

# Lived Experiences of Neurodiverse Students: A Review

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## Keywords

Asperger syndrome, Autism Spectrum Disorder, neurodiversity in the classroom, neurodiverse students.

## Abstract

This study aims to examine available literature on neurodiversity, particularly as it relates to neurodiverse students' lived experiences. This study utilized the scoping review method to effectively map how research about neurodiverse students has been designed and conducted. Through a thorough search of four databases, articles were selected for data extraction and review based on the named criteria. Among all the studies reviewed, one of the themes that stood out was the view that only a few research directly assessed the needs of students with neurodiversity. It is also worth noting that of all kinds of neurological conditions, Autism Spectrum Disorder and Asperger Syndrome received due attention among all the papers about neurodiversity. Autism Spectrum Disorder (ASD) and high-functioning autism received greater attention, followed by Asperger syndrome. Research efforts concerning the lived experiences of neurodiverse students are limited, particularly in Africa, where this research found no article that captured the lived experiences of neurodiverse students from their perspectives. These findings build on existing research by ascertaining whether neurodiverse students' voices are acknowledged enough by researchers who could influence inclusion in academic planning, curriculum design, social activities and general academic life. Findings from this research imply that it would be of utmost assistance to researchers if gaps in neurodiversity research are identified to inform ideas for future research. Future studies ought to focus on African countries to explore the situation and academic life of neurodiverse students and not merely depend on the input of teachers, parents and neurodiversity professionals.

## INTRODUCTION

Neurodiversity refers to the diversity of brain function caused by various developmental conditions and experiences (McLean, 2022). Proposed in the late 1990s by Judy Singer, the concept and true meaning of neurodiversity have since been debated and contested. However, similar to all the debates is the idea that the concept is often associated with the accommodation of 'natural variation' in the human genome. According to the World Health Organization (2018), the number of people living with disabilities worldwide is nearly one billion, or 15% of the population. In particular, 110 million to 190 million people suffer from severe disabilities around the world or nearly one-fifth of the total population. Developing countries tend to have a higher prevalence of disability, Africa inclusive, and such disabilities include neurological diseases such as Autism Spectrum Disorder (ASD). According to the US Centers for Disease Control and Prevention (2014), one out of 42 boys and one out of 189 girls live with autism in the United States. Over time, the number of students with autism and other neurological diseases entering higher education is increasing, and they constantly face several challenges as they navigate the education system. This makes academic success twice as hard compared to other students. Diseases of the central and peripheral nervous system are classified as neurological disorders, according to the World Health Organization (2018). Several of these disorders are linked to autism spectrum disorders, Asperger syndrome, epilepsy, Alzheimer's disease and dementia, cerebrovascular diseases, such as Parkinson's disease, strokes, traumatic brain disorders, multiple sclerosis, and neurological disorders caused by malnutrition. With this, the need for appropriate support structures for their academic, social, and personal success at school and beyond has never been greater. However, a lack of student perspective in research on students with ASD, poor handling of

students' transitions into higher education institutions and general ignorance of their unique needs can result in poor performance, anxiety, bullying, and stigmatization (Evans, Granson, Langford & Hirsch, 2023).

As part of its efforts to promote inclusion, the United Nations (UN) established inclusion practices, which include integrating disabled children into mainstream education. Ensuring their success in mainstream schools has proven problematic over time due to schools' inability to cater to their unique needs, reducing their potential to succeed alongside their peers. As part of SDG 4, the UN strives to ensure that everyone has access to quality education and lifelong learning opportunities, ensuring that all levels of education and vocational training are accessible to the most vulnerable individuals, including those with disabilities. Furthermore, the proposal calls for constructing and upgrading inclusive, safe, and nonviolent education facilities for children, people with disabilities, and women of all genders. Similarly, Goal 10 aims to reduce inequality between and within countries by improving all social, economic, and political inclusion. The public declaration made by the United Nations (UN) means that every child has a right to equal educational opportunities without discrimination. The UN also raised awareness of the concept and practice of inclusion, which involves integrating children with disabilities into mainstream schools (UN General Assembly, 2015).

Nyarambi et al. (2011) posit that there are many children in Africa with autism and that they have been placed in mentally impaired facilities or psychiatric facilities under heavy 24/7 dosage of medication daily, as opposed to helping them navigate life's hurdles by enrolling them in institutions of learning. Based on the foregoing, this research aims to examine existing literature and empirical research on the experiences of neurodiverse students in Africa and subsequently ascertain whether they are well integrated into mainstream schools and society as recommended by the United Nations or otherwise discriminated against based on their disability. In addition, this study seeks to identify the voices that are heard in such studies and determine where knowledge gaps exist. This research aims to examine available literature in the line of neurodiversity and assess the level of inclusivity and voices of the research subjects, which would inform future research directions.

## METHODS

### Study Design

According to Peters et al. (2020), a scoping review is an effective method for assessing how prior research on a specific topic has been conducted. This present scoping review was conducted to identify certain characteristics in the articles, map and discuss certain features. The Joanna Briggs Institute procedure for scoping review was followed in this study, while the PRISMA-ScR flow chart illustrates the process that produced the final result. Prior to this research, search terms targeted at providing precision for each of the concepts included in this review were developed: (a) children and youths with neurodiversity and (b) neurodiverse students. Following the preliminary search, the researcher added additional search terms to the list based on the first search results.

### Information Sources and Database Search

This scoping review was conducted with articles selected from four databases: Google Scholar, PubMed, Cochrane, and PsycINFO. The researcher developed search terms with which qualitative and quantitative research papers written in English were carefully selected. Some of the search terms were: "neurodiversity in the classroom", "neurodiversity in higher education", "neurodiverse students", "neurodiverse students", "Parkinson's disease", "neurodiversity education" and "neurodiversity". The reference lists of the articles included in the search were further reviewed.

### Eligibility Criteria

Certain eligibility criteria were considered while choosing publications for this scoping review. After removing duplicates, the researcher read the title and abstract of the selected search results and removed unrelated papers. The remaining articles were confirmed eligible after reading the complete texts, and the exclusion factors were noted in line with the specified criteria. Any discrepancies in study selection were addressed following due consultation with a senior researcher. Since the study's purpose is to review literature that explored the experiences of neurodiverse students, not from teachers and parents' perspectives but that of the affected students, a study was regarded as fit for inclusion if it (a) is a full-text primary research written in English; (b) included neurodiverse students who are enrolled in any institution of learning; (c) included voices of students who fall under the spectrum of any neurological condition. On the contrary, a study was deemed ineligible if it (a) covers neurodiversity in general (rather than in the context of education), (b) if it targeted both participants with neurological conditions in conjunction with other conditions, (c) if it covered only participants' perspectives other than those of neurodiverse students.

### Study Selection and Data Extraction

#### Screening

Before the first screening, a thorough search of each database was done, relevant papers were selected and imported to Zotero, duplicates were removed, and the first screening was done to ensure inter-rater reliability. The inter-rater reliability

involved the random selection of ten abstracts reviewed independently by two reviewers. Their results were compared afterwards to obtain >90% agreement. Another screening was then carried out using the web tool Rayyan. Papers with uncertain eligibility status at this stage were kept aside for further review in the assessment stage.

## Selection

The full text of articles that remained after screening, was independently read by two reviewers who determined their eligibility. Discrepancies were resolved, and 27 articles met the standards for inclusion.

## Data Extraction Process

In the extraction phase, relevant information from all included papers was extracted and placed in a table with the following columns: Author and year of study, study objective, method, findings, location, forms of neurodiversity covered by the study, and age range/educational levels of participants.

## RESULTS AND DISCUSSIONS

### Selection of Sources of Evidence

An electronic search of the four databases identified 388 articles, of which 267 remained after removing duplicates. Most of the articles identified did not focus on the experiences of neurodiverse students but on the perspectives of teachers, institutions and families of such students. Some others were secondary analyses and opinion articles on the concept of neurodiversity. One hundred and fifteen articles focusing on neurodiverse students remained after screening, while 27 articles ticked all boxes and were chosen for data extraction and review (see Figure 1).

### Study Characteristics

Findings revealed that the 27 articles selected for data extraction were published between 1997 and 2023 (see Table 1). The research was mostly conducted in the United States (12 studies) and the UK (6 studies); two studies were conducted in Australia and Canada, and one study each was from Germany, New Zealand, Belgium and Sweden. Also, one of the papers had participants from the UK and Spain.

Although a few papers on neurodiversity and neurodiverse students came from African countries such as South Africa, Morocco, Nigeria, Kenya and Tanzania, none were selected for final review since they did not meet the inclusion criteria. Additionally, most of the studies focused on Asperger Syndrome (AS) and Autism Spectrum Disorder (ASD). Very few combined either ASD and AS, Autism and Attention Deficit Hyperactivity Disorder (ADHD) and or high-functioning autism

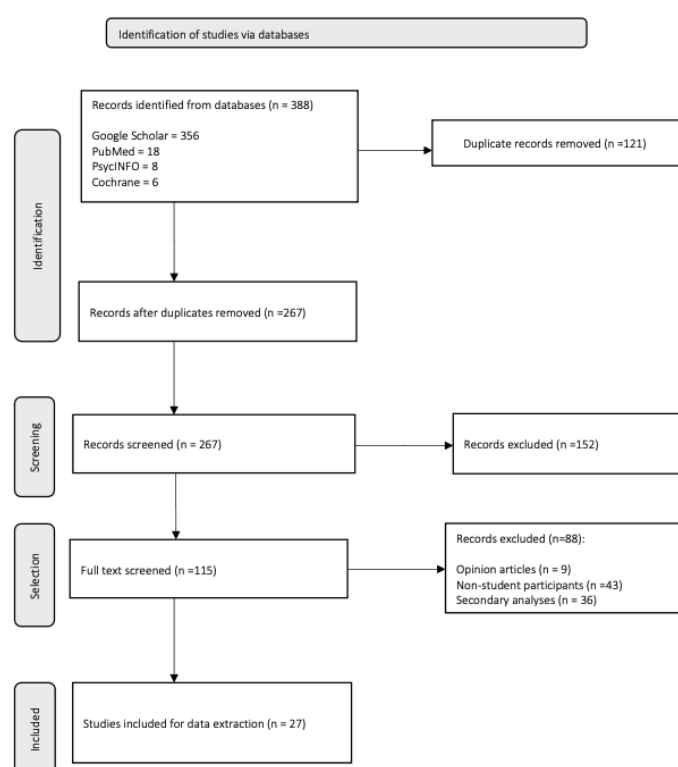


Figure 1. Flow chart illustrating the screening and selection process of this scoping review

Table 1. Empirical literature that captured the voices, views and perceptions of neurodiverse students

Author, Year	Study Objective	Method	Findings	Location	Form of neurodiversity covered	Age range/ educational level
Casement et al (2017)	To explore the experiences of Asperger Syndrome students in the UK and Spain.	Comparative exploratory study	The desire to receive clear, unambiguous, and structured information from academics among AS students.	UK, Spain	Asperger syndrome	University
Knott and Taylor (2014)	To identify the achievements, struggles, barriers, and support that students with AS/HFA face.	Focus Groups discussion	Mental health issues, social difficulties, and concerns about disclosing diagnosis were reported by all groups.	UK	Asperger syndrome (AS) or High-Functioning Autism (HFA)	University
Tippett (2004)	An assessment of how well teachers are aware of AS and whether AS students have positive or negative experiences.	Interviews, Questionnaires	In spite the low level of knowledge about AS among teachers, the majority expressed a desire to learn more about the subject. On the other hand, students were found to have negative educational experiences.	New Zealand	Asperger syndrome	6-12 years
Martin (2012)	To examine what could improve the university experience and increase the chances of success for 28 Cambridge University students.	Focus group discussion, One-on-one interviews	Several students with AS commented on various aspects of university life that could be improved through simple and inexpensive changes.	UK	Asperger syndrome (AS) or High-Functioning Autism (HFA)	University
Osler and Osler (2002)	Analyzed an AS student's experience excluded from two mainstream secondary schools.	Case Study	Several barriers exist that prevent parents from being genuine partners in education for their children.	UK	Asperger syndrome	Secondary school
Beardon et al. (2007)	To find out the views of AS/HFA students about college challenges and support services.	Aspect / Emancipatory research methodology	Findings revealed that AS/HFA Students experienced difficulties relating to other student's	UK	Asperger syndrome/high-functioning autism (AS/HFA)	University

Simmeborn (2012)	To assess whether the university's support facilitates or hinders student success	Case study	ideas about their condition. Participants needed to be alone but also enjoyed friendship and fellowship with other students.	Sweden	Asperger syndrome	Higher education
Madriaga (2010)	To examine the transitions of AS students into higher education.	Year-long longitudinal study	Some respondents said they had trouble engaging in social life at university, while others felt they had no problem.	UK	Asperger Syndrome	Higher education
Lacava et al (2007)	Investigate how assistive technology can be used to teach children with autism spectrum conditions how to recognize emotions.	Pretest-post-test experimental group design	After the intervention, participants were able to express basic and complex emotions better with their faces and voices.	Germany	Asperger Syndrome	8-11 years
Sciutto et al. (2012)	To examine the unique perspectives of AS children and caregivers on their school-related challenges and instructional practices.	Online survey	Teachers and school personnel demonstrated a desire for a greater understanding of AS.	USA	Asperger syndrome	6-18 years
Marks et al. (2000)	To provide the basis for other researchers in the field to investigate potential solutions to meet the needs of AS students	Focus Group discussion, Interviews	Students had many characteristics in common, especially the triad of impairments linked with Asperger's syndrome.	USA	Asperger syndrome	13 – 15 /Secondary school
Accardo et al. (2019)	To identify certain kinds of support that might be necessary to improve their outcomes	Survey and semi-structured interviews	Findings reveal that university disability service centers, counseling services, and faculty must liaise to support ASD students.	USA	ASD	College
White et al. (2016)	To assess challenges facing ASD students in	Online survey and focus group discussion	Poor emotional regulation, limited interpersonal competence, and	USA	ASD	College

	post-secondary education.		managing competing demands were identified as the most common challenges.			
Gurbuz et al (2019)	To find out the social and academic experiences of both autistic and non-autistic students.	Survey	Students with autism reported more challenges and mental health issues compared to their non-autistic peers.	UK	ASD	University
Van Hees et al (2015)	To investigate the challenges faced by ASD students in higher education.	Semi-structured interviews	ASD students had difficulty coping with unexpected changes in their lives.	Belgium	ASD	Higher institutions
Harrell et al. (1997)	A peer network strategy was used to examine the effects it has on social interaction and social-communicative skills for three students with autism	Multi-Option Observation System for Experimental Studies	Use of peer network intervention and augmentative communication system increased students' interactions.	USA	ASD	6-7 years /Elementary school
Cai and Richdale (2016)	To assess the support services enjoyed by students with autism in universities.	Semi-structured focus groups	In most cases, students felt supported educationally but not socially.	Australia	ASD	Post-secondary
O'Connor et al (2004)	To examine how three kinds of facilitation affect reading comprehension among 20 adolescents with autism spectrum disorders.	Within-subjects design	Conditions differed significantly in their effects on reading comprehension	Canada	ASD	Adolescents
Boutot et al (2005)	To explore three constructs of social integration for students on the autism spectrum in inclusive.	Participants survey	Students with autism in inclusive settings are just as accepted, visible, and part of their peers as others with autism.	USA	Autism Spectrum Disorder	Grade 2-5/ 7-10 years
Anderson et al (2017)	To evaluate autistic students' access to support services and willingness to	Online Survey	Respondents indicate low use of support but high rates of academic and non-academic	Australia	Autism Spectrum Disorder	College

	disclose their conditions at higher institutions of learning		difficulties. Delayed disclosures were associated with fewer support and a worse overall university experience.			
Hillier et al. (2017)	To evaluate the efficiency of a support group model to improve psychological and functional outcomes for university students with autism spectrum disorder	Focus Groups Discussion	Findings revealed reduced feelings of loneliness and general anxiety and increased self-esteem among ASD students at the end of the program.	USA	Autism Spectrum Disorder	Higher education
Colclough (2016)	To explore the social experiences and retention impact of college students with autism	Person-first descriptive study, semi-structured interviews	The readiness and success of college students with autism spectrum disorders is impacted both directly and indirectly by a unique set of circumstances	USA	Autism Spectrum Disorder (ASD)	College
Walters (2015)	To explore how existing conversations ignore students with ASD	Case study	Neurotypical assumptions are revealed in some writing pedagogies.	USA	Asperger Syndrome	University
Evans et al (2023)	To examine the academic, social, institutional, and environmental challenges faced by students with autism spectrum disorders	Cross-sectional mixed-methods	People with neurodiverse traits often experience difficulties interacting with neurotypicals in an environment that is perceived to be poorly prepared to support them.	USA	Autism Spectrum Disorder	University
Ale (2017)	To assess the experience of students with Autism Spectrum Disorder in college transition programs.	Q Methodology	Findings reveal the absence of a detailed narrative on self-advocacy, inclusion, career exploration, relationships, and non-traditional accommodations to make campus life successful.	USA	Autism Spectrum Disorder, Asperger's Syndrome, High-Functioning Autism	18-30

Bayeh (2022)	To examine neurodivergent students at a large university and their mental health status	Online survey	The results call for an intersectional perspective on neurodivergence that considers the interaction of neurodiversity and other forms of diversity in mental health.	Canada	All neurodiverse students.	University
Rhoades and Santhanam (2021)	To explore the challenges neurodiverse students face with group work.	Online survey and semi-structured interview	57% of students indicated they do not prefer group work, 36% said they had a neutral preference, and 5% said they preferred it.	USA	Autism spectrum and dyslexia or Attention Deficit Hyperactivity Disorder (ADHD)	18-45 (College)

This study's aim was to review the available literature on neurodiversity, to determine the level of inclusivity in researchers' choice of sources/participants, and ultimately determine if neurodiverse students' voices are acknowledged. This study found that the majority of studies on neurodiversity focused mostly on autism spectrum disorder (which included high-functioning autism) and Asperger syndrome. For schools to effectively take care of the needs of this unique set of students, it is only rational to hear from them and have them reveal their needs. A report by Dillon (2007) revealed that neither research nor effective educational support have directly examined the experiences or needs of people with autism spectrum disorder. According to Dillon (*ibid*), in higher education, most of the information about supporting students with ASD is based on professional experience and expertise. It has been over 16 years since Dillon made this assertion, giving ample time for more researchers to look into this aspect of research, remember neurodiverse students and factor in their perspectives. This informed the need for this current research, which has now found that only about 27 reports captured the voices of neurodiverse students out of over 300 studies on neurodiversity. Cai and Richdale (2016) surveyed 23 students with ASD and 15 family members to understand their needs. Students reported receiving proper educational support but unsuitable social support, while parents reported that their children received neither.

Also, findings from one of the papers (Van Hees et al., 2015) reviewed by this researcher revealed that students with autism prefer not to disclose their diagnosis due to peers' and teachers' poor knowledge of and several generalizations about ASD. Other reasons for students' failure to disclose their diagnosis were doubts about privacy, lack of favorable policies and the desire to make a fresh start. Students only tend to reveal their diagnosis when they can no longer cope with the stress, when they no longer feel safe or experience a specific needed support. They disclosed their diagnosis to the Disability Office to help secure 'reasonable accommodations' but failed to disclose it to peers and academic staff (Van Hees et al., 2015). Another study by Beardon et al. (2009) revealed the difficulties students face in trying to understand other people individually and in groups. Neither social nor academic support seemed available to help them through the minefields of social life and academics.

The concept of neurodiversity in Africa is seemingly new, judging from the paucity of research conducted in this aspect. The first database search conducted by this researcher with only 'neurodiversity' as a keyword did not return studies conducted in Africa. However, subsequent searches with specific keywords such as "Autism" and "Asperger syndrome" returned the very few papers referred to earlier in this research, which, upon screening, still did not meet the inclusion criteria. Therefore, future studies should focus on African countries to find out the situation and academic life of neurodiverse students and not merely depend on the input of teachers, parents and neurodiversity professionals. One of the limitations of this study is that it is not a systematic review but a scoping review, which makes it less efficient. As with a typical scoping review, this study did not assess the rigor or quality of studies but mapped available literature on neurodiverse students in Africa to lay the groundwork for a systematic review. With the foregoing, it is recommended that future researchers diversify by covering other kinds of neurodiversity apart from the ones examined in this paper. Although Parkinson's disease was one of the specific keywords searched for in this study, this researcher found no study on the academic life of students with Parkinson's disease, which makes it one of the many neglected neurological conditions that should be given due consideration in future research.

## CONCLUSIONS

Judging from the available literature reviewed by this researcher, it is safe to say that neurodiverse students are still the relatively forgotten ones, especially when it comes to meeting their unique needs, considering their perspectives in policy-

making processes and giving them a voice in the educational sector which would ultimately help them transition into the society as independent adults. Among all 27 studies reviewed by this researcher, one of the themes that stood out was the view that only a few research directly examined the needs of neurodiverse students. It is also worth noting that of all kinds of neurological conditions, only autism spectrum disorder and Asperger syndrome received due attention among all 388 papers on neurodiversity. Autism received greater attention, followed by Asperger syndrome. This explains the neglect faced by students who neither belong to ASD or AS spectrums. Similarly, studies relating to ASD were mostly conducted in the United States, while that of Asperger syndrome mostly came from European countries. Although a few studies were conducted in some African countries, as revealed during the database search and screening stage, none met the inclusion criteria.

### CONTRIBUTION OF THE RESEARCH TO KNOWLEDGE

These findings build on existing research by ascertaining whether neurodiverse students' voices are acknowledged enough by researchers who could influence inclusion in academic planning, curriculum design, social activities and general academic life. Out of all the studies on neurodiversity, only a few included neurodiverse students as voices and participants in their research, leading to a more informed result and output, which is believed to serve as resource materials for policymakers and academic administrators who would find it useful for future policy implementation. Findings from this research imply that it would help researchers identify gaps in neurodiversity research to inform ideas for future research.

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