘adult(s)’ and ‘adulthood’ (n=29); and ‘elderly’ (n=10). The remaining eight terms were keywords used in only one paper, e.g. ‘geriatric psychiatry’, ‘late diagnosis’, ‘aged’, and ‘age trends’. The final three terms were not older-age specific, e.g. ‘adolescence’ and ‘early life’.

Discussion

The present study sought to identify the trends in research with older autistic participants. We found that almost four times as many papers were published in the nine years since 2012, compared to all the years preceding 2012. Second, and consistent with this, the rate of publications on older autistic people has sharply increased since 2012. Despite this encouraging increase, autistic children are still the focus of the majority of research papers, with older age research accounting for less than 1% of all publications over the past decade.

Our categorisation of the autism aging abstracts returned by our review suggests that the focus of research thus far has been on factors about the autistic person, and less about their context or wider needs. For example, the majority of studies focused on socio-cognitive factors[e.g. 11], physical[e.g. 12] or mental health[e.g. 13,14] conditions, brain imaging [e.g. 15], and genetics.[e.g. 16] Quality of life (QOL) has been identified as an important outcome for autistic people[17]; and we identified a number of studies that focused on QOL in older adults.[18,19] For reasons of space, we are unable to explore more thoroughly the content of the included studies, and we direct interested readers to a recent review which comprehensively examined the characteristics of samples used in older autism research and explores the areas of research covered (which are consistent with what we present here; Tse et al., 2021).

A final interesting finding was the scant number of papers taking a dimensional or trait-wise approach with samples of older people[20–28]. Given the accumulating evidence that autistic traits are continuously distributed in the population[e.g. 29–31] and share genetic influences with diagnosed autism[32], extending dimensional research approaches into older age could offer promising insights. Those who endorse higher autistic traits show similar difficulties to diagnosed autistic adults in understanding social situations[27], and mental health[33]. Indeed, in the general population, elevated autistic traits at age 45 are associated with poorer health and faster aging (even controlling for sex, childhood IQ and childhood SES[34]). Given the difficulties of diagnosing autism in the elderly[35] and likely under-diagnosis in older adults, research with high-trait individuals may help with testing supports or interventions for older, diagnosed, autistic people. Of course, any such interventions would need to be co-designed through participatory autism research methods[36].

Research agenda

From our survey of the literature, there was little consideration, if any, of the practicalities that older autistic people face. For example, what should accommodation (e.g. residential care) look like for older autistic people?[37] Given the often-precarious living arrangements of autistic people[38], this is a pressing concern. Moreover, studies with younger samples have identified difficulties in forming social networks[39]; this is also a vital question for older autistic people, given the risk of isolation in old age generally. Finally, very few (N=8) of the identified papers focused on older autistic people with co-occurring intellectual disability[40–45].

Whilst some topics salient to the autism community (physical and mental health) are well represented, based on our search results, the following areas are in need of more study:

- Autism and Intellectual Disability
- Quality of life
- Support needs and support preferences
- Sensory processing
- Studies that utilise longitudinal methods to examine age-related change

Therefore, it is imperative that autism researchers engage with older autistic people (i.e. consultation and co-production) to identity topics for research that could improve their lives.

Recommendations to the field

Clearly, there are many pressing and open research questions remaining for this under-researched group. We suggest that, in addition to ongoing research in the areas we identified, that autism researchers consult with older autistic people to identify the research areas important to them.

Our search highlighted the relative difficulty of identifying papers on autism and old age, from keywords, titles and abstracts. Search terms such as ‘older’ and ‘senior’ bring up a large number of false positives (e.g., ‘older children’, ‘senior manager’); trying to remove these was difficult and time consuming. Even with our stringent search strategy there were still abstracts that did not focus on autism or aging. This is potentially problematic for researchers interested wanting to gather research literature on autism in old age.

The use of a bespoke keyword for autism research papers addressing older adult issues could help identify this literature more clearly. Drawing on findings in market research, utilising unique keywords with low online search indexing can increase the ease of identifying relevant materials and reduces the number of false search results[46]. We therefore propose that the autistic community, stakeholders, and researchers could be consulted on the creation of a new indexing keyword that could be used in future research publications. The creation of this keyword could be a very useful way to clearly mark papers that focus specifically on samples of older (age 50+ years) autistic people. We are

not suggesting that the creation and use of this keyword would replace other strategies to identify relevant literature, as this would be inappropriate. Rather, we suggest that authors could add this keyword to ensure their work is identified in searches for older age autism research. At present, it is not inconceivable that relevant material slips through the net when combining broader keywords that have high online search indexing (e.g. aging/older age, autism/ASD) in more complex search terms. Indeed, this can be seen from the diversity of search terms used in the abstracts we reviewed. Thus, the implementation of a unique keyword would be a useful aid to identifying older age autism research for members of the autistic community, relevant stakeholders, and researchers.

Strengths and limitations

Ours is the first study, as far as we are aware, to examine how the publication rate of autism research with older autistic people has changed over time. We developed our second search iteratively and applied a more stringent search strategy, in order to maximise the number of relevant papers and minimise the number of false positives. Moreover, the a-priori set of research themes was reasonably robust - all of the themes captured at least one study and enabled us to provide an overview of the current topics of research attention.

There are several caveats to our approach. First, we set out to ascertain the trends in aging research according to our criteria, we did not intend to conduct a systematic review. Thus, we only examined the abstracts for information about each study with older autistic adults. As not every study reported the participant age, it is uncertain how relevant every abstract was to autism in old age. Second, a large number of studies could not be accommodated within our coding framework. Many of these addressed very 'niche' research questions, and we wanted to avoid a long list of categories with single papers. Future studies taking the present approach could attempt to refine the coding framework used here. Our search strategy did not explicitly include terms related to intellectual and/or learning disability (ID/LD). Thus, our count may underestimate the research literature on older autistic people with co-occurring ID or LD (see Tse et al.'s 2021 report on the characteristics of samples of older autistic people, which includes 16 studies with participants with ID; and Maguire et al., 2021 for a systematic review of autism and ID studies). Additionally, despite a comprehensive search strategy, a large number of papers were manually added to the final older age total by the authors as they were not captured by the three databases. Finally, our methodology was based on the review conducted by Mukaetova-Ladinska et al and was intended to be a broad overview of the literature, rather than systematic. We sought to identify if any changes could be detected since that often-cited paper, using a similar search strategy. Whilst not deeply exploring every paper (as a systematic review would) we sought to identify trends by examining abstracts only. Our results are consistent with other reviews, namely that there is a marked under-representation of older autistic people in autism research publications; however, we provide the novel finding that there is a small but consistently increasing trend for research with this group. Related to this, we did not examine

whether the focus of the study was on aging, or whether it simply included older autistic people among the participants. Thus, although we have examined the trends in papers based on our searches for autism and older age, we have not specifically tracked trends in research which has as its primary focus the ageing autistic population.

Conclusions

We found that there is still a dearth of autism research focused on older autistic people. What does exist focuses mainly on cross-sectional intra-individual factors (such as cognition, brain structure/function, and genetics). We make the case that autism researchers exploring older age ought to focus on areas such as quality of life and support needs (amongst others) and that active engagement with stakeholders (i.e. older autistic people) is essential. Additionally, studies that utilise longitudinal designs to examine age-related change are vital.

Given the difficulty in identifying research on autism in later life, we propose that a new unique keyword could be created and included in papers when reporting on research with older autistic people. This would help demarcate and raise the profile of the small but steadily growing literature on autism in old age.

Authorship confirmation statement

All authors designed the search strategy; DM and GRS performed all searches, and tabulated the data. All authors contributed to the writing of the manuscript.

Conflict of interest

The authors have no conflicts of interest to declare.

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There was no funding attached to this study.

Ethical statement

Ethics approval was not required for this study because there were no animal or human participants.

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Figure legends

Figure 1: Schematic illustration of the process of data collection for the four age-bands used in the search.

Figure 2: The main graph illustrates the average number of search results from each data base using each age group search criteria 1) pre-2012 and 2) 2012 and later (i.e. post Mukaetova-Ladinska et al, 2012). The inset graph illustrates the number of older age search results with a reduced axis scale.

Figure 3: The main graph illustrates the publication trends for the childhood, adolescent, adult, and older adult searches. The inset graph illustrates the number of older age search results over time with a reduced axis scale. The y-axes denote number of studies published.

Table 1: Number of records identified in the search, sorted by age group and database

	PubMed	PsychINFO	Embase	Average
Childhood & Early Life	31,919	35,138	37,561	34,873
Adolescence	5,607	6,046	7,018	6,224
Adulthood	9,011	8,612	10,540	9,388
Older age (initial)	291	419	647	452
Older age (stringent)	137	124	250	187

Note: A subtotal of 145 unique older age papers were identified across the three stringent searches. An additional 67 papers were identified through reference searching and papers known to the authors, making the final total of unique older age papers n = 212.

Table 2: A-priori research themes, with the number of older age autism papers coded into each theme

Theme	Frequency	% of total	% excl. Irrelevant.
General Health [a]	17	8.0%	11.8%
Genetics/Molecular	16	7.5%	11.1%
Reviews [b]	16	7.5%	11.1%
Cognition	15	7.1%	10.4%
Autism Characteristics/Traits	11	5.2%	7.6%
Mental Health	10	4.7%	6.9%
The Brain	10	4.7%	6.9%
Diagnosis/Prevalence	9	4.2%	6.3%
Miscellaneous	9	4.2%	6.3%
Support Needs	9	4.2%	6.3%
Quality of Life	8	3.8%	5.6%
Letter to Editor	6	2.8%	4.2%
Sensory Processing	5	2.4%	3.5%
Physical Health	3	1.4%	2.1%
Irrelevant	68	32.1%	-

Note: Total unique papers n = 212 (of which 145 identified by stringent search, and 67 added by searching reference lists and other papers known to the authors). Total unique papers excluding Irrelevant n = 144.

[a] papers that include both mental and physical health; [b] we included all reviews here, which may overlap with other categories (i.e. a review of sensory processing would go here, rather than in the sensory processing category.

'The brain' covers imaging and anatomical studies. ‘Genetics/Molecular' covers genetics, animal models, and fundamental science studies. 'Autism characteristics/traits' covers trait-based studies e.g., outcomes/experiences in the broad autism phenotype.

Figures

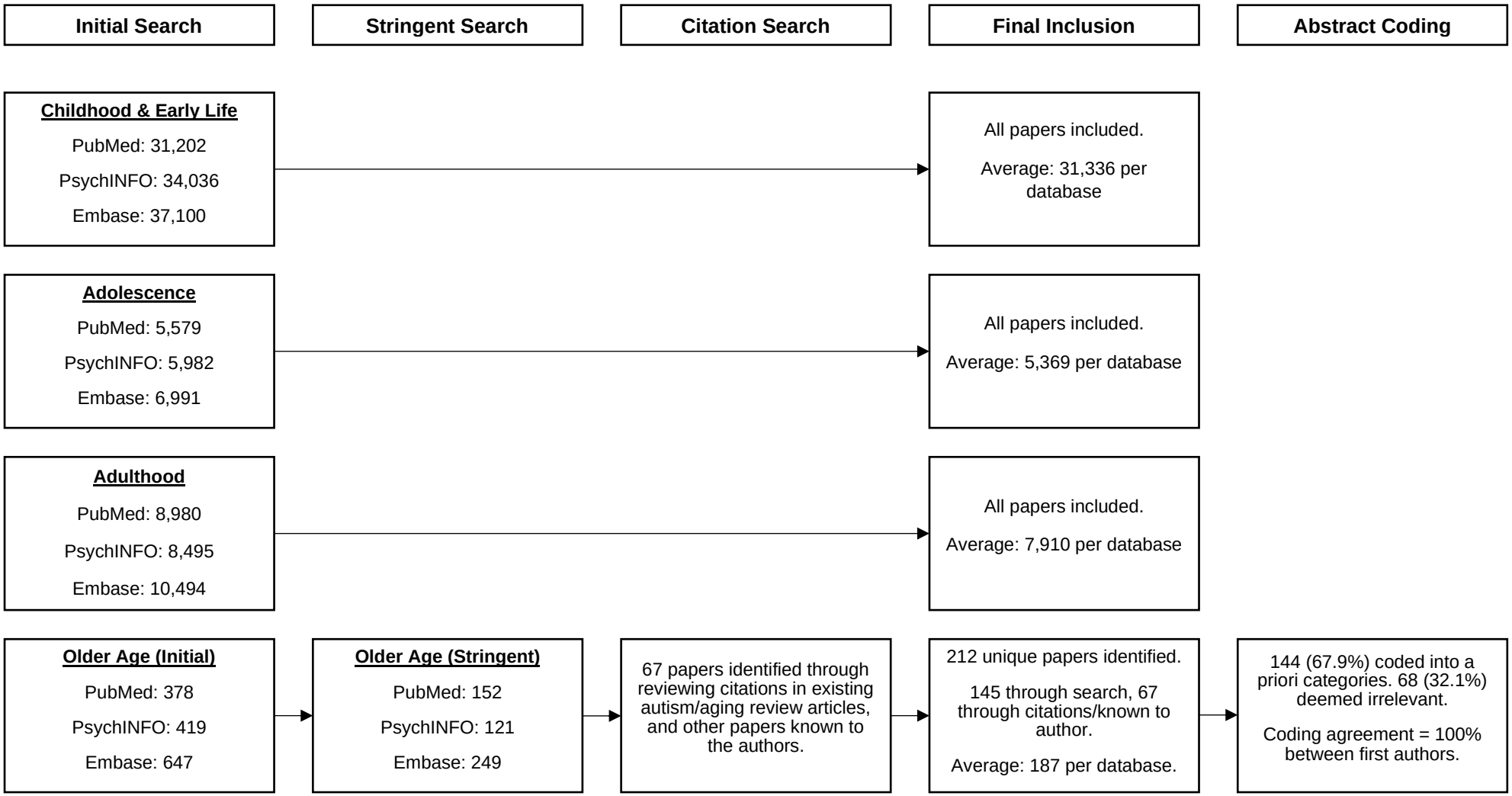


Figure 1: Schematic illustration of the process of data collection for the four age-bands used in the searches.

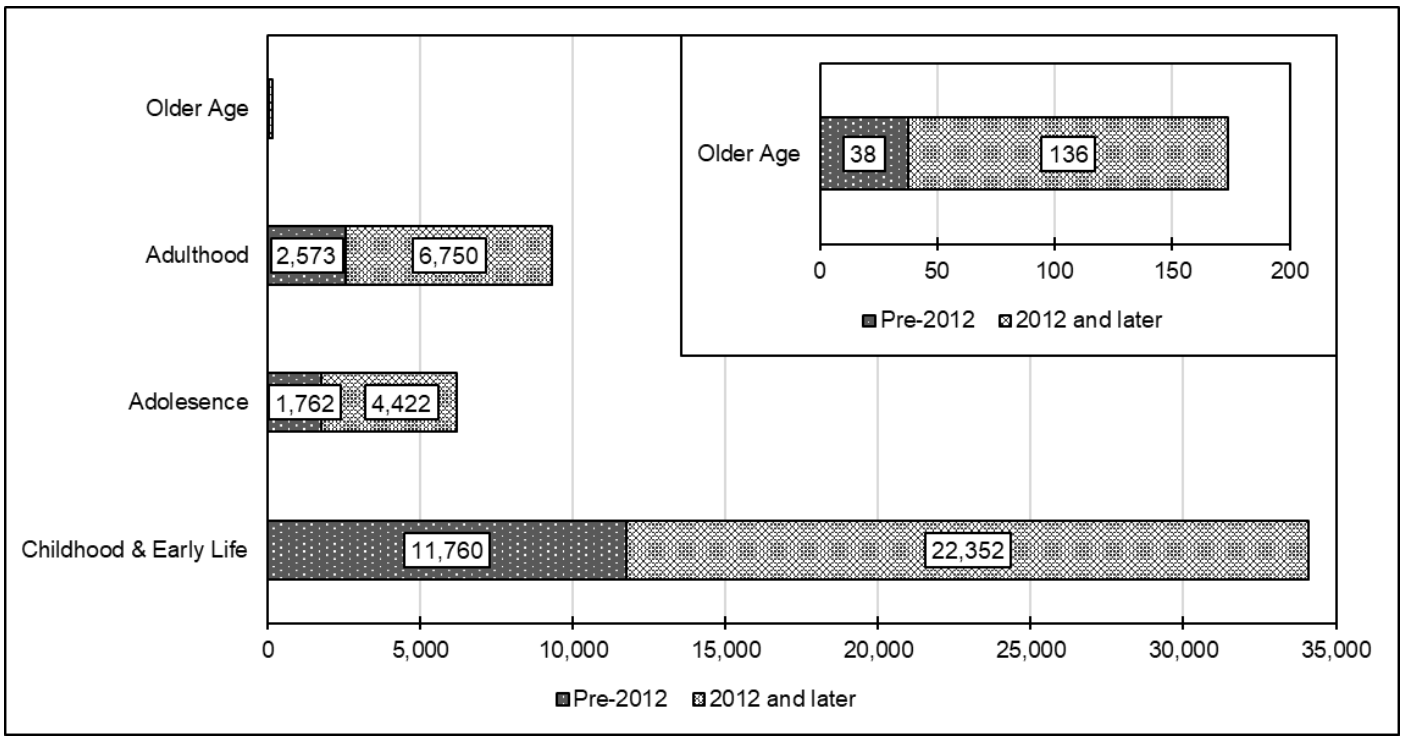


Figure 2: The main graph illustrates the average number of search results from each data base using each age group search criteria 1) pre-2012 and 2) 2012 and later (i.e. post Mukaetova-Ladinska et al, 2012). The inset graph illustrates the number of older age search results with a reduced axis scale.

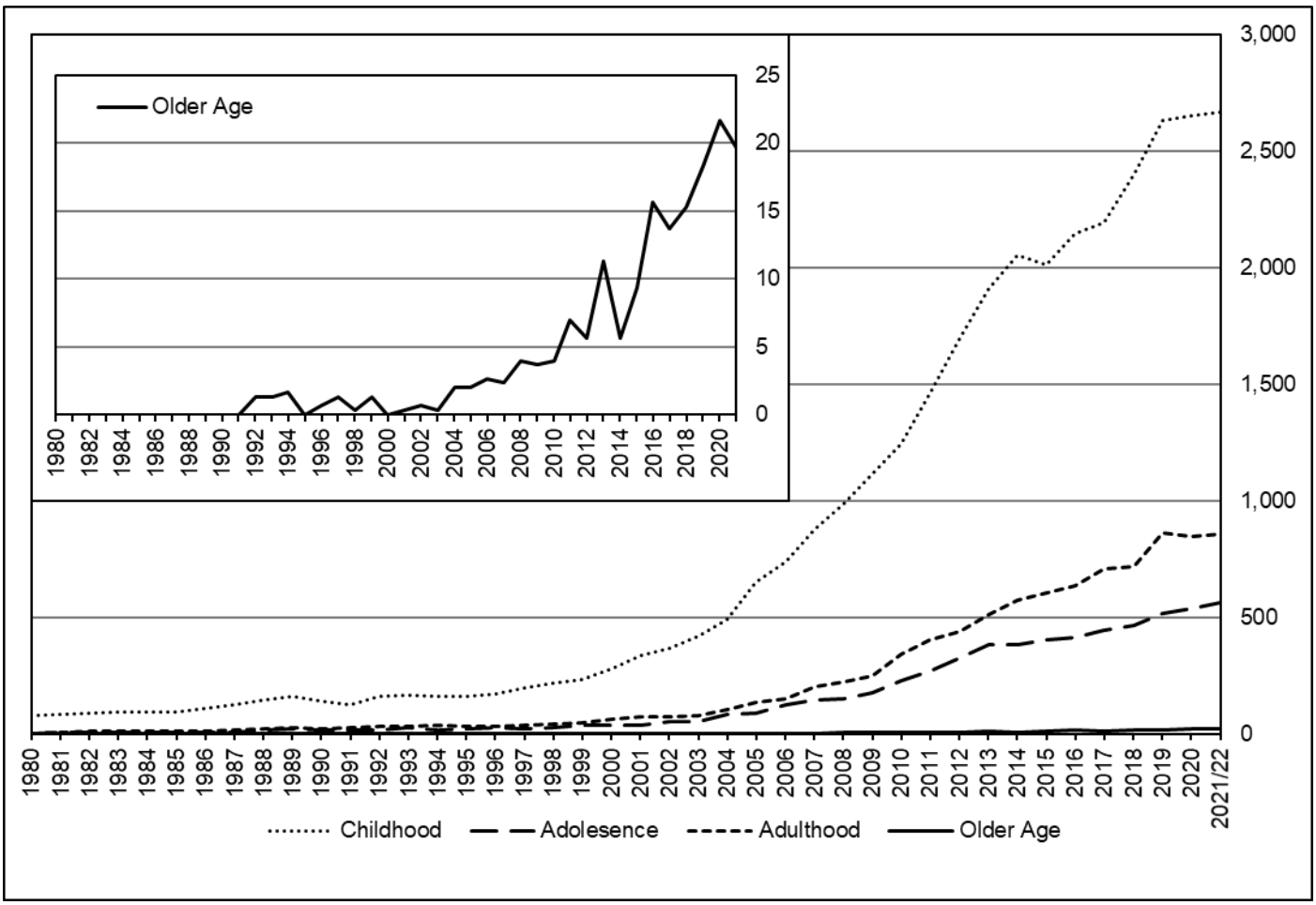


Figure 3: The main graph illustrates the publication trends for the childhood, adolescent, adult, and older adult (stringent) searches. The inset graph illustrates the number of older age (stringent) search results over time with a reduced axis scale. The y-axes denote number of studies published.

Supplementary Material 1: Comparison of search terms between the present search and Mukaetova-Ladinska et al's (2012) study:

Search term	Present study	Mukaetova-Ladinska et al.
Autism*	✓	✓
Autism spectrum disorder	✓	✓
Autistic*	✓	✓
Autistic disorder	✓	✓
Autistic symptoms	✓	✓
Asperger*	✓	✓
PDD-NOS	✓	
Toddler	✓	
Infant	✓	
Infancy	✓	
Child*	✓	
Children	✓	✓
Adolescence	✓	
Adolescent*	✓	✓
Teen*	✓	
Adult*	✓	✓
Young adult*	✓	✓
Old age*	✓	✓
Older age	✓	
Older adult	✓	
Elderly		✓

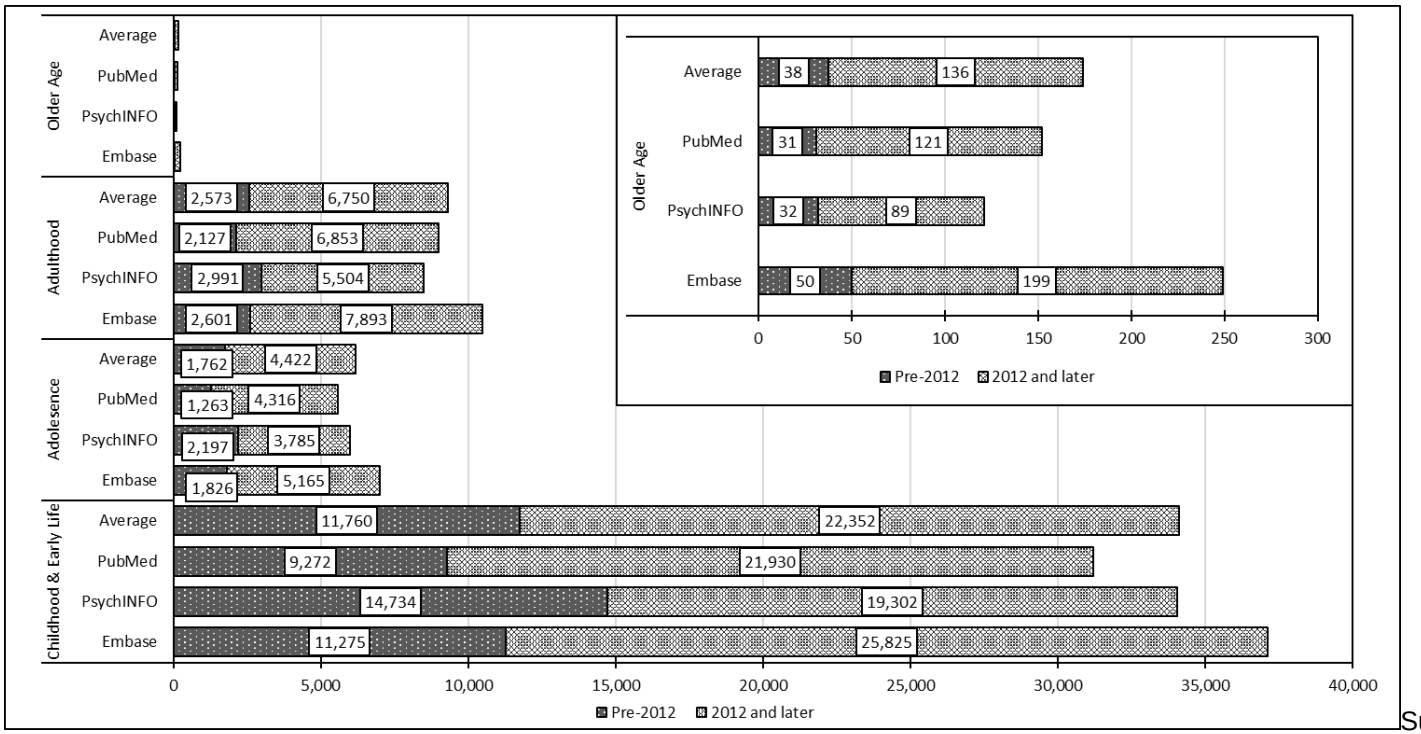
Elder*	✓	
Senior	✓	
Late* adulthood	✓	
Developmental disorder		✓
Aged		✓
Aged, 60 and over		✓

Note, the '*' used in conjunction with a search term is a wildcard. This will return all permutations and potential endings for the search term. For example 'autism*' will return 'autism', 'autism spectrum disorder', 'autism spectrum condition', 'autistic', 'autistic disorder' etc.

Supplementary Material 2: Example search strategy used in Embase for the older age group

1	Autism*
2	Autism spectrum disorder
3	Autistic*
4	Autistic disorder
5	Autistic symptoms
6	Asperger*
7	PDD-NOS
8	1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7
9	Old age*
10	Older age
11	Older adult
12	Elder*
13	Senior
14	Late* adulthood
15	9 OR 10 OR 11 OR 12 OR 13 OR 14
16	8 AND 15

Supplementary Material 3: Publication results by database



Supplementary Figure 1: The main graph illustrates the number of search results from each data base using each age group search criteria 1) pre-2012 and 2) 2012 and later (i.e. post Mukaetova-Ladinska et al, 2012). The inset graph illustrates the number of older age search results from each database with a reduced axis scale.

Supplementary Material 4: Full list of articles included in the stringent search, by a priori category

General Health (n=17)		
Title	**First Author**	**Year**
Executive Functions in Older Adults With Autism Spectrum Disorder: Objective Performance and Subjective Complaints	Davids, R. C. D.	2020
Health status of Medicare-enrolled autistic older adults with and without co-occurring intellectual disability: An analysis of inpatient and institutional outpatient medical claims	Gilmore, D.	2020
General health of adults with autism spectrum disorders - A whole country population cross-sectional study	Rydzewska, E.	2019
Is the Autism Boom Headed for Medicaid? Patterns in the Enrollment of Autistic Adults in Wisconsin Medicaid, 2008-2018	Rubenstein, E.	2019
The physical and mental health of middle aged and older adults on the autism spectrum and the impact of intellectual disability	Bishop-Fitzpatrick, L.	2019
General health of adults with autism spectrum disorders – A whole country population cross-sectional study	Rydzewska, E.	2019
A Danish register-based study on involuntary treatment in anorexia nervosa	Clausen, L.	2018
Older Adults with Autism Spectrum Disorders in Sweden: A Register Study of Diagnoses, Psychiatric Care Utilization and Psychotropic Medication of 601 Individuals	Nylander, N.	2018
Using machine learning to identify patterns of lifetime health problems in decedents with autism spectrum disorder	Bishop-Fitzpatrick, L.	2018

Prevalence of long-term health conditions in adults with autism: observational study of a whole country population	Rydzewska, E.	2018
Prevalence, types and associations of medically unexplained symptoms and signs. A cross-sectional study of 1023 adults with intellectual disabilities	Osugo, M.	2017
Health conditions and functional status in adults with autism: A cross-sectional evaluation	Fortuna, R. J.	2016
The health status of adults on the autism spectrum	Croen, L. A.	2015
Developmental Disorders and Dementia	Midorikawa, A.	2015
Prevalence of selected clinical problems in older adults with autism and intellectual disability	Kats, D.	2013
Prevalence of physical and mental health conditions in Medicare-enrolled, autistic older adults	Hand, B. N.	2006
The velocardiofacial syndrome in older age: dementia and autistic features	Evers, L. J. M.	2006

Genetics/Molecular (n=16)		
Title	**First Author**	**Year**
Conditional knockout of MET receptor tyrosine kinase in cortical excitatory neurons leads to enhanced learning and memory in young adult mice but early cognitive decline in older adult mice	Xia, B.	2021
Digging Signatures in 13-Month-Old 3xTg-AD Mice for Alzheimer's Disease and Its Disruption by Isolation Despite Social Life Since They Were Born	Gimenez-Llort, L.	2021
Sex bias in seizure susceptibility of a mouse model of the risk gene for autism spectrum disorder, CHD8	Muhle, R. A.	2021
ADNP differentially interact with genes/proteins in correlation with aging: a novel marker for muscle aging	Kapitansky, O.	2019
Heterozygous loss of function of IQSEC2/Iqsec2 leads to increased activated Arf6 and severe neurocognitive seizure phenotype in females	Jackson, M. R.	2019
Phenotypic characterization of an older adult male with late-onset epilepsy and a novel mutation in ASXL3 shows overlap with the associated Bainbridge-Ropers syndrome	Verhoeven, W. M. A.	2018
Increased Paternal Age at Conception Is Associated with Transcriptomic Changes Involved in Mitochondrial Function in Elderly Individuals	Nevalainen, T.	2016
A truncating mutation in Alzheimer's disease inactivates neuroligin-1 synaptic function	Tristán-Clavijo, E.	2015
Overlapping and distinct sex-specific serum molecular profiles in schizophrenia, depression, bipolar disorder, and Asperger syndrome	Ramsey, J. M.	2014
The effects of aging on the BTBR mouse model of autism spectrum disorder	Jasien, J. M.	2014

Genome-wide scan of healthy human connectome discovers SPON1 gene variant influencing dementia severity	Jahanshad, N.	2013
Fragile X-associated tremor/ataxia syndrome	Leehey, M. A.	2012
Differential usage of transcriptional start sites and polyadenylation sites in FMR1 premutation alleles	Tassone, F.	2011
Reduced glutathione regenerating enzymes undergo developmental decline and sexual dimorphism in the rat cerebral cortex	Dukhande, V.V.	2009
Chromosomal abnormalities in clinical psychiatry: A report of two older patients	Verhoeven, W. M. A.	2007
Presence of large deletions in kindreds with autism	Yu, C. E.	2002

Reviews (n=16)		
Title	**First Author**	**Year**
Autism spectrum disorder in older adults with intellectual disability: a scoping review	Maguire, E.	2021
Diagnosis of autism in adulthood: A scoping review	Huang, Y.	2021
Aging in Autism Spectrum Disorder	Wise, E. A.	2020
An overview of autism in the elderly	Amanullah, S.	2020
Annual Research Review: Looking back to look forward – changes in the concept of autism and implications for future research	Happé, F.	2020
Autism in Later Life: What Is Known and What Is Needed?	Sonido, M.	2020
Characteristics of Older Autistic Adults: a Systematic Review of Literature	Tse, V. W. S.	2020
Older Adults with ASD: The Consequences of Aging. Insights from a series of special interest group meetings held at the International Society for Autism Research 2016-2017	Roestorf, A.	2019
Aging and autism spectrum disorder: A naturalistic, longitudinal study of the comorbidities and behavioral and neuropsychiatric symptoms in adults with ASD	Wise, E. A.	2017
Old Age in Adults with ASD: Psychosocial Aspects—a Systematic Review	Parchomiuk, M.	2016
Autism spectrum disorders in elderly	Hasegawa, N.	2013
Ageing in people with autistic spectrum disorder	Mukaetova-Ladinska, E. B.	2012
Into the unknown: aging with autism spectrum disorders	Perkins, E. A.	2012

Aging in autism spectrum disorders: A mini-review	Happé, F.	2011
Autism spectrum disorders in older adults: toward defining a research agenda	Piven, J.	2011
Neurodevelopmental conditions and aging: report on the Atlanta Study Group Charrette on Neurodevelopmental Conditions and Aging	Janicki, M. P.	2008

Cognition (n=15)		
Title	**First Author**	**Year**
Age-Related Effects on Social Cognition in Adults with Autism Spectrum Disorder: A Possible Protective Effect on Theory of Mind	Yarar, E. Z.	2020
Short-term memory span and cross-modality integration in younger and older adults with and without autism spectrum disorder	Ring, M.	2020
Exploratory study of executive function abilities across the adult lifespan in individuals receiving an ASD diagnosis in adulthood	Abbott, P.	2019
Age group differences in executive network functional connectivity and relationships with social behavior in men with autism spectrum disorder	Walsh, M. J. M.	2019
The influence of age and ASD on verbal fluency networks	Baxter, L. C.	2019
Comparing Intellectual and Memory Abilities of Older Autistic Adults with Typically Developing Older Adults Using WAIS-IV and WMS-IV	Tse, V. W. S.	2019
Associations between executive functions and mental health outcomes for adults with autism spectrum disorder	Zimmerman, D.	2017
Executive Function and Functional and Structural Brain Differences in Middle-Age Adults With Autism Spectrum Disorder	Braden, B. B.	2017
Patterns of age-related cognitive differences in adults with autism spectrum disorder	Powell, P. S.	2017
Atypical working memory decline across the adult lifespan in autism spectrum disorder?	Lever, A. G.	2016
Age-related differences in cognition across the adult lifespan in autism spectrum disorder	Lever, A. G.	2016
Relational Memory Processes in Adults with Autism Spectrum Disorder	Ring, M.	2016

Executive Functions in Older Adults With Autism Spectrum Disorder: Objective Performance and Subjective Complaints	Davids, R. C. D.	2016
Executive Functioning in 60+ Autistic Males: The Discrepancy Between Experienced Challenges and Cognitive Performance	Geurts, H. M.	2015
Elderly with autism: executive functions and memory	Geurts, H. M.	2012

Autism Characteristics/Traits (n=11)		
Title	**First Author**	**Year**
Aging and autism spectrum disorder: Evidence from the broad autism phenotype	Wallace, G. L.	2020
The Mental and Physical Health Profiles of Older Adults Who Endorse Elevated Autistic Traits	Stewart, G. R.	2020
Theory of mind performance in younger and older adults with elevated autistic traits	Stewart, G. R.	2020
Aging with elevated autistic traits: Cognitive functioning among older adults with the broad autism phenotype	Stewart, G. R.	2019
Autism characteristics in older adults with depressive disorders	Geurts, H. M.	2019
Is Older Age Associated with Higher Self- and Other-Rated ASD Characteristics?	Lever, A. G.	2018
Is older age associated with higher self-and other-rated ASD characteristics?	Lever, A. G.	2018
Subjective cognitive impairment and the broad autism phenotype	Caselli, R. J.	2018
The Mental and Physical Health of Older Adults With a Genetic Predisposition for Autism	Stewart, G. R.	2018
Sleep problems and mental health difficulties in older adults who endorse high autistic traits	Stewart, G. R.	2016
Self-reported autism symptoms in adults with autism spectrum disorders	Bishop, S. L.	2012

Mental Health (n=10)		
Title	**First Author**	**Year**
Anxiety and Depression from Adolescence to Old Age in Autism Spectrum Disorder	Uljarević, M.	2020
Autism spectrum disorder and risk for psychosis: A psychiatric case register study in the Netherlands	Schalbroeck, R.	2017
Aging and Autism Spectrum Disorder: A Naturalistic, Longitudinal Study of the Comorbidities and Behavioral and Neuropsychiatric Symptoms in Adults with ASD	Wise, E. A.	2017
Psychiatric Co-occurring Symptoms and Disorders in Young, Middle-Aged, and Older Adults with Autism Spectrum Disorder	Lever, A. G.	2016
Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study	Sheehan, R.	2015
Self and informant reports of mental health difficulties among adults with autism findings from a long-term follow-up study	Moss, P.	2015
Anxiety symptoms across the lifespan in people diagnosed with Autistic Disorder	Davis, T. E.	2011
Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders	Hofvander, B.	2009
Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities	Cooper, S. A.	1997
Clinical psychopathologic study of aged chronic schizophrenics in residential homes for the elderly--relapsed and non-relapsed	Mastuzawa, N.	1994

The Brain (n=10)		
Title	**First Author**	**Year**
Age-variant and age-invariant features of functional brain organization in middle-aged and older autistic adults	Bathelt, J.	2020
Becoming Stressed: Does the Age Matter? Reviewing the Neurobiological and Socio-Affective Effects of Stress throughout the Lifespan	Mañas-Ojeda, A.	2020
Impaired motor skills and atypical functional connectivity of the sensorimotor system in 40- to 65-year-old adults with autism spectrum disorders	Linke, A. C.	2020
Autistic traits modulate the activity of the ventromedial prefrontal cortex in response to female faces	Murakami, Y.	2018
Lifespan oxytocin signaling: Maturation, flexibility, and stability in newborn, adolescent, and aged brain	Sannino, S.	2017
Age-related differences in autism: The case of white matter microstructure	Koolschijn, P. C. M. P.	2016
Gray Matter Characteristics in Mid and Old Aged Adults with ASD	Koolschijn, P. C. M. P.	2016
Motion and morphometry in clinical and nonclinical populations	Pardoe, H. R.	2016
The neural correlates of perceptual closure in adults and elderly with autism spectrum disorders	Grützner, C.	2014
Heparan sulfate deficiency in autistic postmortem brain tissue from the subventricular zone of the lateral ventricles	Pearson, B. L.	2013

Diagnosis/Prevalence (n=9)		
Title	**First Author**	**Year**
Differential diagnosis personality disorder versus autism spectrum disorder in older adults	Videler, A. C.	2020
Is Autism inborn and lifelong for everyone?	Whiteley, P.	2019
Autism or personality disorder in older adults? Guidelines for the differential diagnosis	Videler, A. C.	2018
Screening of Autism Spectrum Disorders in Geriatric Psychiatry	Heijnen-Kohl, S. M. J.	2017
Demographic and Cognitive Profile of Individuals Seeking a Diagnosis of Autism Spectrum Disorder in Adulthood	Happé, F.	2016
Identifying the lost generation of adults with autism spectrum conditions	Lai, M. C.	2015
Screening of autism spectrum disorders in the elderly: a contribution to a psychometric approach	van Alphen, S. P. J. B	2012
Diagnosing autism spectrum disorders in elderly people	van Niekerk, M. E. H.	2011
Diagnosis of Asperger syndrome in a 66-year-old male presenting with depression	Naidu, A.	2006

Miscellaneous (n=9)		
Title	**First Author**	**Year**
Isolating residents including wandering residents in care and group homes: Medical ethics and English law in the context of Covid-19	Liddell, K.	2021
Refractory catatonia in old age: a case report	Bean, E.	2021
‘A way to be me’: Autobiographical reflections of autistic adults diagnosed in mid-to-late adulthood	Lilley, R.	2021
Priority concerns for people with intellectual and developmental disabilities during the COVID-19 pandemic	Tromans, S.	2020
Evaluation of employment-support services for adults with autism spectrum disorder	Nicholas, D. B.	2018
Euthanasia and Assisted Suicide of Patients With Psychiatric Disorders in the Netherlands 2011 to 2014	Kim, S. Y. H	2016
Diogenes syndrome and autistic spectrum disorder	Sadlierm, M.	2011
Age-related differences in restricted repetitive behaviors in autism spectrum disorders	Esbensen, A. J.	2009
Acquired 'theory of mind' impairments following stroke	Happé, F.	1999

Support Needs (n=9)		
Title	**First Author**	**Year**
Care providers' perceptions and awareness of health services and programs for autism spectrum disorder among the aging population	Vega, K.	2021
A Meta-analysis of Outcome Studies of Autistic Adults: Quantifying Effect Size, Quality, and Meta-regression	Mason, D.	2020
Correlates of daily functioning in older adults with autism spectrum disorder	Wise, E. A.	2019
Growing older with autism – The experiences of adult siblings of individuals with autism	Moss, P.	2019
Suddenly the first fifty years of my life made sense: Experiences of older people with autism	Hickey, A.	2018
Characteristics of adults with autism spectrum disorder who use residential services and supports through adult developmental disability services in the United States	Hewitt, A. S.	2017
Co-Creating the Autistic Satisfaction with Care Holistic Interview to Examine the Experiences of Older Autistic Adults in Residential Care	Crompton, C. J.	2016
Old age and people on the autism spectrum: a focus group perspective	Barber, C.	2015
Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children	Howlin, P.	2013

Quality of Life (n=8)		
Title	**First Author**	**Year**
Quality of life in adults with autism spectrum disorder: influence of age, sex, and a controlled, randomized mindfulness-based stress reduction pilot intervention	Braden, B. B.	2021
Quality of life for older autistic people: the impact of mental health difficulties	Mason, D.	2020
Aging and autism: Understanding, intervention and proposals to improve quality of life	Ruggieri, V.	2019
Aging well on the autism spectrum: an examination of the dominant model of successful aging	Hwang, Y. I.	2018
Child and Adult Factors Related to Quality of Life in Adults with Autism	Moss, P.	2017
Model of social exclusion of the elderly people in Siberian Regions	Maximova, S. G.	2017
Quality of life in autism across the lifespan: a meta-analysis	van Heijst, B. F. C.	2015
Behavior problems, psychiatric symptoms, and quality of life for older adults with intellectual disability with and without autism	Totsika, V.	2010

Letter to the Editor / Editorial (n=6)		
Title	**First Author**	**Year**
Research, Clinical, and Sociological Aspects of Autism	Whiteley, P.	2021
Talking about autism-thoughts for researchers	Robison, J. E.	2019
Autism prevalence and outcomes in older adults	Robison, J. E.	2018
Aging with autism spectrum disorder: an emerging public health problem	Hategan, A.	2017
What is Life Like in the Twilight Years? A Letter About the Scant Amount of Literature on the Elderly with Autism Spectrum Disorders	Bennett, M.	2016
Why we need research about autism and ageing	Michael, C.	2016

Sensory Processing (n=5)		
Title	**First Author**	**Year**
Assessing sensory processing dysfunction in adults and adolescents with autism spectrum disorder: A scoping review	DuBois, D.	2017
Age and sensory processing abnormalities predict declines in encoding and recall of temporally manipulated speech in high-functioning adults with ASD	Mayer, J. L.	2014
Sensory processing in adults with autism spectrum disorders	Crane, L.	2009
Sensory sensitivities and performance on sensory perceptual tasks in high-functioning individuals with autism	Minshew, N. J.	2008
Sensory correlations in autism	Kern, J. K.	2007

Physical Health (n=3)		
Title	**First Author**	**Year**
Self-reported parkinsonism features in older autistic adults: A descriptive study	Geurts, H. M.	2021
Women with autism in the Netherlands: Health and healthcare disparities	Waltz, M.	2019
High rates of parkinsonism in adults with autism	Starkstein, S.	2015

Irrelevant (n=68)		
Title	**First Author**	**Year**
A media intervention applying debunking versus non-debunking content to combat vaccine misinformation in elderly in the Netherlands: A digital randomised trial	Yousuf, H.	2021
Diagnostic progression to bipolar disorder in 17,285 adolescents and young adults with attention deficit hyperactivity disorder: A longitudinal follow-up study	Chu, C. S.	2021
Extracellular Vesicles in Neurological Disorders	Mazurskyy, A.	2021
Medical Students and SARS-CoV-2 Vaccination: Attitude and Behaviors	Szmyd, B.	2021
Participatory autism research: Early career and established researchers' views and experiences	Pickard, H.	2021
Polypharmacy is a risk factor for mortality, severe chronic kidney disease, and liver disease among privately insured adults with cerebral palsy	Whitney, D. G.	2021
Reduced multisensory facilitation exists at different periods of development in autism	Ainsworth, K.	2021
Transgenerational epigenetic information through the sperm: Sperm cells not just merely supply half of the genome for new life	Osumi, N.	2021
Vitamin D: A Pleiotropic Hormone with Possible Psychotropic Activities	Marazziti, D.	2021
Chromosome instability, aging and brain diseases	Yurov, Y. B.	2021
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