

PRIVACY IN SPECIAL AND INCLUSIVE EDUCATION RESEARCH

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Abstract: *Protecting the privacy of students with Special Educational Needs and Disabilities (SENDs) is critical, given the potential for stigmatization and discrimination. This study examines privacy protection measures in research on special and inclusive education in the region. Drawing on a systematic literature review of 53 studies published between 1995 and 2023, this paper explores the documented procedures for protecting participants' privacy. It highlights the challenge of research in small Caribbean communities. While a significant proportion of the literature addresses confidentiality, many studies lack specific details on privacy protection procedures, indicating a need for greater transparency. Examples from the literature illustrate how researchers navigate conducting studies in small societies and methods used for privacy protection. Recommendations include enhancing methodological transparency, integrating ethical considerations into research reporting, and including clauses related to privacy protection in Special and Inclusive Educational policies throughout the region.*

Keywords: *special education, inclusive education, privacy, confidentiality, Caribbean*

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INTRODUCTION

Protecting students' right to privacy and confidentiality when conducting educational research is essential for the most vulnerable student populations, including those with Special Educational Needs and Disabilities (SENDs) (Economic and Social Research Council, 2005). While the privacy of students with SENDs is vital in general, it becomes even more critical in small countries and communities where students may experience stigmatization, discrimination and social and educational exclusion. Efforts to protect the privacy of this group are visible in international policies surrounding SENDs, including the Individuals with Disabilities Education Act (2004) in the United States and the Special Educational Needs and Disability Codes in the UK (Department for Education & Department of Health, 2015). In addition, the right to privacy has been addressed in Article 22 of the United Nations Convention of the Rights of Persons with Disabilities (2006), which has been signed and ratified by most countries in the Caribbean, including Barbados.

In Barbados, research conducted in educational settings is reviewed by a Research Ethics Committee (REC) or the Institutional Review Board (IRB), which are the governing bodies of ethics review for research conducted by individuals within The University of the West Indies and the Ministry of Health and Wellness. Protecting the "dignity, human rights, health, safety and privacy of human participants in research" is the responsibility of The University of the West Indies Research Ethics Committee (The University of the West Indies, 2011). The IRB requires researchers to specify in detail the methods for protecting participants' privacy and confidentiality and include copies of proposed informed consent forms when applying for approval to conduct educational research. In addition, researchers must be trained before applying to the IRB for research project approval, and this training involves completing the CITI Course in the Protections of Human Research Subjects. The course includes modules on Privacy and Confidentiality, Research with Children, and Research in Public Elementary and Secondary Schools. It is delivered online and is managed by the University of Miami.

International standards guide the IRB, including the first core ethical principle in the Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research produced by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1979). This principle, "Respect for Persons," consists of "the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy." Children fall into the category of those with diminished autonomy, and students with SENDs often fall under a particularly vulnerable umbrella of this group of individuals who require special protection. When taken together, the IRB's foundation in international research ethics standards, the prerequisite

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of researcher training in ethics as delineated by these global standards, and the specific information regarding privacy and confidentiality required for approval by the IRB, all indicate a strong emphasis on conducting ethical research in Barbados and the wider Caribbean.

While it is apparent that there are internationally accepted ethical frameworks that guide our research practices, as well as guidelines and expectations of local ethics governing bodies, how can we ensure that the principle of protecting privacy and confidentiality translates into our specific context and is delineated in our methodologies? A recent study by PAHO in Latin America and the Caribbean used the strategic approach of investigating research ethics systems using objectives and associated indicators. It was found that most countries in the sample had implemented national bodies to oversee research ethics committees and that research ethics governance had strengthened with the globalization of clinical trials, mainly related to drugs and devices, but that there must be a focus on all research involving human subjects as research ethics systems mature (Aguilera et al., 2022). Further, in a comprehensive review of the historical developments of ethics systems in the Caribbean, it was noted that while great strides have been made in the area in the past 20 years in terms of the establishment of Research Ethics Committees and training in ethics for professionals, more needs to be done to firmly engrain ethical principles and procedures in the minds of researchers in the region (Aarons, 2019).

Caribbean Research in Special Educational Needs and Stigma

Stigmatization, discrimination, and social and educational exclusion of individuals with disabilities are still widespread in the Caribbean (UNESCO, 2018). While Ministries of Education are making efforts to provide inclusive education for students with SENDs, only 5% of Latin American and Caribbean countries have laws outlining these provisions for inclusion (UNESCO, 2020). The fact that children with SENDs are particularly vulnerable is compounded by the fact that privacy is vital when investigating topics that can be potentially stigmatizing (Graham et al., 2013). Stigma has, therefore, been noted as an ethical issue that should be considered when developing ethical reviews in Barbados (Campbell & Emmanuel, 2016).

The literature across the Caribbean consistently highlights negative attitudes towards students with SENDs. Mahon (2021) interviewed SEN teachers in various schools, programs, and units across Barbados. These teachers reported widespread misconceptions about SENDs and noted that even physical spaces associated with SEND programs were often stigmatized as undesirable. The teachers described this as a cyclical issue where SEND spaces were avoided, leading to unfamiliarity and perpetuating the stigma. In Trinidad and Tobago, Harry (2019) conducted a study where parents of children with disabilities expressed the view that “persons with disabilities have traditionally been isolated by stigma and superstition yet cherished by those closest to

them” (Harry, 2019, p. 4). In Dominica, children with disabilities may face stigma and discrimination in the home or from their wider community. Participants reported that families often try to hide individuals with disabilities from their community and prevent them from participating fully in society, including school, or forming relationships with people outside their immediate family (Mickle et al., 2019).

The stigmatization of students with SENDs in the Caribbean means that several aspects of research in special and inclusive educational research should be considered. Individuals are more easily identifiable in small societies due to close social connections and limited population sizes. Descriptive data or verbatim quotes may lead to deductive disclosure or what has been termed a violation of “internal confidentiality” (Tolich, 2004). This can lead to the increased identifiability of participants and may potentially lead to the disclosure of sensitive information about participants’ disabilities and expose them to social stigma or discrimination within their community. In addition, small communities rely heavily on trust and interpersonal relationships. Unintentional breaches of privacy or confidentiality can erode trust within small societies and between research participants and researchers themselves (Ellis, 1995). Any undermining of confidence can cause far-reaching consequences that impact research participation in the future, engagement of communities and the overall well-being of individuals with SENDs. In this cultural context, these potential risks highlight the importance of maintaining participant privacy for all stakeholders: children, parents, and teachers.

To ascertain what reported measures are being taken to protect the privacy of Caribbean students with SENDs, as well as their teachers and parents, a review of the documented procedures used for privacy protection was undertaken as part of a more extensive systematic literature review.

METHOD

A systematic search of grey and academic literature via The University of the West Indies Libraries’ Information Connexion (UWIlinc) was conducted in June-July of 2023 to identify Caribbean studies in special and inclusive education. This portal includes the library catalogues of the four campuses of The University of the West Indies (UWI), intellectual output from UWI, and subscribed resources, including databases, electronic journals and books. In addition, searches were carried out on PsycINFO, Novanet, and Google Scholar. An abstract screening checklist (Table 1) was used to determine the articles eligible for full-text review.

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Table 1

Abstract Screening Checklist

Screening Item	Yes	No
Was the study published in a peer reviewed journal, edited book, or as a doctoral thesis?		
Was the study published in English?		
Was the study published after 1995?		
Was the study conducted in a CARICOM state or member state?		
Does the study include primary and/or secondary school students (4-16 years old) with special educational needs and/or teachers and/or principals and/or parents of this population of students?		
Decision	Exclude	Include

This study included only CARICOM (Caribbean Community) members and associate member states, all classified as Small Island Developing States (SIDS). A concept table including the research question, core databases and search parameters was developed (Table 2), and based on this concept table, search terms were as follows:

Caribbean OR Antigua OR Barbuda OR Bahamas OR Barbados OR Belize OR Dominica OR Grenada OR Guyana OR Haiti OR Jamaica OR Montserrat OR St. Lucia OR St. Kitts and Nevis OR St Vincent and the Grenadines OR Suriname OR Trinidad and Tobago OR Anguilla OR Bermuda OR British Virgin Islands OR Cayman Islands OR Turks and Caicos Islands

AND Quantitative OR Qualitative

AND Education AND Inclusion

OR Education AND Disabilities

OR Special Education OR Special Needs Education OR Remedial Education OR Inclusive Education.

Table 2*Concept Table for Systematic Review of Literature*

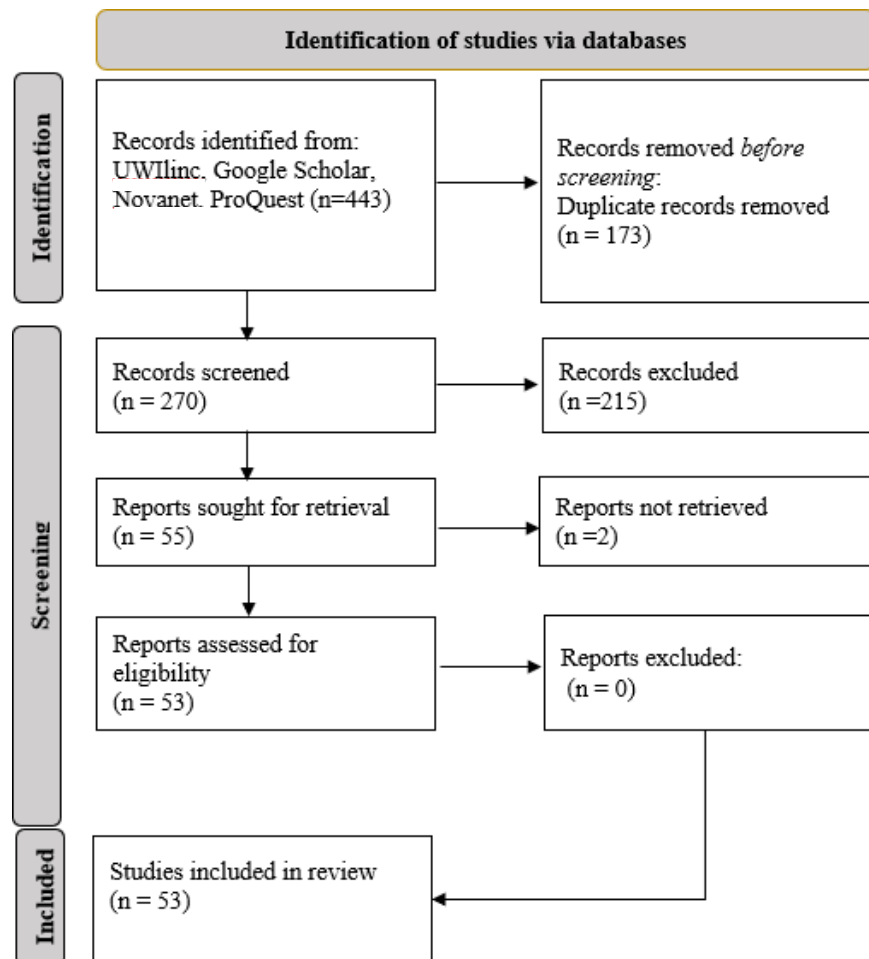
Research Question	Core Databases	Limits
What reported measures are being taken to protect the privacy of Caribbean students with SENDs and their teachers and parents in educational research?	UWllinC PsycINFO Novanet Google Scholar	Language: English/translated to English Years: 1995 – present Age groups: primary and secondary school students (4-16 years old) Publication types: Journal articles, books and book chapters, dissertations and theses Geographical: CARICOM Member and Associate Member States

Four hundred and forty-three records were identified; 53 were eligible for inclusion in the review. The literature consisted of 12 chapters in edited books, 16 doctoral dissertations, and 25 journal articles reviewed for content related to privacy and confidentiality procedures. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram for new systematic reviews (Page, 2021) shows the number of studies involved in the screening and inclusion procedure (Figure 1).

A full-text coding checklist was developed based on the research question and key concepts being investigated. Each article was coded and entered in the Statistical Package for the Social Sciences (SPSS). Descriptive statistics were used to analyze the data. Excerpts from the articles that further illustrated the codes assigned on the coding checklist were added to a separate database and analyzed across privacy and confidentiality themes.

Figure 1

PRISMA 2020 Flow Diagram for New Systematic Reviews



RESULTS

The 53 studies reviewed were published between 1995 and 2023 and were conducted across a range of 14 Caribbean countries. Research in the three nations of Barbados, Jamaica, and Trinidad represented 62% of the sample, with no published work found for several CARICOM countries. This does not necessarily mean that research in special and inclusive education has not been conducted in these countries; instead, it was not found using the search terms in the specified databases. The list of countries represented in the literature can be found in Table 3.

Table 3*Research Studies Conducted in Caribbean Countries*

Country	No. of studies
Antigua and Barbuda	1
Anguilla	0
Bahamas	4
Barbados	13
Belize	1
Bermuda	0
British Virgin Islands	0
Cayman Islands	1
Dominica	1
Grenada	2
Guyana	1
Haiti	6
Jamaica	12
Montserrat	0
St Lucia	2
St Kitts and Nevis	3
St Vincent and the Grenadines	2
Suriname	0
Trinidad and Tobago	14
Turks and Caicos Islands	0

Of the 53 studies reviewed, 40% were primarily qualitative, 32% were mainly quantitative, and 28% used a mixed methods research design. Overall, confidentiality was mentioned in 38% of the articles, 21% mentioned privacy, and 43% gave specific details on procedures to maintain privacy and confidentiality. For example, some researchers reported the use of unique identifying numbers or pseudonyms, the omission of personal information that may make participants identifiable, or physical measures such as securing private spaces for interviews. For 34% of the studies, there was no mention of privacy, confidentiality or any report of the measures taken to protect participants' privacy or maintain the confidentiality of the information collected.

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Dissertations

All of the dissertations reviewed included some information on privacy protection measures, with 63% providing specific information. For example, St Louis (2021, p. 95) provided particular details regarding the measures that were put in place to address privacy in the Grenadian context, including the use of pseudonyms as recommended by Creswell (2007):

Confidentiality was also upheld by the researcher's and participants' employer who signed a Letter of Cooperation, agreed to the confidentiality of information collected and authorized access to relevant non-public data ... signed letters of confidentiality were obtained from everyone who had access to the data. Prior planning determined data storage, transmission and availability. Transcripts were kept in a locked drawer with the keys solely kept by the researcher.... The confidentiality agreement was signed by the teacher who then reviewed the protocol, questions, and probes. I also signed a form attesting to confidentiality for the data provided by the participants. All identifying information regarding level of education (primary or secondary) and role (e.g., itinerant teacher or vice principal) were removed to augment confidentiality.... The peer reviewer signed the confidentiality agreement as second coder, listened to the recordings, and reviewed the transcripts from each focus group sent by the researcher for accuracy and completeness (pp. 95-100).

Several dissertation authors acknowledged the challenges of data collection in small island settings and described how they dealt with these challenges. For example, Hodge (2017, p. 63) acknowledged, "Also in dealing with small communities such as those found in the countries of the OECS [Organization of Eastern Caribbean States], persons may be able to identify participants by a process of elimination." Similarly, Lashley (2021, p. 92) noted, "The two schools studied are in tightly knit communities, which made preserving total anonymity very challenging or almost impossible even with the use of pseudonyms." Another author, Joseph (2014, p. 90), acknowledged the importance of the use of thick and rich descriptions in case studies and went on to explain how he addressed this challenge: "I further found it necessary to be purposively ambiguous when discussing some of the findings, including details of participants' positions and roles to protect their identity."

Journal Articles

Roughly half (48%) of journal articles mentioned privacy and confidentiality, with 32% providing specific details on how this was done. For example, Blackman (2010, p. 6) explained, "I ensured rooms used to conduct interviews were private. In addition, the pupils and teachers were given pseudonyms so that their identities remained protected." The possible impact on student-teacher relationships as a potential consequence of breach of privacy was also discussed, with Blackman (2010, p. 6) noting that, "The kind

of information collected had the potential to cause harm to the relationship between pupils and teachers if details of the conversations I had with pupils should be divulged in any way.”

In addition to explaining specific procedures for collecting and handling sensitive data, other researchers justified using particular data collection methods to address the challenges associated with data collection in special and inclusive education settings. For example, Conrad and Brown (2011, p. 1021) acknowledged that the richness of responses may have been limited by the decision to use written responses instead of face-to-face interviews (Streubert & Carpenter, 2007) but went on to explain:

However, given the tensions associated with inclusive education in T&T [Trinidad and Tobago], the co-researchers considered this the most effective way to build trust with respondents. The written responses to seven guiding questions shared the respondents’ perceptions on the efficacy of and barriers to inclusive education generally; and more specifically within their schools. Participants were invited to respond anonymously to the guiding questions and encouraged to share their perspectives in detail.

Conrad and Brown (2011, p. 1021) justified their approach by asserting that because the topic was so sensitive and the sample size so small, the choice not to have face-to-face meetings would allow for “greater ‘invisibility’ and thicker description” as outlined in the correspondence method (Harris, 2002).

Book Chapters

Of the book chapters reviewed, 42% mentioned and provided specific information on measures taken to protect privacy. The majority of these referred to the use of pseudonyms for students to maintain confidentiality (Blackman et al., 2018; Lainy, 2023; Regulus, 2023) and pseudonyms for schools involved in the study (Borris-Lezama & Conrad Popova, 2018).

DISCUSSION

The findings of this review shed light on the privacy protection measures in research on special and inclusive education in the Caribbean. Safeguarding privacy and confidentiality in special and inclusive education research is paramount, particularly in small countries and communities where stigmatization, discrimination and social exclusion may be prevalent.

There are unique challenges related to confidentiality in research in small island nations. MacPherson (2001, p. 61), in a discussion of this challenge in Grenada, states that:

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Researchers often discount the risk of broken confidentiality in their studies and fail to describe plans to maintain it. Confidentiality is a concern in communities like Grenada, where most people are distantly related by blood or marriage, and everyone seems to know everyone else's business. News travels quickly by word of mouth. When a crime is committed, people in nearby neighborhoods spread the news before it is reported by the media. Local doctors confirm that they (like most nurses and neighbors) know who has HIV in the community, and who suffers from mental illness.

While a significant portion of the literature addresses the topic of confidentiality, a considerable percentage of studies did not provide specific details on the procedures used to maintain privacy and confidentiality. This does not suggest that procedures were not in place; however, there is a lack of transparency regarding the extent to which participants' rights to privacy were upheld. Transparency in research reporting ensures that researchers, participants and stakeholders understand the procedures for safeguarding privacy and confidentiality. Methodological transparency is essential in this context, where there is a shortage of research in this area of education. Researchers must take the opportunity, where possible, to acknowledge the challenges of collecting data in small societies and describe how they dealt with those challenges.

There were several examples of researchers who acknowledged the unique cultural contexts, the possible implications of breaches in privacy, and descriptions of how participant privacy was protected in the contexts of special and inclusive education. These examples can serve as a blueprint for other Caribbean researchers who aim for transparency in their projects. The finding that all of the authors of the dissertations discussed measures taken to protect participant privacy is positive in that it demonstrates an awareness of the need to report on ethical considerations when conducting research in the Caribbean. Though the extract from St Louis (2021), in particular, provided a detailed description of privacy protection measures, this may not be feasible in shorter articles such as book chapters and journal articles. However, it provides an example of a researcher who is acutely aware of the small community context and the procedures that should be put in place to protect participant privacy.

When reporting results, researchers and authors of articles in all formats should make it a point to explicitly discuss ethical issues and how privacy and confidentiality were maintained, which can help Caribbean researchers navigate these issues in future research. This type of transparency can assist in constructing ethical, collaborative cultures and forming trust, which is essential to research project culture building. In the vein of creating ethical, collaborative research cultures, Gabbidon and Chenneville (2020) emphasize the importance of using research strategies that can prevent the further stigmatization of individuals already experiencing stigma and make several recommendations for each stage of the research process. They highlight the importance

of transparency about the research process, ethical concerns and researcher positionality, member-checking, and avoiding inadvertent breaches of confidentiality when describing data and using direct quotes.

While this paper has attempted to address the ethical issues of privacy and confidentiality in the context of research, it is worth noting that policy also plays a critical role in research ethics. Several international policies aim to provide privacy protection for students with SENDs, such as the Family Educational Rights and Privacy Act (FERPA – 20 U.S.C. § 1232g; 34 CFR Part 99, 1974), which protects the privacy of student records, and the Individuals with Disabilities Educational Act (IDEA-34 CFR Part 300, 2006), which provides guidelines on what information should be kept confidential, how this should be done and by whom. These policies can serve as guidelines for Caribbean nations that are in the process of developing their special education policies. They also highlight parental rights in accessing their children's records. Many Caribbean governments are writing and adopting SEND policies. These should include clauses that address protecting the right to privacy within research conducted with students with SENDs and their parents and teachers. All researchers, teachers, principals, and educational professionals should have an excellent working knowledge of these policies once they are in effect.

There are several limitations to the current study. Research in education in the Caribbean is scattered across various databases, and there may have been articles that could have been included but were not found. The analysis for this review was based solely on what researchers reported. Thus, other considerations for participant privacy and data confidentiality may have been made. While every effort was made to objectively code articles using the developed codebook, there is the potential for human error in coding.

Further suggestions for research include investigating how comfortable students with SENDs, their parents, caregivers, teachers, principals, and other stakeholders are with disclosing personal information to researchers. This is particularly relevant to the Caribbean, which is comprised of small island developing states, and in light of this new era of global data privacy concerns.

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