



Time to Change How We Measure Quality of Life and Well-Being in Autism: A Systematic Review

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Abstract

This review examines methods used to report on the QoL and/or well-being of autistic people. A search of four databases (June 2023) identified 256 studies that reported on the QoL and/or well-being of at least one autistic person. The quality of studies varied. Results were synthesised on who reported, who was reported on, how information was obtained including accommodations and community involvement. One-third used proxy informants, over 80% used generic measures of QoL and/or well-being, autistic people with intellectual impairment and communication disorders were underrepresented, one quarter included accommodations, and few studies included community involvement. Despite the growing research on QoL and well-being of autistic people, more accessible and inclusive research is required to understand autistic people's experience.

Keywords Autism · Co-occurring conditions · Participatory research · Life outcomes · Wellness

Autism is a heterogenous presentation of characteristics including social communication differences and behaviours that are present across the lifespan (American Psychiatric Association, 2013). Although autism is a single diagnosis,

there is significant variability in autistic profiles and characteristics, depending in part on age, intersectionality, and myriad other contextual and environmental influences. Thus, each autistic individual has their own unique profile of strengths and challenges, which may influence not only a person's experience of well-being, but also their definition of what constitutes their specific well-being. Furthermore, many autistic people are reported to have co-occurring conditions including mood disorders, psychiatric conditions, medical conditions, intellectual impairment, and language impairments (Hossain et al., 2020; Lai et al., 2019; Maenner et al., 2023). Some of these conditions are observable from an early age, with as many as 95% of autistic children reported to have at least one co-occurring condition (Soke et al., 2018), 30% of autistic children estimated to have a co-occurring intellectual disability (Maenner et al., 2023), and an estimated 30% of children designated as non-speaking (Tager-Flusberg & Kasari, 2013). The complexity and constellations of these factors suggest that what constitutes quality of life or well-being for an autistic person may be different to normative societal views and that assuming that non-autistic experiences of well-being neatly 'map' onto autistic experiences of it likely does a disservice to our attempts to promote autistic flourishing (Pellicano & Heyworth, 2023).

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One of the most widely used definitions of QoL is from the World Health Organization (WHO): ‘Quality of life is defined as individuals’ perceptions of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’ (World Health Organization Division of Mental Health, 1996, p. 3). As such, QoL is a multidimensional construct that includes subjective perceptions of the interactions of physical health, psychological state, level of independence, social relationships, and education/vocational satisfaction. World Health Organization Division of Mental Health (1996) further described that this definition is focussed on perceptions of QoL, differentiating this from well-being as a separate construct. There is ongoing discussion of what constitutes QoL or well-being in autistic individuals and whether definitions or measures developed for neurotypical individuals are applicable or appropriate. McConachie et al. (2020) explored the perspectives of autistic adults across four countries on the relevance of questions on the World Health Organization QoL questionnaire (WHOQOL-BREF) and the WHOQOL Disabilities add-on module. Although the questions within these questionnaires were identified as relevant, the autistic adults identified important themes missing from the questionnaires. These included positive autistic identity and their contribution to society, societal understanding and attitudes, and environmental influences on quality of life. This study was conducted with a small number of autistic adults and additional themes or differences in themes may be evident for other autistic people of different ages, abilities, cultures, and socioeconomic status. This may be particularly pertinent to autistic individuals with complex needs whose priorities, preferences, and abilities may differ. For example, vocational engagement, independent living, or socialisation may differ from the aspirations or interests of neurotypical individuals, with these embedded in measures of QoL developed by or for neurotypical individuals. Furthermore, the wording, response options and structure of items used in measures designed for neurotypical populations may create a barrier for autistic people (Nicolaidis et al., 2020).

Using standard measures, QoL has been found to be lower for autistic adults than for non-autistic adults (see review with 14 adult studies; Ayres et al., 2018). However, the inherent limitation of this approach is the assumption that the same domains for QoL apply to autistic people and non-autistic people. Additionally, this approach does not capture potential individual differences in what constitutes QoL between individuals. In response, recent efforts have focused on creating QoL measures for specific conditions to measure factors specific to particular populations. This has included creating additional items to include autism-specific features to the World Health Organization Quality of Life-Brief version (WHOQOL-BREF; McConachie et al., 2018) as well

as revising an existing measure (Patient-Reported Outcomes Measurement Information System [PROMIS-10] for autistic individuals; Williams et al., 2023). This is an emerging area of research, with McConachie et al. (2018) the first to validate a measure of QoL with autistic adults.

Well-being may be viewed as a related, but separate construct to QoL. Well-being for neurotypical individuals has been conceptualised in many ways, which can be categorised broadly as either subjective or objective. Subjective well-being refers to the self-evaluation of one’s emotional and cognitive well-being, including being engaged in interesting activities, experiencing frequent pleasant feelings and infrequent unpleasant feelings, and experiencing an overall subjective experience of life as satisfying (Diener, 1984). ‘This subjective definition of quality of life is democratic in that it grants to each individual the right to decide whether his or her life is worthwhile’ (Diener, 1984, p. 34). Medvedev and Landhuis (2018) proposed a global well-being dimension that encapsulated connected terms such as subjective well-being, happiness, and psychological quality of life. An objective conceptualisation ‘defines well-being in terms of the degree to which a person is fully functioning’ (Ryan & Deci, 2001, p. 141). However, a person’s functioning focuses on normative achievements which may not reflect well-being for an autistic person (Lam et al., 2021; Robeyns, 2016). For example, full time employment is a normative achievement identified in well-being measures. Autistic people identify positives associated with this which align with a normative approach (e.g. financial independence) but also negative impacts on their subjective well-being (e.g. discrimination, trauma) not encapsulated in the normative achievement (Raymaker et al., 2023). This example highlights well-being is influenced by the environment and feelings of well-being may be dependent on the autistic person’s context (Lam et al., 2021). Taken together, these perspectives suggest well-being may be conceptualised as including subjective (e.g. perceived satisfaction with social support) as well as objective (e.g. amount of environmental social support, food/nutrition, money, employment, housing, safety) components. Compared to QoL, well-being is an underresearched area in autistic individuals, but there are interesting philosophical discussions on the construct and how neurotypical models may or may not apply to autistic individuals (e.g. Robeyns, 2016; Rodogno et al., 2016). To broaden the understanding of autistic well-being requires and critically reflecting on current methods used and diversifying approaches to respect the diverse range of experiences of autistic people across the lifespan (Lam et al., 2021).

In the last 5 years, there have been a number of reviews published summarising the QoL or well-being of autistic people. Evers et al. (2022) reported on the subjective and multidimensionality of QoL of autistic people, but their

review was limited to quantitative methodological studies and as such did not include studies that may have provided deeper understanding of the perspectives of autistic people on their QoL or well-being. Other reviews have been limited by focusing on a participant demographic including autistic adults (Ayres et al., 2018; Lam et al., 2021), autistic women (Yau et al., 2023), and autistic people without co-occurring intellectual disability (Krumpelman & Hord, 2021). As such, these reviews provide snapshots of information but fail to provide an overview of the QoL and well-being research in autistic individuals across the lifespan.

Objectives

Previous reviews on quality of life and/or well-being of autistic people have been limited by the demographics of the study participants and the methodology of studies. The aim of this study was to provide a comprehensive review of the research literature looking at how QoL and/or well-being of autistic people was being measured and who was included in this research. This is important so as to identify any groups where the research is more established as well as any groups where the research is only just emerging. This can help guide researchers' focus for future work and also help guide those interpreting the research (e.g. clinicians) to know the extent of the literature that conclusions are being based upon.

This included asking the following questions:

- (a) Whose QoL and/or well-being is being described?
- (b) Who is reporting on the autistic person's QoL and/or well-being?
- (c) What methods are used to measure QoL and/or well-being?
- (d) What accommodations (if any) were provided to support broad participation in the study?
- (e) What proportion of studies included autistic or autism community involvement and to what aspects of the study did they contribute?

Method

The protocol for this systematic review was registered online with the International Prospective Register of Systematic Reviews (PROSPERO; registration number: <removed for anonymised review>). The review was conducted in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analyses checklist (PRISMA, Page et al., 2021).

Community Involvement

Community input held significant value for achieving the primary objective of the research. This participatory approach provided access to personal and collective perspectives, experiences, and insights and ensured that the voices and lived experiences of the autistic and autism communities are represented and integrated into QoL and/or well-being research. Members of the autistic and autism communities were involved in each stage of this project. The research project was commissioned based on the priorities identified by the autistic and autism communities. The research team included members of a national autism organisation and multiple autistic researchers and worked with an advisory group comprised of representatives from five end-user organisations—some of whom identify as part of the autistic community—and two autistic experts who use augmentative and alternative communication and identify as having complex communication or support needs. At each stage of the project, feedback from the community was provided. This feedback was shared during the advisory group meeting and/or through feedback on the meeting points for discussion. This meant that community input was instrumental to identifying and shortlisting search terms, interpretation of the results, and the dissemination of the findings. For example, initially the focus had been on individuals with complex communication and/or support needs. There was some disagreement between members in regard to how to describe search terms for this group. A survey of terms was sent to all members involved (format was individualised for the autistic experts), and they were asked to rate if the terms would be included or not. As a result, the search terms encompassed a broad population (see Table 1, search terms 3 and 4) to respect the viewpoints of all involved. Community input was sought for all decisions. If there was any disagreement, the issue was discussed and all point of viewpoints considered until an agreed outcome was reached.

Search Strategy

PROSPERO was first searched to confirm that no other systematic reviews on this topic were underway. The search strategy was then co-developed by the authors. The initial search was conducted in October 2022, with an updated search in June 2023. There were no date limits set with papers retrieved published between 1998 and June 2023. Four electronic databases (PsycINFO, ERIC [Proquest], Scopus, and PubMed) were selected to cover the broad range of disciplines relevant to autism research. A comprehensive range of search terms were used to identify studies which included autistic people as a subgroup (i.e. where the focus of the study was on different conditions, but some participants were autistic). The two areas of interest were (a) quality of life or well-being and (b) autism. Search terms reported in Table 1

Table 1 Search terms

Number	Factor	Search terms
1	Quality of life	Quality of life OR QoL OR health-related QoL OR HRQOL OR 'health-related quality of life'
2	Well-being	Well being OR wellbeing OR well-being
3	Autism	autis* OR ASD OR Asperger* OR 'pervasive developmental disorder' OR PDD* OR
4	Co-occurring conditions	AAC OR augmentative and alternative communication OR catatonia OR complex care OR complex support OR complex need* OR complex communication OR communication deficit* OR delay* OR disabl* OR disabilit* OR disorder OR impair* OR non speak* OR nonspeak* OR non verbal OR nonverbal OR limited speech OR multimodal communicat* OR min* verbal OR retard* OR handicap OR neurodevelop* OR neurodiver* OR 'medical condition'

* truncation

reflected these two areas of interest. They were combined for each database using the search string of (1 OR 2) AND (3 OR 4). When full text articles were not able to be located for articles identified for inclusion at title and abstract, the authors of studies were contacted for a full text.

Eligibility Criteria

Inclusion criteria were as follows: (1) original research (including theses) reporting data from human participants; (2) written in English; (3) title/abstract states that the article reports on quality or life and/or well-being; (4) include and report on the quality of life and/or well-being of people who identify as having an autism diagnosis (diagnostic label may be autism spectrum disorder [ASD], autism, autistic disorder, Asperger's syndrome, pervasive developmental disorder not otherwise specified [PDD_NOS]); (5) in studies that have participants with mixed diagnoses, the quality of life and/or well-being of autistic individuals are reported separately. Exclusion criteria were as follows: (1) not reporting on QoL or well-being of an autistic subgroup separately; (2) reported on another person's QoL or well-being rather than the autistic individual (e.g. parent); (3) did not report on QoL or well-being (e.g. happiness); (4) conference papers, intervention studies, and editorials; (5) not published in English.

Review Process

Results of the database searches were initially imported into Endnote where duplication screening was conducted. Results were imported into Covidence systematic review software where a further duplication of the search results was conducted. A document detailing full inclusion and exclusion criteria was developed and tested by the team of reviewers (see Supplementary File 1); wording was modified for clarification and then used by the team of reviewers who screened title, abstracts, and full texts. The title/abstract screening was conducted by the research team with 20% checked for

inter-rater reliability (Kappa coefficient = 0.42) showing moderate agreement. Disagreements were investigated and it was identified that at this level the team raters were more likely than the inter-rater to include articles, highlighting that the team were being cautious and ensuring all possible articles were further considered. At the subsequent full text level, the articles that were subject to disagreement were excluded by the team. Then, full texts were checked against inclusion criteria, with 20% checked for inter-rater reliability (Kappa coefficient = 0.79) showing substantial agreement. The disagreements were reviewed by the first author who determined if articles met the inclusion criteria.

Data Extraction

A data extraction template was developed in Covidence. Information extracted included study data (author, year, country, study design, sample size), informant (age, gender, ethnicity, diagnoses including co-occurring conditions), the autistic individual reported on (age, gender, ethnicity, diagnoses including co-occurring conditions), the data collection method (method used to obtain information on QoL and/or well-being, measure of QoL and/or well-being) and QoL and/or well-being outcomes. Reliability of data extraction was ensured by dual extraction for 20% of the studies.

Data Synthesis

Data synthesis involved creating categories addressing the research questions and collating key information from eligible studies. Categories include the participant being described, the informant (i.e. self/other), accommodations incorporated to facilitate participation, and measurement used. Synthesis included quantitative (number/percentage of studies, measures) and qualitative (e.g. description of measures).

Assessment of Study Quality

Included studies were evaluated for methodological quality. As studies may include qualitative, quantitative, and mixed- or multi-methods studies, the 13-item Quality Appraisal for Diverse Studies (QuADS; Harrison et al., 2021) was selected. Four possible responses were provided for each item ranging from 0 (not mentioned or included) to 3 (detailed evidence or explanation) resulting in a maximum score of 39. The QuADS has substantial inter-rater reliability and face and content validity for different research designs (Harrison et al., 2021). Studies were assessed by three research assistants (two neurodivergent researchers and all trained in psychology with experience in evaluating quality of studies), with 20% double-assessed for inter-rater reliability. Consultation and discussion were conducted to resolve disagreements. In a small number of cases, there was a disagreement in ratings between the research assistants of one point. In these situations, the first author provided the final decision. There was strong agreement between the reviewers (Kappa coefficient = 0.90). Agreement varied across items with Kappa coefficient ranging from 0.69 (clear description of research setting and target population) to 1.00 (the format and content

of data collection tool are appropriate to address the stated research aim/s). Studies were included irrespective of their quality.

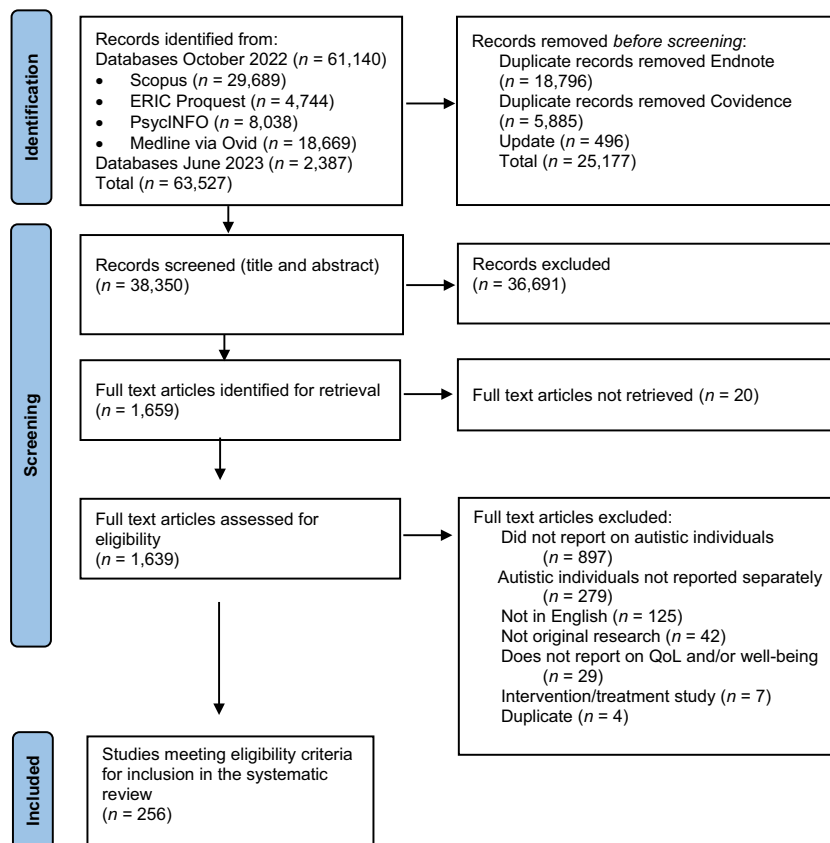
Results

Our search identified 63,527 records (see Fig. 1). After removal of duplicates, 38,350 articles were screened for inclusion. In total, 256 were included in the final database (Supplementary File 2 Reference List).

Quality Appraisal Findings

The mean quality assessment score on the QuADS for included studies was 24.89 (*SD* = 4.68) of 39 possible points, with study scores ranging from 13 to 36. Almost all (90%) of the studies scored 2 or 3 on three items: study design is appropriate; appropriate methods of analysis; and format of data collection. The lowest rated item ‘evidence that the research stakeholders have been considered in research design or conduct’ was rated 1 or below in over 90% of the studies. The complete list of total scores for each study can be found in Supplementary File 3 (Table S1 Summary of reviewed literature).

Fig. 1 Prisma (2020) flow diagram of search and selection results



Whose QoL and/or Well-Being Is Being Described in the Research?

Participant Demographics The included studies reported on the QoL and/or well-being of 51,576 autistic individuals, with sample sizes ranging from 1 to 4910. Three studies did not report the total number of autistic participants. Studies were predominantly conducted in the United States (32.0%, $k = 82$), UK (16.0%, $k = 41$), and Australia (9.8%, $k = 25$). Over half (55%) of the studies were published between 2019 and 2023. One influencing factor during this period was COVID-19, with 5.4% ($k = 14$) of the total studies addressing COVID impacts on the QoL or well-being of autistic people. The key characteristics of the included studies are presented in Table S1 in Supplementary material.

Age and Gender The QoL and/or well-being was reported on autistic individuals across the lifespan (age range 3–83 years). In terms of age, studies reported on autistic children (40.6%, $k = 104$), autistic adults (40.6%, $k = 104$), and both autistic children and adults (11.3%, $k = 29$). Some studies (7.4%, $k = 19$) did not provide the age of the autistic participants. Gender was reported for the autistic individuals in 84.7% ($k = 217$) of the studies. The remaining studies did not report gender for the group or specifically for the autistic population. Binary gender was most frequently reported, with proportionally more males than females (2.2:1) which is lower than previously reported ratios (Loomes et al., 2017). Sixteen studies (6.2%) investigated the QoL and/or well-being in males only and seven studies (2.7%) in females only. Twenty-seven studies (10.5%) reported on the proportion of individuals who do not identify with a binary gender, with one study specifically exploring QoL in this population.

Co-occurring Conditions

Intellectual Functioning Over half the studies (59.4%, $k = 152$) did not provide descriptive information on the autistic person's intellectual functioning. Although autistic people with intellectual disability were the focus of 11.3% ($k = 29$) of the studies, they were excluded from a larger proportion of studies (14.1%, $k = 36$). Additionally, some studies did not specifically state an inclusion criterion on ability but noted that all participants had an IQ > 70 (7.4%, $k = 19$). In 8.6% ($k = 22$) of the studies, autistic people with and without intellectual disability were included together.

Language and Literacy Skills In most studies (85.5%, $k = 219$), autistic participants' expressive and/or receptive language skills were not reported or were not reported separately. In 3.5% ($k = 9$) of the studies, autistic participants were

described as having verbal skills and or verbal comprehension within typical ranges or having high literacy levels; this was an inclusion criterion in two studies. Of the remaining studies, 6.6% ($k = 17$) included autistic participants with a range of expressive and receptive skills from non-speaking to within typical levels, and 4.3% ($k = 11$) identified all participants as having expressive and/or receptive language delays. Hamm et al. (2006) was the only study that identified that the participants were all augmented or alternative communication method (AAC) users, reporting on two autistic people.

Other Co-occurring Conditions In addition to intellectual disability and language impairments, other co-occurring conditions were specifically reported in 105 (41.0%) studies. The most frequently reported co-occurring conditions in these studies were mood disorders (i.e. depression, bipolar; 47.6%, $k = 50$), ADHD (46.6%, $k = 49$), and anxiety disorders (43.8%, $k = 46$).

Who Is Reporting on the Autistic Person's QoL and/or Well-Being?

Informants Informants were autistic adults (i.e. adult self-report; 34.8%, $k = 89$), autistic children (i.e. child self-report; 7.0%, $k = 18$), autistic children and autistic adults (3.1%, $k = 8$), proxy (e.g. parent/caregiver, professional; 34.4%, $k = 88$), autistic child with proxy (10.9%, $k = 28$), autistic adult with proxy (6.6%, $k = 17$), or autistic child or autistic adult with proxy (2.7%, $k = 7$). The informant was not identified in one study where the data had been extracted from a database. Twelve studies identified a proxy informant was used when the autistic person was not able to complete the self-report measure (Carr, 2015; Clarke et al., 2021; Deserno et al., 2017; Domellöf et al., 2014; Garcia-Villamisar et al., 2013; Hamm & Mirenda, 2006; Mason et al., 2018; McConachie et al., 2018; Moss et al., 2017; Rearick, 2015; Totsika et al., 2010; Yetenekian, 2019), and one study excluded autistic informants who did not provide a coherent response (Berkovits et al., 2020). In one study, the children in the control group completed the measure but this option was not provided to the autistic children (Eslami et al., 2018).

How Is QoL and Well-Being Measured?

Quantitative Measures The majority of the studies (87.9%, $k = 225$) included a tool (identified in the study as measuring QoL and/or well-being) that was quantitatively analysed. These included questionnaires, surveys, and structured interviews. Of these studies, 75.1% ($k = 169$) measured QoL, 22.7% ($k = 51$) measured well-being, and 2.2% ($k = 5$) included both QoL and well-being measures. The most frequently used measures of

QoL were the Pediatric Quality of Life (PedsQL; Varni et al., 1998) and the WHOQOL-BREF (The WHOQOL Group, 1998), each used in 22.4% ($k = 39$) of the studies that reported on QoL. The Warwick Edinburgh Mental Wellbeing Scale (WEMWBS; Tennant et al., 2007) was the most frequently used measure of well-being and was reported in 14.2% ($k = 8$) of studies that reported on well-being.

Across the studies that used a quantitative measure, a total of 120 different cited measures were reported (see Table S2 List of Measures, Supplementary File). In 13.8% ($k = 31$) of the studies, a battery of assessments was utilised to measure QoL or well-being. For example, Grove et al. (2018) used three measures of subjective well-being to create an overall subjective measure of well-being. Psychological well-being was determined differently across studies. Hosozawa et al. (2021) measured psychological well-being by using four scales to measure what they defined as different dimensions of well-being—happiness, self-esteem, mood, and self-harming behaviours. In contrast, Losh (2005) assessed psychological well-being on scales of self-competence, anxiety, and depression. There were 92 measures that were only reported once.

In addition, 10.7% ($k = 24$) of these studies reported that they included measures created specifically for their study. These included rating a single question, ‘How would you rate your quality of life?’ using a 5-point Likert scale (Fleming et al., 2014), extracting well-being-related items from larger questionnaire sets (e.g. the UK Biobank population-based questionnaire; Jamshidi et al., 2022), and developing a questionnaire including items related to objective and subjective QoL customary domains (Barneveld et al., 2014).

A small percentage of studies (6.2%, $k = 14$) reported on the development, validation, or use of an autism-specific measure to report on the QoL of autistic people. McConachie et al. (2018) investigated the validity of the Autism Spectrum Quality of Life (ASQoL), an autism-specific, nine-question, add-on measure intended to be used alongside a more general QoL measure. This add-on measure has been used to measure QoL in autistic adults with the WHOQOL-BREF (Charlton et al., 2022; Harmens et al., 2022a; McQuaid et al., 2022; Yerys et al., 2022), with a global item from the WHOQOL-BREF ‘How would you rate your Quality of Life?’ (Oredipe et al., 2023), and as a stand-alone measure (Caron et al., 2022). Three studies (Chezan et al., 2022a, 2022b; Chezan et al., 2022a, 2022b; Cholewicki et al., 2019) reported on the development, validation, and use of the Quality of Life for Children with Autism Spectrum Disorder Scale (QOLASD-C), a caregiver completed assessment that measures three domains (interpersonal relationships, self-determination, and emotional well-being) of QoL in autistic children (5–10 years old). In consultation with the autistic and autism community, Graham Holmes and colleagues (Graham Holmes et al., 2020) identified items from the PROMIS scales that were viewed as relevant to autistic people to create the PROMIS

Autism Battery—Lifespan (PAB-L). The PAB-L provides a scale that can be used across the lifespan to measure QoL in autistic people. There are three scales: 5–13 years (parent proxy), 14–17 years (parent- and self-report), and 18–65 years (self-report). The teens completing the PAB-L were more likely to be in mainstream school and performing at or above grade level. This scale was only reported in one study. The Caregiver Evaluation Quality of Life Scale has been developed (Brown et al., 2019) and revised (Yetenekian, 2019) as a caregiver measure to assess the QoL for the autistic child, self (the parent), and the family unit.

Accommodations or Adjustments to Quantitative Measures

Descriptors of accommodations or adjustments to how the survey/questionnaire was administered were reported in 38 studies. Two studies provided the option of having a parent present while the child completed the measure, but the measures were completed by the autistic person (Adams et al., 2019a, 2019b; Feldman, 2021). In five studies, a support person (e.g. parent, teacher, researcher) assisted the autistic person in completing the measure (Bigby et al., 2018; Ferenc et al., 2021; Knüppel et al., 2018; Lin & Chen, 2022; Mason et al., 2019). In eight studies, the autistic person was provided the option of having the survey/questionnaire read aloud by the researcher, caregiver, or using a device (Błeszyński, 2018; Burgess, 2007; Caron et al., 2022; Feldman, 2021; Garcia, 2003; Lin & Huang, 2019; Sheldrick et al., 2012; Shipman et al., 2011). Having someone present to clarify the questions, provide additional examples or prompts (verbal or visual), and practise questions was reported in 10 studies (Berástegui et al., 2021; Bishop-Fitzpatrick et al., 2017; Craig, 1999; Flores & Delariarte, 2021; Friedman, 2021; Grey et al., 2018; Helles et al., 2017; Ikeda et al., 2016; Lopez-Espejo et al., 2022; van Steensel et al., 2012). Changing the words and providing easy read formats were identified in two studies (Byers et al., 2013; Roestorf et al., 2022) and one study designed the questions at three levels of difficulty, selecting the level that best suited the informant (Grey et al., 2018). Howard et al. (2006) stated that items were adapted but did not identify how this was done. Five studies provided supports for the method of responding: picture response or using a visual scale (Feldman, 2021; Grey et al., 2018; Lopez-Espejo et al., 2022; Potvin et al., 2015; Stancliffe et al., 2009). Seven studies identified adjustments to the environment including providing breaks, extended period to complete questionnaire/survey, and completing it in a noise-reduced environment (Craig 1999; Garcia, 2003; Günal et al., 2019; Khanna et al., 2014; Losh, 2005; McDonald, 2017; Roestorf et al., 2022).

Qualitative Measures Less than one-fifth of the studies (17.2%, $k = 44$) included a data collection method requiring qualitative analyses. This included 11.7% ($k = 30$) of the total

studies that relied solely on methods that were qualitatively analysed and 5.5% ($k = 14$) of the total studies that used a mixed method approach. Semi-structured interviews were the most common method of qualitative data collection used in 84.1% ($k = 37$) of studies including a qualitative component. This included incorporating semi-structured interviews with photo-elicitation ($k = 3$), with focus groups ($k = 2$), and with artefacts and observations ($k = 2$). The remaining studies ($k = 7$) included the use of open-ended questions that were qualitatively analysed ($k = 3$), blogs and articles ($k = 2$), focus groups ($k = 1$), and group discussion with photo elicitation ($k = 1$).

Accommodations or Adjustments to Qualitative Measures

Descriptors of accommodations or adjustments to how the study took place were reported in 23 studies. Accommodations that were individualised for each autistic person based on information from families and individual plans were identified in three studies (Diodati, 2018; Preece & Lessner Lištiaková, 2021; Sturrock et al., 2022). Five studies provided the autistic informants with the interview questions prior to the interview (Berkovits et al., 2020; Cai et al., 2022; Mason et al., 2019; Smit and Hopper, 2023; Sturrock et al., 2022), and two studies (Folta et al., 2022; Hebblewhite et al., 2022) adapted the language to ensure the information sheet and interview questions were clear and unambiguous for the autistic person. In five studies, consideration for the autistic informant was made in regard to the venue location (Cuesta-Gómez et al., 2022; Ikeda et al., 2016; Mayton, 2005; McConachie et al., 2018; Rearick, 2015). This included using an accessible venue as well as providing the autistic informant with the choice of location or type of location. Including an opportunity for rapport building was reported in two studies (Diodati, 2018; Ikeda et al., 2016). Seven studies identified methods they incorporated to facilitate discussion (Boström and Broberg, 2018; Diodati, 2018; Foley et al., 2012; Hebblewhite et al., 2022; Howard et al., 2006; Smith et al., 2019; Zazzi and Faragher, 2018). This included the use of verbal prompts (e.g. directing questions and introducing well-being as an example) and visual prompts including the use of pictures, photos, drawings, and physical objects (e.g. ludo blocks).

Five studies provided options for different modes of responding (e.g. Zoom calls with/without video, face-to-face, WhatsApp calls, WhatsApp chats, text, email, written, telephone) including the option of changing their method of responding during the project (Bailey et al., 2020; Foley et al., 2012; Harmens et al., 2022a; Seers and Hogg, 2022; Smit and Hopper, 2023). One study (Lam et al., 2020) used a timer to ensure that each person got the opportunity to share their viewpoints.

Autistic and/or Autism Community Involvement

In 12.1% ($k = 31$) of the studies, some level of autistic and/or community involvement was reported. This included

autistic people ($k = 20$), with six studies including an autistic researcher (Cai et al., 2022; Capp et al., 2022; Harmens et al., 2022b; Oredipe et al., 2023; Sturrock et al., 2022; Williams et al., 2023). The remaining 11 studies described the community involvement from parents of autistic children, autistic community organisations, and members of the autism community. Community involvement was most commonly utilised in designing and developing the research instruments, format and ease of questions, and functionality of the online survey ($k = 26$). Less commonly, community involvement was utilised in data analysis and interpretation of findings (Cai et al., 2022; Caron et al., 2022; Harmens et al., 2022b; Lam et al., 2020; Sturrock et al., 2022; Taylor et al., 2023). In two studies, autistic people were involved across each stage of the project (Cai et al., 2022; Lam et al., 2020).

Discussion

The aim of this review was to identify how QoL and well-being in autistic people is being reported and who is reporting this information. Despite the increased focus on QoL and/or well-being of autistic people—a change in focus that reflects the research priorities of autistic people (Roche et al., 2021)—this review highlights a number of limitations in the current research. In particular, the research continues to rely on measures developed for neurotypical people that do not consider the autism-distinct aspects of QoL and/or well-being. These measures are completed by a select group of autistic people, or their proxy, who may not have the same QoL and well-being outcomes of autistic people with complex co-occurring conditions, such as intellectual disability and/or communication impairments. Finally, few studies identified adaptations or accommodations to facilitate accessibility for all autistic people, including those with intellectual disability and/or communication differences.

How QoL and Well-Being Are Measured in Autistic People

Research studies and their conclusions relating to the QoL and/or well-being of autistic people were based primarily on measures that were analysed quantitatively. These include standardised measures, elements from measures, and measures developed for the study, all of which provide an overall numerical score to reflect a person's QoL or well-being. To what extent this describes the multidimensional nature of QoL or well-being varied. For example, Fleming and Leahy (2014) used only a single item to measure a person's QoL. In contrast, the WHOQOL-BREF, a broad and comprehensive assessment of QoL, was one of the most frequently used measures. Of concern also is that most of the measures used were not specifically

developed for autistic populations. This is important as the wording used in generic measures may not be suitable for self-reports of autistic people (Nicolaidis et al., 2020; Tavernor et al., 2013) and this was demonstrated with the WHOQOL-BREF. Autistic adults with IQ > 70 reported the WHOQOL-BREF questions were difficult to understand, and they identified further instructions and examples were required for completing this measure (Beck et al., 2023). Even versions of the WHOQOL-BREF adapted for people with intellectual disability (WHOQoL-BREF-ID and WHOQoL-DIS-ID) were reported to have domain items (social relationship) that were viewed as confusing for autistic adults without an intellectual disability (Beck et al., 2023). Furthermore, these generic measures may not include items relevant to measuring the QoL and well-being of autistic people, for example, autistic identity (Ikeda et al., 2014; McConachie et al., 2018).

There is emerging research that reports on developing, validating, and using QoL measures for autistic people, including the ASQoL and the QOLASD-C. While these are positive developments, the measures may require further refinement. For example, Williams and Gotham (2021) performed an independent assessment of the psychometric properties of the ASQoL in a group of 700 autistic adults and suggested that the ASQoL may underestimate the QoL of autistic women. They also found that the global QoL item was poorly related to the other items, recommending further work on the measure. Other studies have reported on the development, validation, and use of the Quality of Life for Children with Autism Spectrum Disorder Scale (QOLASD-C), a caregiver completed assessment of QoL in autistic children (5–10 years old). According to Chezan et al., (2022a, 2022b), this measure shows convergent and divergent validity based on its association with PedsQL 4.0 (Varni et al., 1998) but it has not been assessed independently, which also indicates that further work is needed. It may be that the models of well-being and the conceptualisation of QoL in autistic adults need further development before measures can be accurately developed and explored (Robeyns, 2016; Rodogno et al., 2016). Additionally, at present only two of the autism-specific measures include a self-report scale (ASQoL and PAB-L). While the development of autistic self-report measures is encouraging, neither of these has been used with autistic people with intellectual or communication impairments. Research on these measures is still preliminary, despite a call from Saldana et al. (2009) over 10 years ago for a change in how QoL is measured for autistic people with communicative and cognitive limitations.

Whose Quality of Life?

Of the studies which included self-report methods to describe the QoL and/or well-being in autistic people (n

= 167), 69 studies did not report if participants had a co-occurring condition and 11 studies specifically excluded participants with a co-occurring condition. This is not reflective of the broader autistic population, where 95% of children are reported to experience at least one co-occurring condition (Soke et al., 2018) and over two-thirds (71%) of autistic adults are reported to have at least one co-occurring condition (Roestorf et al., 2022). Additionally, within the 84 studies that did include individuals with co-occurring conditions, these were predominantly those with mood or mental health conditions. Only 11% of the studies that included a self-report component focussed on the QoL and well-being of individuals with an intellectual disability, despite 30% of autistic individuals having a co-occurring intellectual disability. Individuals with an intellectual disability were explicitly excluded in 14% of studies. Only one study identified the inclusion of participants who used AAC. The use of AAC by autistic people of all ages and abilities is increasing (Zisk & Dalton, 2019), so a lack of research which is inclusive of people who communicate using this method is alarming.

The exclusion of autistic people with perceived complex support and/or communication needs, such as those with an intellectual disability or those who use AAC, is not specific to this body of research. Russell et al. (2019) reported that 94% of research studies published in 2016 did not include autistic participants with a co-occurring intellectual disability. The lack of inclusion of autistic individuals with specific profiles leads to a body of research which is not generalisable to the broader autistic population and to a literature base (upon which future interventions or clinical decisions are made) which is biased in its description (Russell et al., 2019). This highlights a clear need for studies which are proactively designed to be inclusive of autistic individuals who have a broad range of support and communication needs. Such designs can and should be informed by the autistic and autism communities, many of whom will have developed effective approaches to communication and inclusion which researchers can learn from and integrate into their work.

Who Reported on the Autistic Person's QoL and Well-Being?

Subjective experiences are based on one's own thoughts and beliefs; arguably then, subjective well-being and subjective QoL can only be rated by the person experiencing them. Over half of the studies identified in this review on autistic QoL and well-being relied on proxy informants. Proxy informants were predominantly used in studies to report on child participants and autistic people deemed not capable of completing the measure or participating in the research project. Proxy informants are useful in their own right and

their experience and insights should be respected. However, it should not be assumed that their ratings are the same as the autistic person would provide. Studies which ask parents to provide standard proxy ratings and then provide the ratings that they think their child would provide suggest that parents of autistic young people have different opinions about their children's QoL than their children do and that they are aware of these differences (Sheldrick et al., 2012). In studies where proxy and self-reports were included, there was a difference in scores. This trend has commonly been reported in research and is usually viewed as a negative factor. However, the value of multi-informants to provide a more comprehensive overview of the situation and between-informant discrepancy as a source of information rather than a problem has been reported in research with autistic children (Adams et al., 2019a, 2019b) and adults (Sandercock et al., 2020).

The combination of the focus on proxy reporting and the tendency to include autistic participants without co-occurring conditions that has been identified in this review results in a lack of opportunity of some autistic people (i.e. usually those with intellectual or language disability) to contribute to the research about themselves and their life. The autistic individual brings a unique insight to their subjective experience of their life that may not be apparent to others. This was illustrated by Saldana et al. (2009) who reported that over half the proxy informants were not able to rate the life satisfaction of the autistic people with high support needs. One of the aims of this work was therefore to identify adaptations and accommodations made in previous studies of autistic well-being and QoL so as to highlight methods for future research to include the perspective of all autistic individuals.

Adaptations and Accommodations

Less than one-third of studies that included self-report by autistic informants with co-occurring conditions reported on any adaptations made to the study process to support participation by participants with a range of profiles, strengths, and needs. Some studies made adaptations so as to reduce the language demands of the research and to accommodate the communication styles and preferences of autistic people with complex support and/or communication needs. This was achieved by rephrasing questions or giving additional explanation to ensure the questions were understood and clear (Bishop-Fitzpatrick et al., 2017; Foley et al., 2012; Hebblewhite et al., 2022; Ikeda et al., 2016); designing questionnaires for different levels of difficulty (e.g. Level 1 contained 'yes/no' questions, to more complex questions; Grey et al., 2018); adapting response formats such as using visual symbols, pictures, and/or a visual scale based on facial expressions to facilitate responding (Boström and Broberg, 2018; Feldman, 2021; Hebblewhite et al., 2022; Lopez-Espejo et al., 2022;

Smith et al., 2019); using flexible wording with pictorial responses (Bishop-Fitzpatrick et al., 2017; Grey et al., 2018); providing a range of formats for the information to be provided (e.g. face-to-face, online, providing written response, selecting pictures from the internet, photos, or drawings; Beadle-Brown et al., 2009; Foley et al., 2012; Zazzi and Faragher, 2018); practice questions (Lopez-Espejo et al., 2022); minimal use of open-ended questions (Garcia, 2003); use of additional prompts (Friedman, 2021); questions read out to the autistic person (Feldman, 2021); having the option of a support person to provide assistance with the interpretation of the questions to be a communication partner or to be support (Bigby et al., 2018; Garcia, 2003; Lin & Chen, 2022). There is limited research to guide people on how to adapt neurotypical questionnaires to be more accessible (Kooijmans et al., 2022). In the absence of this research or of any specific guidelines, it is likely that many of these adaptations are made with good intention but without theoretical basis for change. Given the heterogeneity of the autistic population (and of the co-occurring conditions which many experience), it is unlikely that adaptations from standardised neurotypical questionnaires will make them accessible to all (Emerson et al., 2013), but Kooijmans et al. (2022) recommend a maximum of three response options and the provision of a 'do not know' answer to prevent participants from selecting a random answer if unsure.

Changes to the structure, the timing, or the environment were reported in 33 studies utilising a quantitative approach and in 22 studies utilising a qualitative approach. Examples included allowing time to build rapport; ensuring frequent breaks between tasks; allowing time and space for sensory, behavioural, or communicative differences; taking into account individual needs and preferences; noise reduction and soft lighting; providing the opportunity to complete a survey over multiple sittings or unlimited time; and allowing the autistic person the opportunity to select the location and time to take part in the research. The need to balance between standardised procedures and the need for flexibly adapting to the participant is critical if the research is to respect the needs of the participants.

Community Involvement

Although the importance of community engagement in research has been recognised for over 50 years (Arnstein, 1969) and has been recognised by autistic academics for a number of years, the majority of research is still limited in terms of participatory approaches (den Houting et al., 2021). The 11 studies that incorporated community views on questionnaires and design aligned with the 'consultation' level of participation, which is lower on the hierarchy of participatory research than the studies which included an autistic

co-researcher (Arnstein, 1969). True co-production with autistic people with lived experience of complex support and/or communication needs will aid in the co-development of studies that are proactively designed to be inclusive of a broad range of autistic individuals. As den Houting et al., (2021) highlight, autistic people with complex support and/or communication needs, as well as other groups within the autistic community, have been traditionally underserved by participatory research (and traditional research), with systemic barriers meaning that ‘those with most to gain are most excluded’ (Ooclo & Matthews 2016, p. 629). Researchers therefore have much to gain from establishing relationships with these underserved groups and from working together to co-develop accessible research processes and projects to help redress the imbalance of autism research in the future.

Limitations and Future Directions

The inclusion criteria for this systematic review specified that QoL and/or well-being of autistic people was reported. As a result, studies that focused on topics related to QoL and/or well-being (e.g. thriving [Simpson et al., 2022], social participation [Tobin et al., 2014], or friendships [O’Connor et al., 2022]) may have been excluded. These research studies may add to the understanding and knowledge of what is important for autistic QoL and/or well-being.

The included items were limited to research papers. This meant the findings were limited to those studies reporting on autistic people who had access to the recruitment information and were willing and able to participate in the research project. Autistic people may discuss their views on their QoL and or well-being in less formal contexts, for example, on blogs, analysis of which is a future area for consideration.

The focus of this study was to investigate how the QoL and/or well-being of autistic people was reported. There were 271 studies that included autistic people but did not report on their QoL and/or well-being separately. As a result, these studies were excluded. This inclusion criterion was adopted because it was not possible to determine the intersectionality between autism and the co-occurring condition and how this may be influenced by methods used. The methods used in these studies may provide details of effective methods in supporting the perspectives of autistic people and hence require further investigation.

The findings from this review highlight quality of life and/or well-being in autistic people is primarily reported using measures developed for non-autistic populations. Conducting meta-analyses of studies using the same measures of quality of life and/or well-being would provide further information about reported autistic quality of life/and or well-being. However, little is known about whether these measures are meaningful for autistic people. Further the

limited representation of autistic people with intellectual disabilities, complex communication needs, and child self-report provides a skewed perspective of the quality of life and/or well-being in autism. Discovering what makes a good life for autistic people will require involving autistic people in the research and using methods that engage and support the autistic person to express their views (e.g. Courchesne et al., 2022; Lehenhagen, 2020; Nicolaidis et al., 2020).

Conclusion

QoL and well-being are identified as an important research priority for autistic people. However, progressing this area in a meaningful way is dependent on using measures that are inclusive for autistic people with a range of profiles, strengths, and challenges. Despite the increase in research studies investigating QoL and/or well-being in autistic people, the findings from this review highlight the limitations of this research. This includes the reliance on generic measures of QoL which may not reflect factors important to autistic well-being or QoL, limited inclusion of autistic people in the research about them—in particular, people with intellectual disability and communication differences who are under-represented in the research literature—and the limited use of accessible methods to obtain the perspectives of autistic people. ‘Nothing about us, without us’ means we now need to consider ways that are accessible and inclusive to ensure the voices of all autistic people are heard on matters about their QoL or well-being.

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Data Availability All information re data search results are in the supplementary files.

Declarations

Conflict of Interest The authors declare no competing interests.

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