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## Editor's Message

Greetings to all members and friends of the **International Association of Special Education (IASE)**. It is a pleasure to introduce you to the 2019 issue of *Journal of the International Association of Special Education (JIASE)* with topics covering a broad range of issues concerning students and individuals with disabilities and special needs around the world.

The mission of JIASE is to serve as a professional, peer-reviewed journal for the worldwide dissemination of articles focused on research and models of practice to help the fields of special and inclusive education gain a better understanding of diverse approaches to teaching and learning. The key to the mission of the journal is our commitment to working with international authors, reviewers, and readers to become skilled and creative writers, critics, and consumers of international special and inclusive education research, and innovative practices.

In this 2019 issue of JIASE, articles represent research and practice conducted in several countries, including Zambia, Tanzania, Armenia, India, and the United States. The authors cover the topics of access of students with vision loss to inclusive education; the status of inclusive education in Armenia; quality of inclusive education in India, and others.

It is very exciting and rewarding to see the interest of researchers and practitioners from so many different countries publishing their research and practical experience in JIASE. It is very important that international researchers and practitioners share their findings and experiences with audiences around the world. We encourage you to do the same!

At JIASE, we are committed to working with first-time authors and contributors, who typically do not publish for international audiences, as well as with experienced authors. We welcome new and innovative research and practice topics and approaches within inclusive and special education from all countries.

This publication would not be possible without the dedication, inspiration and encouragement from IASE leadership, JIASE managing editor Thomas J. Donaghy, and our wonderful team of associate and consulting editors, who volunteer many hours to provide professional peer review services for the journal. We thank them all for all they do.

We are always seeking members who would like to serve as consulting editors for JIASE. If interested, please contact Dr. Tichá directly for more information. Also, please consider submitting your work for publication in future JIASE issues. Publication submission guidelines are located on the IASE website at <https://www.iase.org/jiase> as well as at the end of this journal issue. We hope that you will find this issue to be a valuable resource in your own work with students, parents, and teachers all around the world.

Save the date for the 17th Biennial IASE Conference in Ho Chi Minh City, Vietnam, July 11–14, 2021.

With warm regards,  
Renáta Tichá, PhD, Editor of JIASE

# The Learning Conditions Experienced by Students with Visual Impairments at the University of Zambia

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## Abstract

*Recently, higher education institutions (HEIs) have been striving to make matters of inclusion a top priority in their educational environments. Utilizing a qualitative case study approach, this paper provides an exposition of the learning conditions experienced specifically by students with visual impairments (SVIs) in a higher education institution in Zambia. Through qualitative data collected from research participants via interviews, observations, and document analysis, the study revealed that the institutions lack programs and facilities to enhance academic progress. Lack of structured support systems for SVIs, the use of modes of instruction that lack sensitivity for these students and poor assessment practices that do not encourage proper learning among SVIs were the difficulties encountered. The HEI have an opportunity to become inclusive by devising policy guidelines and provisions of resources for all students, particularly those with visual impairments.*

Keywords: *visual impairment, higher education, Zambia, qualitative case study*

## INTRODUCTION

The attainment of higher education provides a diverse set of opportunities both to the affected individuals and their entire society. The provision and attainment of general and higher education is a significant human right (United Nations, 2006). Thus, many, if not all, nations strive to make all educational levels more inclusive. Many nations now view inclusive education as one of the top human rights issues of our time. Internationally, the human right to an inclusive education is becoming enshrined in law. The 2006 United Nations Convention on Human Rights of Persons with Disability (UNCRPD) stipulates that education is a human right, with UNCRPD, 2006, Article 24 (1) stating that all persons with disabilities have a right to education, provided in a non-discriminatory way and that inclusive education shall be the bedrock at all levels.

The nation of Zambia is a signatory of the UN Convention of the Rights of Persons with Disability (UNCRDP) and hence should comply with it in all its endeavors of educational provision and at all educational levels.

At the local level, inclusive education in Zambia goes much further back in time, long before the 2006 UN Convention on Human Rights of Persons with Disability. It started when the Dutch Reformed Church began providing some form of Western education to learners

with visual impairments (Kalabula, 2007). Moreover, Zambia's current national education policy entitled "Educating Our Future," clearly acknowledges that learners with various disabilities have a right to education. The principle is that all individuals, regardless of circumstances, have the right to access and participate in education. This implies that interventions have to be put in place to ensure that the education provided is beneficial (Government of Republic of Zambia, 1996).

For learners with visual impairments, inclusion in all spheres of life entails a holistic approach to development. Learners transition from secondary school, either in special schools for learners with disabilities or inclusive settings where they learn alongside their sighted peers. Many transition into Higher Education Institutions (HEIs), either college or university. At the point of transition, most learners with disabilities lack essential skills required to adapt to any learning situation, e.g. orientation and mobility, compensatory and academic skills, and use of assistive technology (Simalalo, 2017). HEIs also face complexities in terms of making positive reforms toward enhancing the much-desired educational inclusion at the tertiary level. This position is supported by the UNCRPD (2006) that states that all persons with disabilities should have access to tertiary education, vocational training, adult education, and lifelong learning in a non-discriminatory manner, and reasonable accommodations shall be provided.

Thus, institutions that fail to accommodate students with disabilities are perceived as discriminatory. This is because, according to the Persons with Disabilities Act (2012), discrimination takes place when a person with a disability must comply with a condition in which persons without a disability may have an advantage or by not providing services to accommodate the person with a disability.

It is against this background that this article focuses on the experiences of students with visual impairments (SVIs) in HEIs in Zambia. This creates a platform for HEI policymakers and administrators to examine inclusion of SVIs and provide research-based strategies that enhance equity and inclusion for SVIs in higher education in Zambia.

The University of Zambia was established in 1966 under an act of parliament to train the newly-independent country's workforce. Since then, the institution has grown, especially in terms of enrolments and development of many fields of study. The university's operations are guided by the Education Act of 2011 and the Higher Education Act of 2013. Over the years, the university has enrolled students of diverse backgrounds, including those with disabilities. The Education Act of 2011 requires all higher education institutions to educate in non-discriminatory ways. In order to actualise this law, the university has a positive discrimination policy where 10 percent of admissible spaces for first-year students are reserved for vulnerable rural applicants and those with disabilities.

In Zambia and across the world, some students with disabilities transition from secondary schools into HEIs, such as colleges or universities. However, most students, particularly those with visual impairments, lack the skills required to adapt to any learning situation and this is one of the main barriers to proper educational attainment by SVIs (Simalalo, 2017). Most SVIs also struggle to manage and plan their education, plan their independent living, and advocate for themselves. The demands of higher education become a serious challenge to SVIs due to lack of skills (Hong, Haefner, & Slekra, 2011). Another barrier that HEI students with disabilities face is faculty members' lack of knowledge about disabilities. Moreover, in HEIs, SVIs report faculty's negative attitudes towards students with disabilities, an aspect that further impacts the instructional strategies used in these educational institutions (Barnard, Stevens, Siwatu, & Lan, 2008; Fuller, Bradley, Healey, & Hall, 2004). Further, HEI staff attitudes influence their willingness to support students with disabilities. Other challenges include SVIs learning in lectures

where they are supposed to take notes, experience high fieldwork requirements, and misplacement and eventual loss of continuous and promotional assessment tasks, especially those submitted in Braille. It is because of the various challenges faced by SVIs in HEIs that Karten, (2010); Salisbury, (2008); Powell, (2003); and Farmer, Riddick, and Sterling (2002) propose that higher education institutions should consider the needs of SVIs critically when they plan courses and activities. Reasonable accommodations could be done in three avenues. Educational institutions can offer support to students with disabilities, including providing personal or individualized accommodations for the identified needs, offer appropriate training to staff, and show political commitment to the entitlements of students with disabilities. When reasonable accommodations are made, institutions minimise SVIs' academic and life challenges. The purpose of this study was to establish the difficulties encountered by students with visual impairments at the University of Zambia.

## METHODS

### Setting

The study was conducted at the University of Zambia. The institution is located in the capital city of the country, Lusaka. The study focused on the learning experiences of visually impaired students in one institution.

The University of Zambia is the oldest public university in the country. It is an icon of the nation's achievements in producing skilled workforces in different fields. At the time of the study, the institution had been in existence for over fifty years. As a higher education pioneer in the country, the university is expected to provide excellent service to all students in all spheres of training. In the same vein, the institution had for many years enrolled students with various disabilities, including those with visual impairments, most of whom graduated.

### Research Approach

The study approach was qualitative, utilizing case study design. Qualitative research is not intended to generalize the information, but to explain specific issues in a phenomenon—in this case, difficulties faced by SVIs at a university. A qualitative approach was deemed to be most appropriate to gain an in-depth understanding of the topic. Kothari (2004) and Nolen and Talbert (2011) have stated that a qualitative approach is one that investigates a quality or kind of phenomenon. Creswell (2007) agrees that in a qualitative research process the researcher endeavors to understand the participants' interpretation of issues.



### **Target Population and Sample**

The population of the study consisted of students with visual impairments, lecturers, heads of departments, and faculty deans in a university setting. The sample size of the study was 20 with the corresponding codes or identifiers: 10 students (SVIs): 2 females and 8 males whose age range was 22–40; 4 lecturers (LT): 3 males and 1 female aged 40–50; 2 faculty deans (DN): 2 males with an age range of 45–60; 2 heads of department (HOD): 2 males with an age range of 40–55; and 2 institution managers (MN): 2 males with an age range of 50–60. All students with visual impairments at the university from first year to the fourth year of study participated in the project. All the SVIs were enrolled in the Faculty of Education. Students with visual impairments in the study had low vision or blindness. The two deans were selected from the Faculty of Education and the Student Affairs Units. The Faculty of Education was selected because it was the only school with SVIs enrolled. The deans of Student Affairs were responsible for student welfare, both academically and in other areas of university life. The managers were responsible for institutional operations as well as policy interpretation and implementation. The lecturers sampled were from the Faculty of Education and had SVIs in the study areas in which they provided instruction.

Research participants were selected through purposeful sampling. Ghosh (2008) states that purposive sampling is the selection of a sample based on the researcher's judgment. The concept of purposive sampling in qualitative inquiry means that individuals and sites are selected because they can inform the understanding of the research problem (Creswell, 2007).

### **Data Collection Approach**

The primary data gathering instruments for this study were interviews and observations. To supplement these techniques, documents were read to get an insight into the policy framework governing tertiary education. The interviews were in-depth and provided rich information on the issue at hand. The main questions in the interviews were:

- What legal or policy framework guide the provision of education for students with disabilities?
- What facilities does the university have for students with visual impairment?
- How do students with visual impairments access materials in the various courses they study?

An observation checklist on accessibility to the infrastructure and information at the university was developed and used to collect data. The documents analyzed included the Education Act of 2011, Higher Education Act of 2013, the University Act of 1965, Persons with Disability Act of 2012, and Educating Our Future policy of 1996. These provided information on the guidelines on educating persons with disability at all levels of the education system. Data collection instruments were triangulated to capture valid data in line with the objectives of the entire study.

### **Data Collection Procedure**

The interviews were conducted within the university by the researchers who are also authors of this article. All participants were interviewed and each interview lasted between 30 to 50 minutes. With permission from the participants, all interviews were audio-recorded and later transcribed. Observations were conducted by the researchers to check on issues of environmental accessibility as well as information access. The observations lasted about 60 minutes in lectures, the university library, and the physical infrastructure of the institution in relation to mobility of students with visual impairments.

### **Data Analysis Approach**

Data analysis is a systematic search for meaning in data that can be communicated to others. Hatch (2002) states that analysis means organizing and interrogating data in a way that enables the researcher to see patterns, identify themes, discover relationships, and make interpretations or generate theories. This study employed a qualitative analytical approach. In order to identify themes, the researchers engaged in a series of readings of the transcripts, which resulted in generating codes by comparing emerging categories. Data with similar characteristics were coded together and these eventually became themes. This holistic analysis of data was done in order to understand the issues in the study and to come up with propositions. Besides, thematic analysis aided understanding of the complexity and relatedness of the issues (Ritchie & Lewis, 2003).

## **RESULTS**

A number of challenges faced by SVIs are presented here. The challenges range from student factors to institutional operational shortfalls. The main themes identified through this research were: Access to training programs of one's choice; difficulty obtaining government scholarships; the physical environmental not

being accessible enough for students with disabilities, especially those with visual impairments; the learning environment lacking educational materials; and a lack of policy guidelines.

### **Students Experience Limited Access to Training Programs of Their Choice**

This was reported by students and other staff members. One student lamented that he was redirected to another faculty in the university to pursue a career direction that did not interest him, merely because he had a visual impairment. He said the following:

When it comes to the choice of programs one wants to take in the university, I think the system is very discriminatory as blind people are mostly coerced to study special education, even when they are interested to study something else. This is a huge challenge. In other countries, blind people are allowed to study in prestigious programs such as law, engineering, and others, without discrimination.

An administrator acknowledged that most learners with disabilities were redirected to a department whose responsibility was to train teachers in special education and not necessarily responsible for the welfare of SVIs, regardless of their interests. This is what one student had to say:

What usually happens is that students with disabilities are sent to departments which have staff with skills to handle such students because it is very difficult for non-specialized departments to handle such students.

A head of department mentioned that the department received students with disabilities, particularly the blind, every academic year.

Most of the students with vision problems are training to be teachers in special education. It seems they have no wide choice of courses.

Another difficulty SVIs encountered was the struggle to obtain preferential treatment for government scholarships. When HEIs fail to provide accommodations and support for SVIs, these students become overwhelmed and could withdraw from training. During the study, one SVI dropped out of university due to the delay in accessing a government scholarship. The following were the sentiments of a student regarding this matter.

Government has delayed to offer me a scholarship to study at this university. Since I have no money, I just have to leave. The stress of thinking about where I can find money to pay is too much for me.

Another student struggling to finance his university education said the following:

I always wished that I had a 100% government scholarship because being on 75%, I find problems sourcing for the remaining 25%. The realization that most of the people on 100% scholarships are those that do not deserve; it makes me sad.

A head of department clarified that, over the years, the Faculty of Education had taken its own initiative to lobby the bursaries department to consider students with disabilities for sponsorship.

If students with disabilities were to receive sponsorship, then the university and government should be very clear to assist students. We had to lobby, as a department, for scholarships; it is not fair. Students with disabilities already have difficulties by nature, so to deny them easy access to bursary is torture.

Physical barriers in the environment affected the academic and overall adjustment of SVIs at the university. Generally, the HEI was not sensitive to the environmental challenges faced by learners with disabilities. A number of SVIs acknowledged many challenges associated with navigating environments. One participant said:

I am still using guided sight because the environment is not allowing us to move alone, the vehicles are all over the place. Even the infrastructure is not conducive. It is very difficult to find your way in the university. There is no one to show us the environment.

Similarly, another student stated the following:

I find it hard to master the paths in this university, so it is very hard for me to walk unguided.

A dean stated that the university had an orientation program for all first-year students, but it did not cater to students with disabilities.

We have orientation for all new students as a university, but nothing is in place to provide environment orientation to students with visual impairments.



A head of department (HOD1) had a slightly different view about environment accessibility.

It is expected that the students would have been taught how to navigate the environment in schools they have been. By university entry they should have minimal challenges in mobility but it is not the case for the ones we have had.

A check on the infrastructure revealed that the university did not have designated walk paths for students, particularly those with visual impairments. There were ramps in a few places leading to main entrances of lecture rooms. One school with a five-floor building only had an elevator to the third floor. Another observation was that parked cars often obstructed designated crossing points. It seemed regulations were not followed.

Participants mentioned a lack of educational resources accessible to SVIs. Higher education has a different kind of academic demand, which requires SVIs to use varied modes of communication and information. SVIs need to use a wide range of methods to gather as well as disseminate information. However, SVIs are expected to find resources in Braille. One student stated the following:

There are no hard copy books in Braille at our university. Even our course modules are not in Braille. Lecturers can only manage to give notes in soft copy and not in Braille.

Moreover, regarding the issue at hand, one student had the following to say:

We are so much behind as far as technology is concerned and there is a scarcity of computers in this university. The computers are not enough and not all students with visual impairments know how to use them.

However, one manager mentioned that the university was capable of providing resource materials in electronic mode:

We have an e-library. A lot of materials are there, except the computers in the library do not have software for blind students to use.

A lecturer stated that students with visual impairments do receive some support, although not sufficient:

We usually give soft copy notes, but the visually disabled students share with other students who then stop attending class. You find the notes are all over the printing booths for sale. I think twice before giving out notes.

Doubts about SVIs' potential in higher education influenced support for the students. Most people believe that without sight, it is impossible to learn. This orientation undermines the support persons with visual impairments receive from all sectors of society, including families and educational institutions. This came out vividly in the sentiments of one student when he stated that:

Even in my own family, most people think I am not good for anything, that I cannot achieve anything just because I have no sight. All they ask me to do is just to sit and do nothing at all.

Another student observed:

Most people at this university express amazement at how I manage to get about my business as a student owing to my visual impairment. This comes from lecturers and students, too.

One faculty dean stated the following:

Students have challenges, but they do graduate. It's a battle for them.

A lecturer talked about the general advice students receive as they begin their studies:

I usually tell the students to be strong because the environment is not as friendly as the secondary school they were coming from. University is tough and they may fail if they are not careful.

It was observed that there was a lack of structured support systems for SVIs in the university. All HEIs are legally required to provide facilities and equipment for students with visual impairments (Persons with Disability Act of 2012; Higher Education Act of 2013, Article 12 (1, f)). To achieve this, institutions were expected to establish support systems for students with disabilities, but this university had not done so. In line with this issue, one student said the following:

I have not heard of any institutional policy meant to guide the provision of services for students with disabilities at this university. If there was such a policy, we the disabled people could have noticed

a major improvement in the services the institution provides to us. There is no such a thing as a disability policy at this university.

One manager agreed:

The institution does not have a disability policy, but students are supported through the counseling center and academic counseling in various schools.

Similarly, the dean (DN2) mentioned that:

We don't have a facility for them (SVIs), but they are taken care of just like any other students. I am aware that faculty of education and law were trying to assist in drafting the policy, but the system is slow.

Teaching a diverse body of students calls for inclusive approaches. Students reported that some approaches were not especially inclusive and that lecturers often failed to consider the needs of SVIs. Further, SVIs had difficulties because the lessons were prepared and presented based on the premise that all students use sight to learn. The compounding factor is that lecturers who use videos or PowerPoint presentations gave very little explanation or description of the materials on slides. One student had this to say in line with the aforementioned:

One academic challenge I face at this university concerns the issue of lecture presentation. Sometimes lecturers use videos or PowerPoint presentations to teach and it becomes very hard for me to grasp anything from such lectures. My sight is poor.

Along the same lines as above, another student said:

Sometimes, as a blind student, you want to listen and write when the lecturer is teaching, but this is impossible to do sometimes due to many classroom factors. The classes are large and lectures are provided at a fast pace.

Poor assessment practices were identified as challenges for SVIs' academic progress, notably the problem of feedback after assessments. Students with visual impairments claimed that they hardly saw the assessments they submitted to their lecturers. They just received an assessment compilation at the end of the term or semester without seeing the actual assessment items they handed to their lecturers.

In line with this issue, a student stated that:

Mostly, I do not see the scripts I submit as assessments because whenever they go, they do not come back to me for reasons best known to my lecturers that receive them.

Similarly, another student pointed out that:

In terms of assessments, one of the greatest challenges I face as a blind student in this university is that it is always not an easy task to transcribe my work after writing it in Braille for the lecturers to read. This takes a lot of time to achieve.

A lecturer submitted that:

At the moment, we do provide transcription for scripts in Braille. Actually, we provide examinations, in most cases in the mode the student is comfortable with, be it Braille, large print or soft copy. However, there is no guide on how things should be done. In fact, the person who embosses does so because she teaches a course in Braille.

Educational institutions worldwide are expected to implement equity and inclusion. This segment presents suggestions to improve learners' support and inclusion of all students, particularly SVIs.

The university needs an institutional disability support policy. This was a serious gap that must be filled. Policy guidelines within HEIs compel institutions to provide reasonable accommodations in all areas of the lives of students with disabilities, especially the visually impaired. In line with this aspect, one student noted:

A disability policy in HEIs in Zambia would be a positive way to go, as such a policy would ensure the provision of all the major things that SVIs need.

A dean stated the following:

It is difficult to be consistent without guidelines. We are simply assisting because we trained to do so. Students have a right to full service.

Increasing SVIs' access to assistive technology was deemed as one strategy for inclusion and increased participation. In the words of a faculty member:

We need computers in this university to be used as assistive technology by students with disabilities. Computers and other gadgets would make it easy for students to access information from the internet and also communicate with lecturers. For example, with the availability of many computers

in the university, lecturers will be giving their notes in soft copies to their students with visual impairments for them to read at their own time.

However, a manager observed that the university already had some information and communication technology (ICT) devices:

The university has computers, but without software for our blind students. We need to see how we can work with partners to provide information communication technology.

The need to use alternative modes of assessment emerged as a measure to improve SVIs' academic well-being. This arises from the earlier observation on the lack of feedback on assessment tasks written in Braille. The institutions can use oral examinations and video/ audio-taped responses. In line with this aspect, one student said the following:

Since Braille has been problematic for us to use for various reasons in this university, it can be advantageous if the university trained us how to use other means of communication, such as computers and other available devices.

On assessment, a manager posited as follows:

We are not rigid on ways of assessing students. The lecturers have not presented the student need to assess in different modes. We do have oral examination (in some programs) but not specific to disability.

A lecturer mentioned the following:

At the moment, I know that we provide assessment in Braille, computer-based and also large print. I think students need to learn to use a variety of modes, except there is no deliberate effort to train them in other modes of communication.

The need for the creation of disability awareness within the university and other institutions was brought out as a possible solution to challenges faced by SVIs—a need stressed by university faculty members and SVIs as indicated below.

One student stated that:

In order to avoid the negative attitudes and fears people have towards students with disabilities in this university, there is need for people to be made aware of what such students can do. This is because

the general understanding among many is that we are good for nothing, that we should just remain at home doing nothing.

A faculty member had this to say:

I think in order to improve people's perceptions towards students with disabilities, there is need for the university to introduce sensitization teams or classes where people are sensitized on what all people within the university are doing. I am sure they can be amazed to realize that even we the disabled are doing amazing things, contrary to what they think of us as people that cannot do anything positive.

Students, lecturers, and managers reported that the institution needed to establish a disability service department or structured support. To promote better education outcomes, facilities should be provided for students with disabilities, such as resource centers, where various services are offered, including transcription, assistive technology, counseling and other disability-specific skills (orientation and mobility). In line with the above, one student advised as follows:

I think we need a disability service department or some kind of structured support system for students with disabilities in this university. The special education department training teachers in the field of special education is not enough to resolve all the problems we are facing as students with disabilities in this university.

A head of department reiterated:

The room in the school of education is not enough. We need a facility for all, like it is in other universities outside this country.

In a non-committal manner, a manager submitted this:

The institution is always ready and willing to work with other departments to ensure students have facilities.

### **Summary of Results**

The results presented the voices of participants on the difficulty faced by SVIs at the university. The main challenges center on inadequate resources for academic writing, which is compounded by the lack of assistive technologies. The results also revealed faculty teaching methods not tailored to the learning styles of

students with visual impairments. A lack of institutional guidelines on education of students with disability was equally a challenge.

## DISCUSSION

To every learner, whether with or without a disability, admission into HEIs is a career stepping stone. Lack of SVI access to training programs of choice was unfortunate. However, a number of factors were identified to explain this scenario. Career choices begin early in life and can be influenced by many factors, such as role models in the community, the kind of elementary and secondary education received, and the social and economic status of the family, among others. For instance, learners with visual impairments at a secondary school did not have access to a wide scope of science. This was mainly because science-related subjects become progressively more challenging and demand deeper scientific analysis, which learners with visual impairments were not taught. The limited number of subjects that SVIs can take has a bearing on the choice of programs they study at the tertiary level. Students with visual impairments should be eligible to take a course of their choice. When this does not happen, equal access is compromised (Powell, 2003; United Nations, 2006). Therefore, Zambia's education system creates a natural inequality, forcing many SVIs to pursue careers in social science-based programs, particularly in teaching. In the case of the university, students were directed to the Faculty of Education because there were lecturers there knowledgeable in educating persons with disability.

Generally, each year the Zambian government offers highly-competitive scholarships and loans for higher education to a limited number of Zambian students. The lack of preferential treatment of students with disability on obtaining government scholarships often leads to stress and eventual failure. Positive discrimination in favor of SVIs should be embraced by authorities when considering applications for support. Most SVIs are vulnerable and come from poor families and hence they are not able to pay for education (Grech, 2014; Simalalo, 2017). Educational challenges for SVIs begin early in their lives, running through primary, secondary, and tertiary educational levels; these challenges are exacerbated by the negative attitudes held by people within their own families (Simalalo, 2017). Timely financial assistance impacts the student's prospect of completing a study program (Morley, 2012; Powell, 2003; Meijer, 2001).

Most universities, especially public universities, were built between 1965 and 1980, when educational equity and inclusiveness were not prominently upheld or emphasised. Consequently, most of the infrastructure is inaccessible by persons with disabilities. Students with disabilities face the vexing challenge of a lack of environments that are consistent and in line with their limited vision. Observations at the university revealed that crossing points were often obstructed, making it difficult for SVIs to become familiar with the environment. Yet SVIs were generally expected to transfer the orientation and mobility skills they acquired in previous, familiar environments to their new environment at the university. Unfortunately, the teaching of orientation and mobility is limited to special schools (Simalalo, 2017). As such, SVIs enter tertiary education with very limited orientation and mobility skills and usually fail to utilise their skills to enhance independent travel in complicated university environments. Dependence on friends to guide them or help with mobility contradicts universal and government commitments to the inclusion of persons with disabilities in learning institutions (GRZ, 2012; GRZ, 2011; UN, 2006).

Academic success requires available learning resources. Students with visual impairments had limited modes of reading and writing, depending mostly on Braille. Moreover, students lacked skills in assistive technology to enhance information search and knowledge production. Having used Braille in primary and secondary school, SVIs also expected to find reference materials in Braille at a university level, but were disappointed. This is because the demand for information is so extensive at the tertiary level and the volumes of varied resource materials may not be manageable in Braille, because large amount of paper and space would be required. HEIs should have resources available both to staff and students. Staff need adequate resources to support their students. Resources include teaching and learning materials, technological resources, and adapted leaning resources (Zezelew, 2016).

All societies struggle with negative attitudes toward people with disabilities. Negative attitudes are a complex issue and emanate from different perspectives in society. Families and society at large have demonstrated a negative attitude towards people with any form of disability and especially those with visual impairments (Korir, 2015). Usually families and society perceive people with visual impairments as unable to do anything in life independently and dependent on charity. Doubts about SVIs' ability to achieve academically was related to the university practice of training SVIs only



in teacher education programs. Negative perceptions like these can act as a barrier to success in academic pursuits and life in general.

Structured support systems for students with disabilities in general, and visually impaired students in particular, was not available. This indicates the lack of a clear agenda on including SVIs in higher education in Zambia. The institution did not have policy to guide the provision of vital services for students with disabilities in general and SVIs in particular. This makes managing accommodations for students with disabilities in higher education very difficult. Without an institutional agenda, self-advocacy of the needs of SVIs becomes a challenge. The compounding factors in self-advocacy are poor self-determination skills exhibited by most learners with visual impairments (Agran, Hong, & Blankenship, 2007). This failure to provide proper structured support systems for SVIs contradicts the Zambian government's stance on inclusion.

One outcome of technological advancement globally is a tremendous growth of this sector in educational institutions. This is because of the need to promote both efficiency and quality of education. However, SVIs have experienced challenges with computer-based approaches. Students with visual impairments reported lecture delivery methods that were not all inclusive. Lectures at the university were presented with the premise that all students were visual learners. Use of PowerPoint presentations with little explanation of information on the slides was singled out as non-inclusive strategy. Inclusive approaches of teaching need to be planned and the instructor needs to deliberately engage all students.

Beside poor feedback on assessment tasks submitted, SVIs always faced the challenge of an inadequate transcription facility. Without such a facility, it is always difficult to transcribe their work from Braille to print. The Persons with Disability Act of 2012, part IV (f) is clear on the provision of alternatives and formats of communication and supports to students in order to promote inclusion. The challenges in assessment were related to the lack of guidelines in service provision and the absence of a disability service department.

Study respondents suggested strategies to promote equity and inclusion of visually impaired students in higher education. Kumar and Wideman (2013) posit that most HEIs subscribe to the medical model of disability that puts the responsibility on persons with disabilities to overcome learning barriers. On the contrary, educational institutions should have systems in place to offer support facilities to all students with disabilities.

These strategies are meant to promote equity and inclusion, particularly for SVIs.

The need for the institutional disability support policy is an important matter. Despite the stipulation of provisions for the improvement of the education of students with disabilities (SWDs) by the 2006 UN Convention, the 2012 Persons with Disability Act, Zambia's current 1996 national education policy, there is a lack of a disability policy at universities.

Shepherd (2001) in Zelelew (2016) further recommended that HEIs must have relevant and clear policy guidelines at all levels of operations. With policy and guidelines in place, SVIs are empowered to demand standards as stipulated therein. In fact, UNESCO (2010) emphasized that having a disability policy is an institutional strategy to make opportunities equal for all students. Therefore, a disability policy should be clear on ways to promote inclusion of students with disabilities.

Access to assistive technology is vital for all students with disabilities, particularly those with visual impairments, and universities need to increase this access.

According to Ostrowski (2016), assistive technology includes devices or systems that improve or maintain functional capabilities of students. Without a good support system, most efforts to improve the education of such students in HEIs are based mostly on trial and error. When no training or support is provided, SVIs struggle to fund their own devices and training to ensure they remain afloat in their academic work. Students with visual impairments without assistive technology continue to use the traditional technology or Braille, which has challenges, such as bulkiness, rarity, high cost, and lengthy time for production (D'Andrea, 2012, in Ostrowski, 2016). The challenge related to Braille use could be rectified by training SVIs in assistive technology use, where they present typed work instead of using Braille. Moreover, Braille has fewer readers and hence acts as a barrier to the education of SVIs.

Different types of assessments are given to students at the university level. Modes of assessments take different formats for SVIs. Such assessments include audio presentations, typed work, Braille, and large print (Salisbury, 2008; Powell, 2003). The university should widen assessment options by providing additional tools and physical resources to complete tasks. Other strategies can include providing soft copies of tests and offering additional time during the assessment process. Participants reported that alternative modes of assessment can reduce the challenges SVIs face in their studies.



In most educational settings where persons with disabilities, including the visually impaired, are enrolled, stakeholders, such as teachers, lecturers, and administrators do not seem to know the needs of these learners. Therefore, promoting awareness of the needs of students with disabilities, particularly those with visually impairments, is essential. Awareness will enhance proper attitudes and knowledge towards SVIs. Sensitization at all levels in HEIs can help resolve many misconceptions and fears, particularly about offering support to SVIs. This is in accordance with Reupert, Hemmings, and Connors (2010) stating that overall, the better informed and supported the lecturers are about students with disabilities, legislative obligations, and appropriate accommodations, the more likely it will be for students with disabilities to achieve their full educational potential.

Training programs to share knowledge and skills among students, lecturers, administrators, and staff on the needs of SVIs in order to promote their educational attainment are required. According to Izzo, Murray, and Novak (2008), awareness programs include specific academic needs and appropriate teaching strategies. Moreover, Wynants and Dennis (2017) argue that the training offered to the members of the institution is equally instrumental in improving attitudes that enhance inclusion of student with disabilities.

The provision of services for students with disabilities in any learning institution calls for structured support. This is particularly important at a university. A service facility specially designed for students with disabilities fosters inclusion of all. However, most HEIs in Zambia were designed without catering to the diverse needs of students. At the time of the study, the institution did not have a disability service department to exclusively offer support to students with disabilities. The university had a teaching department that trained teachers in special education, but it provided only limited support to students with disabilities and with sufficient guidelines.

Although the institution did not have a deliberate program to teach skills to SVIs, the learners found other avenues, such as joining classes in assistive technology in government departments. A disability service department can have the mandate to offer transitional skills to SVIs. This facility also generates individualized plans for SVIs when they enrol in HEIs. Further, the university should have full-time advisors, who provide assistance about all matters, ranging from coursework to library use to examinations before entry, all the way to graduation (Clayton, Poe, Piti, & Goodman, 2010; Salisbury, 2008; McCarthy & Hurst, 2001).

## CONCLUSION

It is a major requirement to make inclusive education a top priority in all educational environments globally, because the attainment of education in general and higher education in particular is perceived as a human right. This article has indicated that a Zambian perspective on equity and inclusion in higher education institutions (HEIs) is not granted the attention it deserves. This is especially true regarding the various learning barriers experienced by visually impaired students.

The challenges encountered by SVIs jeopardise equally their access and participation. The findings indicated that service provision there was generally inadequate. The services that were available lacked adequate guidelines and were limited in content and scope. The university could scale up the activities and support provided by the special education department. The efforts of the teaching department had prevented SVIs from failing and dropping out of the university. The institution needs to adopt and operate the different provisions of policy and legislation on inclusion of students with disabilities in Zambia.

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# **“It is not our Fault. We are the Victims of the Education System”: Assessment of the Accessibility of Examinations and Information for Students with Visual Impairment in Tanzania**

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## **Abstract**

*This paper assessed the accessibility of examinations and information for students with visual impairment, across different education levels in Tanzania. The study was guided by three research questions. While the first research question explored barriers to the accessibility of examinations for students with visual impairment, the second research question investigated barriers to the accessibility of information for students with visual impairment. The third research question focused on strategies that can improve the accessibility of examinations and information for students with visual impairment. The target population were students with visual impairment from two selected higher learning institutions. Purposive sampling procedure was used to select 16 students with visual impairment to be involved in a semi-structured interview and focus group discussion. Thematic analysis was used to identify, analyze, and record themes and sub-themes from the data generated.*

*The study established five barriers to examinations access: inappropriate examination formats and administration procedures, lack of examinations feedback from teachers, delays in examination time, incompetence of transcribers, and inappropriate grading system. The study further identified absence of assistive devices and/or lack of skills in assistive technology as major challenges to access printed information. Strategies to enhance the access to examination and information for students with visual impairment are also provided. It is recommended that the Tanzanian government allocate a special budget and encourage community participation in the provision of assistive devices and technology to enhance accessibility of examinations and information to students with visual impairment.*

*Keywords: visual impairment, examination access, assistive technology, assistive devices, inclusive education*

## **INTRODUCTION**

### **Students with Visual Impairment**

From a legal perspective, visual impairment (VI) is defined as someone with visual acuity of 20/200, meaning that which a blind person sees at a distance of 20 feet, a person with normal vision can see 200 feet away (Heward, 2013). However, an educational perspective perceives visual impairment by focusing on the relationship between vision and learning or method of reading instruction. In this study, students with visual impairment include both blind students and those with low vision. Whereas students with low vision use vision as a primary means of learning to read printed material using large-print books and/or magnifying devices, a blind person receives no useful information through the sense of vision and thus they learn through tactile (Braille print) and auditory senses (Heward, 2013). Nevertheless, with advancements in technology, students with low vision now find assistive technologies to be more useful than print books (Douglas et al. 2011; Hallahan, Kauffman, & Pullen, 2012).

In addition to Braille print and the audio method of learning, students with VI also need orientation and mobility training. Such training enhances independent mobility skills in both familiar and unfamiliar environments, thus reducing over-dependence on sighted students when in need of on-campus mobility (Jones & Maloney, 2015). Orientation involves the ability to know where one is going, and how one will get there. Mobility involves moving safely and efficiently from one point to another (Hallahan et al., 2012; Heward, 2013). Orientation and mobility support involve the long cane, sighted guide/human guide, tactile maps, and guide dogs. According to Heward (2013), the long cane is the most widely used device for adults with severe VI, while the guide dog is the least-employed strategy.

### **Accessibility of Examinations and Information for Students with Visual Impairment**

Access to information and examinations for students with visual impairment (VI) can be enhanced either by making materials accessible or assistive technology readily available. Whereas accessible materials include the provision of information in either Braille or large-print format, assistive technology (AT) incorporates the



use of either software (audio method) or devices that enlarge standard print (Douglas et al., 2011; Lueck et al., 2003). AT is any resource or facility acquired, modified or customised to increase, maintain or enhance the functional capabilities of a person with a disability. In this regard, AT entails devices and/or software that support and facilitate the education of these students. These devices include Low Vision Aids (LVA), Closed-Circuit Television (CCTV), automatic high-speed book scanners, and screen reader technology (Argyropoulos & Thymakis, 2014; Douglas et al., 2011; Hewett, Douglas, McLinden, & Keil, 2017; Wong & Law, 2016). Although both accessible materials and AT provide information, it is the use of the former, for example, Braille and large-print format, that are most commonly used to educate students with VI (Datta & Talukdar, 2017; Douglas et al., 2011; Mwakyeja, 2013).

### **Benefits of Assistive Technology/Devices in Accessing Information and Examinations**

Assistive technology (AT) has improved access to education for students with VI in terms of reading and writing skills as well as widening their communication ability (Silman, Yaratan, & Karanfiller, 2017). Generally, reading and writing skills are vital in enhancing students' competencies during examinations. Regarding writing skills, AT helps students with VI to improve their typing fluency and accuracy (Argyropoulos & Thymakis, 2014). In terms of comprehension and reading speed among students with low vision, no significant differences have been observed between a student reading 10-point font sizes with assistive technology and the one using 18-point, large-print fonts (Corn et al., 2003; Douglas et al., 2011). However, in the provision of large-print materials for examinations, teachers are obliged to consider each student's optimal print size to enhance his/her reading efficiency (Lueck et al., 2003; Kisanga, 2017). After all, reading speed increases with print size (Lueck et al., 2003). The implication is that when students with low vision take an examination that does not consider their optimal print size, they require more time to compensate for their compromised reading speed.

Moreover, AT students with VI access audiobooks or e-books which, in turn, solve the problem of the absence of Braille and large-print books (Lueck et al., 2003). In this regard, AT provides an alternative solution for developing countries, such as Tanzania, where libraries usually lack books in either Braille or large-print format (Kisanga, 2017). As students with VI often depend on sighted students to access information, AT

reduces this dependence by expanding the students' access to standard print materials (Argyropoulos & Thymakis, 2014; Douglas et al., 2011). Comparatively, AT tends to be more useful than accessible materials, such as large print, because they augment information accessibility. Moreover, AT provides students with an opportunity to access materials at any place and time, unlike large-print books (Corn et al., 2003; Douglas et al., 2011). Overall, to access information and/or examinations effectively, students with VI need either the information/examination presented in accessible materials, that is, Braille or large-print formats. In fact, this should be in their optimal print size, or the information/examination to be presented in standard print with AT to enhance its accessibility.

### **The Present Situation of Accessibility of Examinations and Information**

Various literatures worldwide have reported difficulties in accessing information and/or examinations among students with VI, largely due to their inaccessible formats, lack of access to AT, as well as lack of AT skills among supporting staff and students alike (Ghulam, Rukhsana, Misbah, Mahwish, & Dur-e, 2014; Hewett et al., 2017; Kelly, 2011; Morris, 2014; Mwakyeja, 2013; Reed & Curtis, 2012). However, the matter is even worse in developing countries, such as Tanzania, due to the low level of technology and unreliable source of power. In Tanzania, students with VI access their examinations mainly using two methods: Braille prints and typewriters (Kisanga, 2017; Mwakyeja, 2013). Studies there on students with VI have tended to focus on barriers to learning and teaching in general and not on the accessibility of the examinations and information in particular (Kiomoka, 2014; Nasiforo, 2015; Mwakyeja, 2013). In addition, the inaccessible examination system has been associated with low academic achievement among students with VI in Tanzania (Mwakyeja, 2013). This raises doubts about the accessibility of examinations and information to these students. This study, therefore, responds to this knowledge gap by exploring barriers experienced by students with VI in accessing information and examinations across educational levels in Tanzania.

The following research questions guided the study:

1. What are the barriers to the accessibility of examinations for students with VI in Tanzania?
2. What are the barriers to the accessibility of information for students with VI in Tanzania?



3. What strategies can improve the accessibility of information and examinations for students with VI in Tanzania?

## METHODS

### Setting

The study used purposive sampling to select two Higher Learning Institutions (HLIs) in the country, one public institution based in an urban area and a private institution located in a rural area. In this study, the two HLIs are referred to as Institutions 1 and 2, respectively. Established in 1961, Institution 1 is the oldest university in the country, and beginning in 1978, it became the first institution in Tanzania to enrol students with special educational needs (Tungaraza, 2012). Established in 2007, Institution 2 is relatively new and is privately-owned. Institution 2 offers more degree programs in special education than any other higher education institution in the country (Kapinga, 2012). Institution 1 enrolls over 15,000 students per year, which is about 10 times more than the enrolment at Institution 2 (University of Dar es Salaam [UDSM], 2017; Sebastian Kolowa Memorial University [SEKOMU], 2019).

### Study Design

This study employed a case study design to explore barriers to the accessibility of examinations and information for students with visual impairment and strategies to enhance the accessibility of examination and information. The case study design was appropriate in this study because it allowed the researcher to collect in-depth and detailed information from respondents that could otherwise not be obtained through the deployment of other designs, such as using survey data.

### Study Population, Sample, and Sampling Technique

The target population for this study were students with visual impairment in HLIs. Purposive sampling was utilised to select all 33 students, who were available in the two institutions involved in this study. However, only 16 agreed to participate in the study. Out of 16 students, 14 were undergraduates and two were postgraduates. In terms of disability categories, seven students were low vision and nine were blind. The age of respondents ranged from 20 to 50 years, where a majority (12) were in their 20s and a few (4) were above 35 years of age. Regarding gender, three students were female and 13 were male. The gender differences reflect the enrolment trends of all students in Tanzania from elementary to tertiary education, where the number of male students exceed that of female students for various

reasons, such as early pregnancy, early marriage, long distances to school, poverty, and the tendency for some Tanzanians' customs and traditions to undervalue educating females (United Republic of Tanzania [URT], 2014) To ensure anonymity, the two institutions in the study are referred to as institution 1 and 2, as mentioned earlier, and respondents as P1 to P16. Similarly, acronyms UG and PG were used to respectively represents undergraduate and postgraduate students.

### Study Procedure

This study used semi-structured interview and focus group discussions to answer the proposed research questions. The semi-structured interviews explored barriers to examinations and information experienced by students with visual impairment across different levels of education: primary school, secondary school, and higher education. They further captured ways that can be used to improve accessibility of examinations and information. Semi-structured interviews were appropriate for the study due to the nature of research questions that demanded detailed information from the respondents, and its flexibility in sequencing the discussion that allows the researcher to ask both planned and unplanned questions to enhance understanding of the phenomena (Bryman, 2016; Yin, 2014). The interviews were conducted at a convenient time and place for the respondents. Focus Group Discussion (FGD) was used for triangulation purposes. The FGD was conducted with all 16 students after completing the interviews. It was conducted in the same venue and asked the same questions as in the interview. Just as in the interview session, the researcher lead the discussion and facilitated the interaction while a note-taker took notes. The FGDs captured shared views and opinions among the respondents on barriers to examinations and information, as well as strategies that can improve accessibility of examinations and information. To encourage students' interaction (engagement) in the FGD, the author used two groups of eight students in each FGD. The group size used in this study concurred with Stewart and Shamdasani (2015): a group composed of less than eight members produces a dull discussion whereas a discussion with more than 12 participants can become unmanageable. The following are examples of guiding questions used during interviews and focus group discussions:

1. Using your experience during primary, secondary, and tertiary education, describe how you were assessed during test and examination periods.

2. What barriers did you experience in accessing examinations during your educational endeavors?
3. How did you access information during your primary, secondary, and tertiary education?
4. What barriers did you experience in accessing information during your educational endeavors?
5. In your opinion, suggest strategies that can be used to enhance accessibility of examinations and information.

### **Data Analysis**

Thematic analysis was used to identify, analyze, and record themes extracted from the respondents' responses. Thematic analysis was preceded by transcriptions of the interview data from a digital sound recorder. After transcriptions, the author reviewed all the transcripts to obtain a holistic understanding of the barriers related to examinations and information, as well as strategies to enhance accessibility. Thereafter, responses from one interview question to another were read across all the transcripts to familiarize the author with the research data and identify recurring concepts among respondents (Bryman, 2016). Similar procedure was done with the responses from FGDs. After familiarization with the research data, the researcher coded themes and sub-themes manually, using paper and pencil, by identifying recurring concepts in the transcripts that were also related to the research questions. To arrive at a theme, the researcher reduced the number of codes by categorizing data with common elements. For example, codes which focused on issues related to either examinations format or administration, formed a new theme called, *Barriers in examination format and administration procedures*.

Four major criteria were used to construe themes and subthemes:

1. How often the concept was repeated among respondents.
2. How closely it related to the research questions.
3. In how many different ways the respondents described their situation.
4. How many similarities and differences there were in discussing barriers the respondents encountered in accessing information and examinations (Bryman, 2016).

### **Trustworthiness of Qualitative Research Data**

This study ensured credibility of the findings through triangulation of research methods and the use of a member check. Dependability was assured by following the necessary procedures of conducting qualitative research and kept "an audit trail" of all important phases of

the research process. To enhance transferability of the findings to similar contexts, the researcher involved students with visual impairment from two different higher education institutions to have a good representation of students drawn from different inclusive schools in different regions (provinces) of the country. Similarly, to reduce researcher bias in analysis and interpretation (confirmability), the researcher used verbatim quotations to support the findings and provide readers with access to the original data.

## **RESULTS**

**Research Question One:** What are the barriers to the accessibility of examinations for students with VI in Tanzania?

### **Examinations-Related Barriers**

Five themes emerged during analysis of the findings. These included: (1) barriers in the examination format and administration procedures, (2) incompetence of transcribers during grading, (3) inappropriate grading system, (4) delays in examination time, and (5) a lack of examination feedback from teachers. Two barriers out of five emerged across all education levels, that is, from primary schools to HLIs: barriers in the examination format and administration procedures, and the incompetence of transcribers during grading. It was also observed that delay in examination time featured more in HLIs than in primary and secondary schools. Students in primary and secondary schools reported a lack of examination feedback from instructors, but that was not the case in HLIs. Students in both elementary levels of education and HLIs reported the problem of information inaccessibility. This section starts by presenting findings on barriers inherent in examinations, followed by barriers to information access and strategies to improve accessibility.

### **Barriers in Examination Format and Administration Procedures**

Findings from the study indicate that examination format and administration procedures both in special and some inclusive primary schools were accessible to students with VI as they attend tests, assignments, and examinations in Braille and responded in Braille format. Barriers reported in most of the inclusive primary and secondary schools revealed that students used typewriters in formative assignments and Braille during their final examinations held by the National Examination Council of Tanzania (NECTA). In the two HLIs under review, students at Institution 2 do their examination

in Braille, whereas those at Institution 1 are given an examination paper in Braille format and respond either using typewriters or computers, depending if they are skilled in computers. Comparatively, students with VI seemed more comfortable with the examination format and procedures in primary schools than in secondary schools and HLIs, because Braille format dominated in their primary schools.

In secondary schools, students raised concerns about three types of examination administration procedures. The first approach involved students typing out their examination in Braille format on the examination day, and subsequently responding to questions using Braille. Most of the respondents with VI reported that this administration procedure was tiresome as it involved two different tasks: typing the examination and then responding to it. Other students had a different experience: They received the examination orally, and responded orally, as stated by P12, “Teachers used to read out the test questions and I provided my answers orally too...” (P12, male, UG). P12’s statement implies that the absence of transcribers (who could prepare the examination in Braille format for the students with VI) and lack of special resources, such as Perkins Braille and typewriters to assist students in responding to their examination questions in Braille, hindered accessing and responding to examinations easily and timely.

The third approach combined the oral method and Braille, whereby teachers read out questions to the students who responded straight away in Braille format. Although teachers used this method to relieve students from a typing exercise, students with VI found this approach difficult, as exemplified in the following quotation:

... During a test or exam, teachers would read for us one question after another. Then we responded using Braille. This was very involving especially with multiple-choice questions with 4 to 5 distracters. By the time the fifth distracter has been read, you have forgotten the first one (P15, female, UG<sup>1</sup>).

P15’s statement highlights one of the adaptation strategies teachers employed in administering examinations in secondary schools. This adaptation strategy suggests either the absence of Braille transcribers or lack of Braille skills among teachers.

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<sup>1</sup> P = Participant/Respondent; UG = Undergraduate; PG = Postgraduate

## Problems with Typewriters

Students reported two major limitations with the use of typewriters: (1) the inability to edit students’ work when a mistake emerged, and (2) the risk of students submitting incomplete examinations if the carbon paper fell out of their typewriters without students’ knowledge. As P8 explained, “...the major challenge of using a typewriter is the inability to read and edit your work during typing...” (P8, male, UG). P8’s comment suggests that students with VI seem uncomfortable with typewriters when responding to examinations. However, they lacked a viable alternative due to the limitations associated with the examination format offered to them.

## Incompetence of Transcribers During Grading

Some transcribers who grade examinations written in Braille were reported to be incompetent in Braille skills. This was reported both in secondary schools, especially for transcribers who grade national examinations conducted by NECTA, and in HLIs, especially at Institution 2, where students respond to their examinations using Braille. Transcribers’ incompetence constituted a major challenge to the grading of ordinary secondary school national examinations, as claimed by P10: “... the use of what they call specialists to mark [grade] Form Four National examinations written in Braille is a problem because most of those specialists are incompetent in Braille” (P10, female, UG). P15 made a similar comment:

During our teaching practice at a certain inclusive secondary school for two years consecutively, we were asked to assist teachers from different departments to prepare their exams in Braille and to grade them, although the school had qualified degree-holding transcribers but who were incompetent in Braille reading and writing. Unfortunately, they were also included in the marking [grading] of National Examinations (P15, female, UG).

The statements from P10 and P15 imply distrust in the competence of Braille transcribers, as further reinforced by P10’s assertion: “The use of what they call specialists.” P15 questioned why incompetent transcribers employed in some inclusive secondary schools, who could not transcribe standard print paper to Braille or grade examinations papers written in Braille, were selected to grade national examinations written in Braille. P15’s claim also suggests that transcribers for grading national examinations are selected in a top-down manner because it was inconceivable that the heads of

school, who were aware of the transcribers' incompetence in Braille, would recommend them for grading national examinations held by NECTA.

A similar experience emerged in one of the HLIs under review. As reported earlier, students with VI at Institution 2 respond to their examinations using Braille machines instead of typewriters. Although students are comfortable with this approach, they doubted the competence of transcribers who grade their papers. Commenting on this aspect, P1 said:

...There was a certain section in one exam where we were supposed to write either True or False, that is, T or F. Unfortunately, all the areas where I wrote 'T' for true were wrongly transcribed as 'B'; and you can imagine that the level of education of this transcriber was at a bachelor's degree (P1, male, UG).

This comment implies that when students with VI obtain examination results without questioning papers, it is possible for these examination candidates to get wrong grades resulting from incorrect transcriptions. Unexpectedly, students with VI found transcribers with a Certificate/Diploma in Special Education Needs (SEN) or a blind teacher to be more competent in Braille than degree-holding transcribers. Possible reasons for the incompetence in Braille skills among degree-holding transcribers could be the duration of training and a shortage of Perkins Brailers. Transcribers holding certificates in SEN learn Braille for a year whereas degree holders learn it for only four months—hardly enough time and exposure to master Braille.

### **Delays in Examination Time**

This theme was reported only in HLIs, particularly at Institution 1. Students with VI who take their examinations in a special education resource room reported that they did their examinations from 30 to 60 minutes late because of the lecturers' delays in delivering the examinations to the Special Education Unit. Respondents reported that lecturers were supposed to deliver their examination papers to the Special Education Unit before the examination day in either large font for low-vision students or in standard print for converting to Braille format. Nevertheless, lecturers reportedly failed to send their examinations to the special unit in time or forgot to do so altogether, as P14 reported:

...Most of the time lecturers tend to forget to take our exam to that place [Special Education Unit]. In addition, they forget to print my exams in large

font. This has been happening frequently and in all these incidents I have complained about this awkward situation, but things are not changing (P14, male, UG).

P8 and P16 supported the claim and offered a possible explanation for such delays during examinations at Institution 1: "Whenever staff in the Special Education Unit reminded our lecturers to bring our examination paper, they would always ask, 'Is there any student with visual impairment in my class?'" (P8, male, UG). P16 added:

Whenever we complained about this matter to our staff in the special unit they said, "The problem with your lecturers is that they think that if they provide us with the question paper beforehand, we will provide you with sample answers, which is not the case" (P16, female, UG).

The statements from P8 and P16 attribute lecturers' tendency to delay sending examination papers to the Special Education Unit to two reasons: Some are unaware of the presence of students with VI in their courses; others deliberately delayed sending the examination papers for fear of examination dishonesty. On the one hand, P8's comment implies that some lecturers overlooked checking for the existence of students with VI in their courses before the teaching session began in earnest. On the other hand, other lecturers fear that sending examination papers to the special unit before the examination time would enable cheating. Furthermore, examination delays are also attributed to the reluctance of department heads to release examinations at the required time.

### **Inappropriate Grading Systems**

Grading systems in secondary schools, particularly for results of National Examination subjects such as Mathematics, Biology, and Agriculture, was reported to be unfair to students with VI; this resulted in inappropriate grades and division classification because the grading system ignored the fact that these students were only partially involved in some subjects, such as Biology and Agriculture. In these subjects, students with VI were allowed to participate in theory classes only and not in practical classes. In the same vein, students with VI only sat for theory examinations; however, their final grade was computed in the same manner as for students without VI, which was an average of grades scored in both theory (in which students with VI participated) and practical examinations (where they



did not). Moreover, students with VI reported lacking access to learning other subjects, such as Mathematics, Physics, and Chemistry at the secondary school level due to a scarcity of special resources and trained teachers to support them. Nevertheless, they incurred a penalty meant for those who fail in Mathematics. Indeed, all students who scored an “F” grade in their final examination (Certificate of Secondary Education Examination) in Mathematics were penalised in their overall performance; that is, even if they had points for the first division<sup>2</sup>, they were placed in the third division as a punishment. P9 raised this concern thusly: “My Form Four results is actually a Division I because I had 16 points, but it is written Division III because of a fail grade in Mathematics” (P9, male, PG). Similarly, P1 said:

I also become a victim of the grading system because I got 17 points which is Division I but, on my certificate, it is written Division III because of Mathematics. This is unfair to my fellow students and me because it was not our fault that we did not learn Mathematics; we are the victim of education system [that allowed this situation to exist] (P1, male, UG).

P9 and P1 suggest that penalising students who fail Mathematics was indiscriminate as it applied even to students with VI, who could not sit for the Mathematics examination, as the system did not allow them to study the subject. Regarding the subjects of Biology and Agriculture, P11 explained:

... it is impossible for us to score above “D” grade in Biology and Agriculture because whatever we get in theory is divided by two, just as those sighted students who sat for both papers (P11, female, UG).

In other words, such a grading system worked against the majority of students with VI who sit for Biology and Agriculture examinations because they ended up receiving an “F” grade and very few receive a “D” grade under such circumstances. This anomaly exposes the limitation in the computerized grading system, whose program did not factor in the differences of educating students with SEN.

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<sup>2</sup> Division 1= 7–17 points; Division 2=18–21 points; Division 3=22–25 points; Division 4=26–33 points

### **Lack of Examination Feedback**

Some students with VI reported not receiving feedback from their examinations done in Braille, especially for continuous assessment, due to the absence of transcribers and teachers’ lack of knowledge and skills in Braille. In this regard, the study found that most of the secondary schools had no transcribers who could support teachers in inclusive settings to grade examination papers written in Braille format, as exemplified by P11’s remark:

From Form One up to the end of Form Three, I do not remember getting any examination results from our continuous assessment and annual examinations. The only examination results that we received were for the Form Two National Examinations (P11, female, UG).

P11’s statement highlights one of the major barriers students with VI have to contend with in Tanzania’s secondary schools. A lack of transcribers in any educational setting with students with VI implies limited access to learning and teaching resources, curriculum, examinations, and information, unless students have access to AT/devices to access standard printed materials. In some circumstances, students with VI had to sacrifice their school holidays to assist teachers in grading exams written in Braille by reading what they had written to obtain their examination feedback. As P15 explained, “... whenever we needed our examination feedback, we had to postpone our holidays so that we could read our answers to our teachers ...” (P15, female, UG). Indeed, in some inclusive schools in Tanzania, students with VI and those with SEN had to overcome the barriers they experienced on their own with little or no aid from teachers or school authorities. This implies a medical model approach that perceives learning difficulties as originating from an individual impairment/condition rather than limitations in the education system to accommodate students’ diverse needs.

Research Question Two: What are the barriers to the accessibility of information for students with VI in Tanzania?

Students with VI also reported limited access to academic and non-academic information displayed on notice boards, especially in HLIs. This was less of a problem for primary and secondary school students because they generally reported receiving information orally during morning assembly and special school meetings, as narrated by P13:



The primary and secondary school that I attended had only one system: They used to gather students on the assembly ground to make announcements. That is how we used to get information (P13, male, PG).

Information accessibility for students with VI in primary and secondary schools is attributable to the system of providing information in assembly grounds, which was not the practice in HLIs. On the one hand, this modality of providing information on the assembly ground implies that school authorities ensured that information was universally accessible to students with VI. On the other hand, school authorities employed this method as the one readily available to reach most of the students at the same time and inadvertently satisfied the needs of students with VI as well.

However, other secondary schools, as well as HLIs, disseminated information to students using notice boards in printed format that students with VI found inaccessible. Accessibility of the information posted for these students depended much on the support they received from either their readers (designated individuals who read for the VI student) or sighted students. However, students with VI still reported difficulties in accessing information in standard print format posted on the notice board/Internet. Regarding to this matter, P8 said:

During examinations, we sometimes become victims of the situation because we do not have access to the original information; we only depend on what we hear from our fellow students and sometimes they mislead us unintentionally (P8, male, UG).

P10 corroborated this claim by saying:

I remember doing two examinations without any revision because there were changes in the timetable, but no one notified me about them until a few minutes before the exam, when I heard my classmate wishing one another the best of luck [in the examination] (P10, female, UG).

Testimonies from P8 and P10 emphasise the negative impact of information inaccessibility on effective participation in tests and examinations. In this regard, teachers and school authorities need to improve information accessibility for all students, including those with SEN, especially in sensitive matters such as examinations. Whereas some students with VI use computers

to access their results via the Internet, those who are not computer-savvy depend on the favor of sighted students. Explaining, P10 said:

... We do not have a choice as far as examination results are displayed on the notice boards or on the Internet, we have to ask someone whom we trust or a reader to go and read them on our behalf... (P10, female, UG).

What P10 emphasises is a lack of privacy in accessing examination results for students with VI who are not knowledgeable in using computers. The system of displaying examination results in HLIs encourages dependency among these students unless they have the AT skills to access standard printed information via the Internet. Also, for postgraduate students with VIs, limited access to information was a barrier to effective participation in academic-related meetings, such as PhD proposal and seminar presentations. The information concerning PhD proposal presentations and seminars is communicated via letters or notice boards that are inaccessible to postgraduate students with VI:

... I have never attended any PhD presentation at the departmental or school level since I started my PhD... Whenever I complained about this to the PhD students' representative, he always asked, "Didn't you receive my text message?" Even the School of Education is not sensitive enough when it comes to this matter. This is why since 1978 to-date they have not changed their way of giving information, to respond to the needs of students with VI (P13, male, PG).

The retort from the PhD students' representative—"Didn't you receive my text message?"—suggests ignorance among sighted students about the needs of students with VI. After all, P13 is a totally blind student whose ability to access information depends on either touch (through Braille) or audio (sighted individual/AT). In other words, the representative is insensitive to his particular needs. Similarly, P13's statement, "since 1978 to-date they have not changed their way of giving information...", suggests poor consideration of the needs of these students by the university's top authorities.

Research Question Three: What strategies can improve the accessibility of information and examinations for students with VI in Tanzania?

### **Ensure Accessibility of Assistive Technology/Devices**

Students with VI cited the use of computers as an appropriate alternative to typewriters in doing examinations. They argued that computers would allow lecturers to access examination answers in their original format, without passing through a third party (the transcriber). Moreover, a computer with AT solves the typewriter problems experienced by students with VI, such as inability to proofread the typed work. As for students with low vision, they also acknowledged the relevance of assistive devices in accessing information: “For us with low vision, at least we have magnifiers which enable us to read books in normal print, although they are not enough; we have only two, and only one is working” (P8, male, UG).

Generally, the use of computers in examinations and other academic matters in Tanzania’s HLIs is limited by various factors: lack of computer experience among some students with VI and their supporting staff, and a shortage of computers. Concerning knowledge in using computers among students with VI, P1 said:

The computer package available is not for us; even the instructors have no skills of teaching us computer applications and most of the time they reject us in their classes, saying, “How are you going to learn to use the computer in your condition?” (P1, male, UG).

Apparently, there is a general lack of awareness among education stakeholders on the relevance of AT for students with VI and those with other special education needs. As the lecturer’s question (“How are you going to learn to use the computer in your condition?”) suggests, the computer programs available in these HLIs appear to exclude students with SEN and students with VI. Similarly, lecturers who teach the use of computer programs seem unable to adapt computer programs to the needs of students with VI. Such lecturers believe VI restricts an individual’s computing ability, when the opposite is actually true, since a computer can serve as a facilitating tool.

### **Use of Blind Teachers in Grading**

Students with VI concurred that blind teachers were more competent in Braille reading and writing than sighted transcribers. These students believe that blind transcribers are better at transcribing examinations than sighted transcribers because the former used Braille throughout their education. Regarding grading of national examinations, P10 said:

The government should rather use teachers who are blind to mark [grade] papers written in Braille because these teachers are very familiar with Braille. Or they could let students use typewriters so that any sighted teacher could mark their papers rather than use the so-called specialist in marking (P10, female, UG).

P1 supported the use of blind transcribers in grading university examinations: “For us, we prefer our teacher to use our fellow students who are blind to read our work than to use sighted transcribers who learnt Braille for only four months...” (P1, male, UG). The remarks of P10 and P1 highlight how students with VIs distrust transcribers’ competence in Braille skills. Moreover, there appears to be a simmering conflict between students with VI and their specialists in Braille, which has engendered a sense of distrust.

Whereas the Ministry of Education, Science, Technology, and Vocational Training relies on the certification of an individual as a qualification to employ a specialist in matters related to students with SEN, students with VI believe that a certificate alone is not enough. Other factors, such as the experience of an individual in the area concerned, is critical. Therefore, students with VI found blind teachers to be more competent than sighted transcribers because of their accumulated experience in Braille over time. This means that the Education Ministry, through the Tanzania Institute of Education (TIE), as well as HLIs that offer specialization in SEN, should improve its program to ensure the competence of transcribers and the other specialists they prepare, by taking into account the duration of training, and adequate resources, such as Braille machines and papers for the effective practice of Braille skills.

## **DISCUSSION**

This study revealed five major themes related to examinations and information inaccessibility:

1. Barriers in the examination format and administration procedures,
2. Transcribers’ incompetence during grading,
3. Inappropriate grading system,
4. Delays in examination time, and
5. Lack of examination feedback from teachers.

The three examination formats reported in this study suggest: (a) inadequate assistive technology and devices, (b) inadequate computer skills among students

with VI, and (c) inadequate transcription skills among teachers and transcribers working with students with VI in Tanzania.

The oral-based method was another examination format used, but despite the good intentions of teachers in using this strategy, the format demands high memory capacity for the students to remember the questions and alternative answers, especially in objective examinations. However, the reported experience of students with VI on examination format differed from other previous studies, especially those from developed countries (Hewett et al., 2017; Morris, 2014; Reed & Curtis, 2012), perhaps due to an acute shortage of assistive technology and devices in Tanzania.

The study found that students with VI prefer to use Braille in examinations, but this approach seems limited by various factors, including a shortage of transcribers and teachers equipped with knowledge in Braille (Kisanga, 2017). Furthermore, some HLIs are reluctant to use Braille in examinations as the approach involves a third party in grading. To date, at Institution 1, most students with VI use computers to respond to their examinations, with the exception of a few students who are not computer-savvy. However, there are not enough computers available for all students with VI.

The prevalence of incompetent transcribers reported in this study is associated with the shortage of Braille machines and insufficient time to practice Braille in HLIs. It is worth noting that a majority of degree-certified transcribers received their degrees at Institution 2, as it is the only institution in Tanzania offering several degree qualifications in SEN (Kapinga, 2012). The acute scarcity of Braille machines and Braille papers at this institution (Kisanga, 2017) make it unlikely that its graduates would have sufficient practice in Braille reading and writing. Lack of knowledge and skills of working with students with VI has also been reported (Ghulam et al., 2014; Reed & Curtis, 2012; Kisanga, 2017; Mwakyeja, 2013).

Generally, the findings on examinations and information inaccessibility to students with VI in this study concurred with other studies reported in different countries worldwide: the UK (Hewett et al., 2017; Morris, 2014), Canada (Reed & Curtis, 2012), Pakistan (Ghulam et al., 2014), South Africa (Mokiwa & Phasha, 2012), and Tanzania (Mwakyeja, 2013). For example, Hewett et al. (2017) reported that some students with VI in the UK HLIs experience problems in accessing vital information pertaining to timetabling and exam-

ination results because they were displayed in inaccessible formats that required external assistance from a sighted student.

The reasons behind inaccessibility for students with VI include the limited formats of examinations, which does not cater to the diverse needs of these students, students' lack of assistive devices and/or AT skills, and difficulties in accessing graphic learning materials and diagrams due to the absence of assistive devices (Ghulam et al., 2014; Hewett et al., 2017; Morris, 2014). Moreover, there was a problem of incorrect information on the examination venue, allocation of insufficient extra time, and incorrect AT provided (Hewett et al., 2017). Globally, the literature shows that students with VI often lack access to AT. In the U.S., for example, less than 40 percent of these students in elementary and middle schools had access to AT (Kelly, 2011).

The use of computers and other assistive devices was cited as the best strategy to enhance accessibility of examinations and information for students with VI. This concurs with previous findings on the role that AT plays in enabling information accessibility to students with VI and education at large (Argyropoulos & Thymakis, 2014; Corn et al., 2003; Douglas et al., 2011; Silman et al., 2017).

Furthermore, computers solve the acute problem of Braille and large-print books in HLIs, as reported by Kisanga (2017). Indeed, computers with AT provide students with VI access to the materials from the Internet, in addition to facilitating their reading of e-books/journal articles independently, thus reducing their over-dependence on sighted students in academic matters. During examinations, however, students with VI would be required to use computers that were not connected to the Internet to prevent access to online information resources. Notwithstanding the benefit of using computers to these students, the findings revealed a lack of computer skills among students with VI. Hewett et al. (2017) also documented a lack of AT knowledge among students with VI and supporting staff.

## CONCLUSION

The present study explored barriers related to the accessibility of examinations and information for students with VI in Tanzania. Most of the examinations-related barriers in this study can be associated with an acute shortage of special resources such as Braille machines and their accessories, typewriters, computers and AT, as well as insufficient knowledge and skills in Braille and AT. This implies that adequate provision of special resources and AT would not only enhance students' access

to the curriculum and teachers' instructions but would also facilitate their access to pertinent information and participation in examinations. To ensure accessibility of examinations and information to these students and others with SEN, the Tanzanian government should encourage community participation in the provision of special resources in inclusive settings and allocate a special budget for the procurement of crucial resources. Similarly, there is a need to equip students with VI from primary school to higher education with AT skills through special computer training programs to enhance their access to standard print materials and their full participation in learning like their sighted peers. Finally, educational stakeholders, such as school and HLI authorities, teachers, and lecturers should consider students' diverse needs in all matters related to examinations and academic information dissemination to ensure its universal accessibility, regardless of students' physical differences.

#### DISCLOSURE STATEMENT

There is no potential conflict of interest in this study.

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# Inclusive Education in Armenia: Experience of Teachers Reveals Need for Occupational Therapy

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## Abstract

*In this study, researchers sought to understand elementary school teachers' attitudes and needs while working in inclusive classes. Understanding teachers' needs is relevant to occupational therapists, who have the potential to work collaboratively with them within inclusive practice settings.*

*Qualitative interviews were conducted with 12 elementary school teachers with more than 5 years working experience in inclusive schools in Armenia. Thematic analysis was used to explore the data.*

*The findings suggest that teachers were enthusiastic to create equal opportunities for children with special needs. They discussed the need for societal attitudes to change. Teachers were very much aware of their professional gaps, needs, and mentioned the importance of skilled professionals in inclusive schools. They valued inclusion and the rebuilding of physical and social environments to foster the engagement and participation of children with special needs. The teachers expressed ideas shared by occupational therapists, such as the desire to enhance the personal and environmental conditions for each child with special needs in inclusive schools.*

**Keywords:** *inclusion, inclusive education, teachers, children with special needs, occupational therapy*

## INTRODUCTION

In the early 1970s, a movement began to integrate children with special needs into mainstream schools and educate them together with all children in the subjects they were able to follow, supplemented by special education classes to respond to their special needs. Integration in education was actually asking the child to adapt to the school, rather than having the school adapt to the child. When the child was not able to follow what was being taught in the class, he or she was taken out of the class, and this had significant negative effects on their development and outcomes (Office for Standards in Education (OFSTED), 2004). More than 20 years later, following the publication of reports from the United Nations Educational, Scientific and Cultural Organization (UNESCO) conference in Salamanca, Spain in 1994, most European countries adopted the concept of integration whereby children with special needs were included in mainstream schools. By this time, the concept of inclusion had grown: Inclusive education systems were expected to remove barriers limiting the participation and achievement of all learners; respect diverse needs, abilities, and characteristics; and eliminate all forms of discrimination in the learning envi-

ronment (UNESCO, 2018). Children started to learn together and the practice of mere integration or partial participation in class fell into disuse. Ainscow, Booth, and Dyson (2006) defined inclusion as an approach to education representing specific values. According to them, inclusive education is concerned with all children and with overcoming barriers to all forms of marginalization, exclusion, and underachievement. The authors argue that many popular studies still take a much narrower view of inclusion regarding children who have disabilities, or who are otherwise categorized as "having special educational needs" (Ainscow et al., 2006).

The statements above form the basis for discussing inclusion in education as a process of putting particular values into action, which is essential for the achievement of education for all, according to Booth and Dyssegaard (2007). The authors argue that inclusion connects those working for national governments or international organizations involved in planning and implementing education-for-all policies with those struggling to promote educational development within a particular area (Booth & Dyssegaard, 2007). There is extensive literature to show that children with special needs should be educated and included in regular education settings to the maximum extent appropriate

to their needs, and to avoid their exclusion to a separate school, unless education cannot be achieved satisfactorily even with appropriate supplementary aids and services (Allen & Schwartz, 2001; Khochen & Radford, 2012). Within this frame, the teachers' role is to encourage pupils with special needs to make choices, to be free to learn in their own environment, to experience success and act independently. The concept of inclusion is not a new idea. It is based on the idea that students with special needs should not be segregated, but instead included in general classrooms; in particular, they should be able to interact with different children without any discrimination (Egilson & Traustadottir, 2009; Perles, 2012). However, the preparation and support for teachers working with such children in inclusive schools seems to vary widely around the world (Leatherman, 2007).

Seen from an occupational therapy perspective, specialists working in inclusive classes have to be aware of the main "occupational" needs and wishes of children with special needs, connected with the different performance areas, such as productivity and play in school settings, physical school access, and their engagement in the education process (Nilsson & Townsend, 2010). In inclusive contexts, interventions need to enhance pupils' abilities to harness what their academic placements have to offer and further their social skills for full social integration (College of Occupational Therapists, 2007; Hagedorn, 2001). According to Bose and Hinojosa (2008), occupational therapy skills need to be directed at changing the environment for children with special needs, and curricula and learning methods in inclusive schools need to be updated.

The concept of inclusion has always been important within the occupational therapy profession. For example, the Canadian Association of Occupational Therapists (2009) recognizes the right of children and youth to develop healthy patterns of occupations and it supports a rights-based approach for advocacy to protect and fulfill this right. From this perspective, occupational therapy has offered its own unique conceptual contribution—"occupational justice," which is viewed as related to the "rights, responsibilities, and liberties of enablement" (Townsend & Wilcock, 2004). Occupational therapy practitioners are pushing traditional boundaries, undertaking new directions in the understanding of humans as occupational beings (Sadlo, 2004). Inclusion for children with special needs comes within the scope of occupational therapy practice (Gantschnig, Hemmingsson, & La Cour, 2011).

Inclusion helps avoid occupational *alienation*, defined as the absence of meaning or purpose in the occupations of daily life (Townsend & Wilcock, 2004). Sadlo (2004) highlights the importance of creativity in giving meaning and purpose to occupations, which contrasts with the potential boredom and mindless repetition of occupational alienation. The perception of occupations as meaningful or meaningless varies between people, suggesting that the experience of occupational alienation can be unique to an individual or shared within a group in an inclusive context (Kronenberg, Simo Algado, & Pollard, 2007).

Unfortunately, the existing research evidence that supports a multi-professional approach focuses either on teachers' attitudes toward inclusion or on occupational therapy work in inclusive schools, and very few of them study collaboration within inclusive schools. Current evidence is mostly from western European countries, and does not necessarily apply to other countries, such as Armenia, due to cultural differences and inclusive school policies in these countries (Harutyunyan & Harutyunyan, 2014). Teachers and other school professionals in Armenia, for example, do not get the necessary training in special education. From this perspective, there is little understanding of teachers' attitudes and needs regarding integration of children with special needs within inclusive schools in Armenia. There is a need to better understand teachers' thoughts and needs, how teachers play this role of an inclusive educator, and how they try to develop the children's capacities.

The purpose of this study was to better understand the attitudes and needs of elementary school teachers who teach in inclusive schools, especially in countries where political changes have only recently opened up further opportunities. The study's research question was formulated as: *What are the attitudes toward inclusive education and the needs of teachers working with children with special needs, in the inclusive schools in Armenia?*

### **Education System in Armenia**

In 2006, Armenia completed the transition from 10-year schooling to a 12-year educational cycle. The current National Curriculum for General Education is based on a 12-year program, which consists of compulsory primary (grades 1–4), lower secondary (grades 5–9), and upper secondary (grades 10–12) education. In addition, the law states that there should be no more than 35 pupils in one class, and no more than three children with special needs per class (Turpanjian Center for Policy Analysis, 2013).

According to the Armenian government, all schools in Armenia will provide full inclusive education by the year 2022 (*Armenian Government Strategic Report 2017–2022*, 2016). This means that almost all special schools will be transformed into pedagogical-psychological resource centers and their staff will be reassigned to provide support services to children with special needs in inclusive schools. Meanwhile, teachers' assistants will work with teachers and support them. Accordingly, school staff, teachers, parents, and children with and without special needs must be prepared for this new educational system. In 2010, some schools started to provide inclusive education. There are now about 575 inclusive schools in Armenia, where approximately 9,494 children with special needs who require inclusive education are educated ([www.hmk.am](http://www.hmk.am)). In these schools, multidisciplinary teams include a special educator, speech therapist, psychologist, and in some cases, another specialist who supports children with special needs, but shifting to the new system will usually end these multidisciplinary teams. Nevertheless, schools providing inclusive education require general and special education teachers who have sufficient knowledge, experience, and skills to work with students with various special educational needs (Republic of Armenia, 2009).

## METHODS

The investigators of this study used a qualitative research methodology, known as hermeneutic phenomenology. They chose this methodology because it employs the philosophies of both hermeneutics and phenomenology (van Manen, 1997) by synthesizing an interpretation of experiences to understand the nature of a phenomenon. The study was conducted in the interpretive paradigm where the central goal was to develop a rich understanding of the phenomenon of inclusion—being able to help children with special needs cope with their education within an ordinary school context. This was from the perspective of some teachers' experiences in a country where inclusion is a relatively new concept. The location was Armenia, the home country of the first-named researcher, who identified the need for such a study as being symbolic of many eastern European and other countries where equality legislation is still new.

### Participants

In order to investigate the experience of teachers within inclusive schools, a purposeful sampling method was used to select the more established inclusive

schools in Armenia, as this method focuses on selecting information-rich cases to illuminate the questions in the study (Bernard, 2000). This sampling method also selected experienced teachers because they were expected to have greater insights into teaching children with special needs in inclusive schools.

The inclusion criteria were: pioneer inclusive school settings—those five schools that introduced this form of education in Armenia in 2003; and elementary school teachers with more than five years' experience working in inclusive schools were recruited and selected. Within the frame of the current study, 12 participants from five inclusive schools were interviewed.

### Ethical Considerations

Since there are no governmental research ethics organizations in Armenia, gaining official ethical license for research in that country was not possible. Thus, permission was gained from the directors and teachers at the inclusive schools in Yerevan where the study took place, via a written research proposal. Potential participants were then given written information about their rights, the research aims, and the researcher's ethical obligations. Informed consent was introduced to the participants, and confidentiality was assured—the names and any personal information were deleted and numbers were used—such as Participant 1 (P1–P12). Participants were free to end their participation whenever they wished. The researcher reassured participants that their identity and personal data were strictly confidential.

### Data Collection

Data was collected through open, in-depth interviews with the 12 participants, allowing participants to freely respond to questions and probes, and to narrate their experiences without being restricted to specific answers (Morse & Field, 1995). All interviews were conducted in the Armenian language and each participant was interviewed twice, the purpose of the second interview being to verify the evolving analysis and to explore more deeply the topics discussed in the first interview.

The interviews were phenomenological, that is, participants were asked to reconstruct their attitudes and needs. The questions (e.g., “How it is for you as a teacher in an inclusive class?” or “How do you describe inclusion or the inclusive class?”) were open-ended, focusing on how teachers worked to include children with special needs in classroom activities. Each interview was 45–60 minutes in length. During the second interview, participants commented on the written analyses.

## Data Analysis

The data analyses used a thematic analysis method, which helps to search, analyze, identify, and report themes within data (Braun & Clarke, 2006). Thematic analysis searches for concepts and themes that emerge as being important to the description of the phenomenon (Daly, Kellehear, & Gliksman, 1997). The process involved the identification of themes through “careful reading and re-reading of the data” (Rice & Ezzy, 1999, p. 258). The adopted procedure, devised by Braun and Clarke (2006), involved four steps of thematic analysis: (1) transcribing the data into text reading and re-reading; (2) generating meaning units and codes; (3) forming categories; and (4) defining, refining, and naming emerging themes.

This thematic analysis resulted in five clearly defined themes which evolved from a logical “pathway” of codes and categories. The hermeneutic circle was employed during the whole process of thematic analysis, involving the continuous interpretation of one piece of data, or the interview transcript, in relation to the whole of the data.

The themes and the quotations that led to them were translated into English at the end of the analysis period, for wider dissemination purposes.

## RESULTS

Five themes evolved through analysis of the interview data. The teachers offered equal opportunities to children with special needs. Teachers valued inclusion, understood gaps in their own capacities, wanted more society and/or expert support, and realized the need for changes in the school’s built environment and society’s attitudes toward children with special needs. These themes will now be described and explained, in an attempt to understand the elementary school teachers’ experience of their work in an inclusive school. The theme titles use the words of the participants, to enhance authenticity, and were fully agreed upon with the participants.

### 1. Equal Opportunities for Children with Unequal Abilities

Participants strongly supported equal opportunities for all, realizing that no one is immune from disability or from having a child with special needs. Each teacher perceived that all children had the same rights to live and study. Teachers perceived the need for equality not only for the families of these children, but throughout society, where everybody lived and everything happened, where they felt they belonged:

Each parent should know that his child is equal with other children... that’s it... we are working with children— able or disabled... nobody is guilty for being disabled, especially not the child... (P1)

The participants saw the need to include rather than segregate, to prevent isolation from the external world.

Pupils in the classrooms accept the children with special needs as they are, trying to help and support them... mostly, if we have problems, it comes from parents... (P2)

This type of sentence appeared in the interviews very often; teachers saw the positive impact of children’s attitudes toward those with special needs, but contrastingly, parents’ negative attitudes seemed only to increase the meaning and importance of equality for the teachers.

### 2. Teachers Need Help

Participants expressed the importance of help from others in inclusive education:

...we need the help of skilled professionals... when children experience difficulties... for example, during physical culture classes when they have to change their clothes... many of them cannot do it independently, they need an assistant, and we... don’t know how to help them... to do it for them, we do... but we want them to do it independently... (P4)

They raised the importance of a child’s independence and realized they needed both “skilled professionals” and general support. Although most of these teachers seemed unaware of occupational therapy as a profession, they very often expressed a need for help with children’s daily activities, such as accompanying them to the canteen, toilet, dressing/undressing, and so on. The idea of working with others, to share and ask the other for assistance in many areas of their daily teaching seemed vital to them.

Many times I’ve experienced the need... a great need for help, for physical assistance... while transferring the child to toilet... I didn’t know what to do... it was like a shock for me... (P5)

Teachers often wanted assistance, group work, and supportive guidance, which they lacked, but felt they should receive while working in inclusive settings. Participants stated that they were coming to understand the children in the process of working with them and



reported that more understanding leads to more time with the child. Within this frame, they complained of overcrowded classes:

There are more than 20 pupils in the classroom... this is overwhelming... In many cases, teachers mostly concentrated on the special needs children... and the others are ignored; they suffer and this affects our nation, which is very harmful... (P3)

Teachers felt tired and overwhelmed. They were so focused on the students with special needs that they might have to ignore other children in the class. Teachers' home-life was affected due to the very hard work at school.

...We need specialists for assessment of the child's needs, parents' perceptions, and to prepare parents to guide their children in different areas of their lives... and why not to instruct us how to deal with these children... (P5)

Teachers wanted specialists who value special education and could assess students with special needs and offer further assistance; they also wanted to improve their own skills and professional performance. Within this scope one participant said:

The children should be integrated to feel like full members of society... proper assessment should be done to clarify who can study in an inclusive school... professionals-specialists... we need them a lot in inclusive schools... (P7)

Inclusive education was seen as not for everyone. The teachers wanted clear identification about who could study in an inclusive school, because it was frustrating for teachers when a child with dangerous behavior was in class without additional support.

### 3. Teachers Value Social Inclusion

The values of inclusive education were very important for teachers working in inclusive classes. For them, the most important idea of "inclusion" was the social experience, in the sense that inclusive education provides rich life experience:

...there are still lots of issues... but we can see some noticeable outcomes and I can prove to any teacher in our country that inclusive education has its positive results already... if the child isn't in ordinary school... he is weak from a social environmental perspective, he has very poor life experience...

rience... than academically... all the children gain more social experience and that is the most important... (P1)

The teachers stated that children with special needs were happy in the inclusive environment and that was the best indication for the teacher and the most important outcome for the parents, who are education's customers. This was experienced as a very positive outcome of inclusion that helped preserve values and make the right decisions for their work in future. All pupils in the class are seen as the beneficiaries of inclusive education. Daily collaboration with children with special needs and support, and showing tolerance and readiness, was seen itself as the process of integration, influencing the formation of more positive personality characteristics.

I am sure that we've done great work together with all 21 pupils in my class... as it is said, do good things and do not think... someday it will come to you... and I am sure that all my pupils will benefit from everything they are doing for their disabled peers... (P6)

It seemed that the real value of inclusion for teachers was experiencing meaningful work in inclusive settings, which was achieved by enabling them to open the curtains and feel the meaning and importance of making inclusive schools an Armenian reality.

### 4. Society Needs to Change its Attitudes

When a sunflower grows, it turns its head toward the Sun, but not all the seeds inside get the same temperature, nutrition and water... it is never the same... one seed becomes mature, full and the other poor and empty... This is very nice and a right comparison... we throw away the empty seeds, but with people we never can do the same; we should take care... (P3)

Nearly every participant mentioned the importance of society's attitude toward children with special needs, needing support and acceptance. Within that process, teachers outlined the school's and teachers' role, meaning, and importance in the context of recognizing a child with special needs as a full-fledged member of society. Some participants mentioned that inclusive education was a fantastic idea having significance for society, and teachers valued the engagement of the whole society in this inclusive process:



Inclusion is not only about disabled children... it is about help, support... it has something to do with the public...

Many participants described the importance of society support as the main goal they wanted to achieve with the help of inclusive education.

Although the philosophy of inclusion has long been discussed in Armenia, negative attitudes remain—the older generation of teachers do not accept inclusion. They might state that, “in the class these children are not equal, they can’t be educated together; they need another system for better education... they are lost in class... and often cannot find their place in school.” This opinion raises many questions, starting with the arrogance of older teachers and ending with Armenian society’s often negative attitudes towards inclusion and sharing.

### 5. The Built Environment is a Challenge

Participants were concerned about the lack of rights of children with disabilities and the problems inherent within the school environment that caused significant difficulties for them:

There are children with mobility difficulties... they have no learning problems and work very well... But always they experience environmental problems...schools aren’t adapted for wheelchairs... here teachers experience the problem of environmental adaptations and need special help... (P1)

Teachers complained that they weren’t powerful enough to encourage adaptations for children in wheelchairs. These challenges were overwhelming; all of a person’s energies would go towards surviving a situation rather than experiencing or changing it. Very often, the state provides children with wheelchairs, walkers, and other assistive devices, but most are not appropriate to the child’s weight and height. Another challenge is the schools’ physical space, which is not user friendly for those who use assistive devices. In these cases, all staff were searching for solutions for children in wheelchairs:

... it is necessary to create special environmental conditions for these children... it is very difficult for children in wheelchairs... imagine how it is difficult for us to design the schedule in order to have the classes where children with wheelchairs are only on the first floor during the whole day... of course it is difficult, but we realize that it is impossible to keep

these children separated, they have to be with their class always... the child mustn’t feel the difference... (P6)

Teachers reported problems with the environmental standards that did not consider the needs of people with disabilities. One solution might not be suitable for every child with special needs in the current school. They emphasized environmental assessment and reconstruction in the new inclusive context due to children’s disabilities, different abilities, and needs. Teachers said the environment should be adapted to children’s physical needs:

I would like the child to have more of his/her own space in the school, the space where he is independent in all his actions... the space which isn’t a standard one, but created especially for him...

The environment lacked adaptations and thus inhibited children’s actions and movements.

## DISCUSSION

Teachers expressed that children with special needs should be educated in inclusive classes, with no separation taking place. They discussed having positive attitudes towards inclusive education and at the same time experiencing real difficulties, while working within the context of inclusive education. The participants were against such *apartheid*, a concept that emphasizes differences between individuals, groups, and communities, which can diminish meaningful and purposeful activity by segregating people based on social, political, economic, and social status pretexts (Kronenberg et al., 2007). The teachers expressed their concerns about the need to include all children: “All the children are the same for us... we don’t notice their disabilities, they are equals...” The data revealed that teachers perceived inclusive schools to be very important and meaningful communities for all children, presenting the possibility of equal opportunities to children with unequal abilities. They wished parents would not segregate their children. Egilson and Traustadottir (2009), in their grounded theory study, outlined how teachers’ attitudes, school environments, and tasks performed in different educational contexts may affect whether these children apply their skills consistently across various school settings.

The teachers felt responsible for creating meaning and equality. Psychological, political, and social theories point to the human need to belong, which can be fostered by repeating a meaningful activity in an everyday social context (Goleman, 2006). It seemed that

teachers felt that pupils may experience occupational alienation, which has a social meaning associated with lack of participation, involvement, hostility in relationships, etc. (Bryant, Craik, & McKay, 2004). The principles of equality are supported within the core values of occupational therapy, which require that “all individuals are perceived as having the same fundamental human rights and opportunities” (American Occupational Therapy Association (AOTA), 1993, p. 1085). Occupational therapists have supported nondiscrimination and inclusion throughout the history of their profession (AOTA, 2008), which is the first step of giving a child the possibility of belonging to their immediate society and for making opportunities equal, regardless of a child’s abilities. In this complex procedure, the presence of different specialists and services supporting children’s goals, including occupational therapy, should be implemented (Gantschnig, Hemmingsson, & La Cour, 2011).

The second finding revealed that teachers felt they needed help; they saw other skilled professionals as vital. They said they lacked the support of other professionals and resources, both at the classroom and school levels. They felt sure that skilled professionals could make a difference and help overcome their daily difficulties. This finding could be explained by the teachers’ assumption that professionals like physiotherapists and occupational therapists are specially trained to enable people to perform purposeful activities and are ideally suited to provide additional service and support for teachers within inclusive settings. The analysis of everyday occupations and their use in therapy is a recognized core skill of the occupational therapist (Hagedorn, 2001). Without full assessment and further intervention, the school experience for a child with special needs in Armenia may be positive yet not effective enough to achieve their individual aims (Kelleghrew & Allen, 1996). Public services need to address these issues whilst improving the quality of education in inclusive schools and boosting independence and inclusion, which will also create long-term efficiencies (National Development Team for Inclusion, 2005). According to Trombly (1995), activities are the means and aims of the occupational therapy intervention, and therefore occupational therapists could help train teachers in inclusive schools, along with other health professionals such as speech therapists, psychologists, and physiotherapists. This process could be fruitful in Armenian schools where inclusive education is developing.

The finding that teachers value inclusion shows that all children may benefit from this inclusive community, and this benefit is highly valued by the teachers.

Children can acquire more empathy, gain an increased sense of self-esteem, and develop strong social and communication skills. Here the children’s behavior, personality, learning style, and attitude toward their peers with or without special needs is “matched” to the teachers’ style and personality (Smith, 2011). Children see how the teachers behave with children with special needs, copy the teachers’ behavior, and collaborate with each other in class.

The teachers believe that the philosophy of occupational therapy could improve inclusive education in Armenia. The addition of client centeredness and occupationally-focused goals might help teachers to better solve practical problems in everyday teaching (Kronenberg et al., 2007) and help spread these values throughout Armenian society. This transitions to the next finding about changing society’s attitudes towards children with special needs. Within this scope, the growing theory of occupational justice links to social justice and a justice of difference: a justice that recognizes occupational rights to inclusive participation in everyday occupations for all persons in society, regardless of age, ability, gender, social class, or other differences (Townsend & Wilcock, 2004; Nilsson & Townsend, 2010). “School has to help the child with special needs not to stay in the shadow...to have an appropriate attitude toward him from the environment” (p. 400) as an example reflects the collaborative partnership between schools, teachers, parents, children, community, and society, and improves efficacy and attitudes toward inclusion (Lopes, Monteiro, Sil, & Quinn, 2004) to prevent occupational injustice. This is a very important concern inside Armenian schools. The reviewed literature suggests greater collaboration between teachers and occupational therapists in inclusive schools, and for more understanding about each others’ contribution to the success of inclusive practices.

People who experience occupational injustice are isolated from and not accepted by society; occupational therapists work to engage people in occupations and include them in community and society. In inclusive schools, occupations include any activity that provides meaning and purpose in cultural, temporal, spiritual, physical, mental, and emotional contexts (Newton & Fuller, 2005). Children with special needs who may experience occupational injustice need practitioners to advocate for their individual rights and influence policy making. According to Newton and Fuller (2005), this should be society’s commitment, bringing initiatives, including laws, to eliminate occupational injustice.

The last finding of the current study referred to the environmental challenges and obstacles faced by children with special needs. All participants mentioned the negative influence of environmental conditions inside the schools and outlined the importance of environmental changes for children with special needs. Similarly, Anderson et al. (2012) outlined several factors that contribute to disabling environments, including the constructed environment, societal production of space, the perception of disability as different, and the power of educational disciplines. Prevailing ideas about occupation and the environment need to be examined for their contribution to solving these environmental problems in inclusive schools. Anderson et al. (2012) found similar issues in their phenomenological study of children with special needs integrated into classrooms in South Africa. Their research, however, was conducted in settings where occupational therapists had worked in inclusive schools for many years as part of a team. Occupational therapy intervention directed at changing environments for children with special needs helped teachers and other staff in inclusive schools, based on the need for active engagement and participation of all children in school life (Bose & Hinojosa, 2008).

The most important finding of the current research appears to be the fact that any additional professional skilled intervention has the potential to support teacher performance in inclusive classes and improve work circumstances in Armenian schools. This conclusion resonates with a similar relevant research based on a grounded theory approach conducted by Bose and Hinojosa (2008). The scope of support to teachers is very broad, from the initial assessment and collaboration until the full occupational therapy intervention with different client groups inside the school community.

### **Implication for Practice and Future Research**

These findings, from a context where no occupational therapy service was available at an inclusive school, seem to imply the value, efficacy, and importance of occupational therapy in inclusive schools. This might enhance teacher performance in inclusive schools and build the process of “being” in an inclusive context. Constructing the research on the hermeneutic phenomenological approach and interpreting the findings feasibly contributes to the knowledge base in the field of education and occupational therapy. This should lead to further research in this area and to planning appropriate supportive services in inclusive school communities, not only in Armenia, but in other countries as well. Simply working in inclusive classes tends to build positive attitudes toward inclusion.

Despite much research, evidence regarding the importance of meaningful occupation and occupational participation for children with special needs in schools and communities, remains rather theoretical. More research is needed in this field generally and to inform future Armenian occupational therapy and inclusive education practices. Finding evidence of the value of occupational therapy in Armenian life might more clearly point to the role of occupational therapy in inclusive education in that country.

### **CONCLUSION**

All teachers in the study felt that an inclusive school is a vital place for teachers and all children, both with and without special needs. The teachers felt successful in inclusive schools, but still needed more help and the support of skilled professionals and assistants. One of those professions—occupational therapy—might also contribute to the effectiveness of inclusive schools’ policies and practice.

The results of this research point to the need for occupational therapy services in Armenia that could assume a supporting and enabling role within inclusive settings. There seem to be opportunities for occupational therapists to be advisors for educators within inclusive schools (National Clearinghouse for Professions in Special Education, 2000), as there are in other countries. School-based occupational therapy services could provide remediation for a wide variety of issues affecting the ability of children with special needs and enhance demand from teachers working with them in inclusive classes. Occupational therapists could improve the school environment by redesigning the accessibility of environments and learning spaces, increasing the performance of children with special needs through purposeful activities, helping teachers develop or regain the children’s learning skills, participating in different activities, and helping teachers care for themselves. Occupational therapists could collaborate with teachers to evaluate the performance of children with special needs, identify deficits and strengths, develop goals for each child, and evaluate progress. All this is possible because teachers believe they make a major contribution to children in their inclusive schools and keep creating equal opportunities for children with unequal abilities; this was true for all the teachers because they viewed inclusion above all as *being with and belonging to*—which is a fundamental aspect of occupational therapy.

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# Picture Exchange Communication System (PECS) as a Connected Speech Development Tool for Children from Immigrant Families in Armenia

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## Abstract

*Alternative methods of communication skill development, such as Picture Exchange Communication System (PECS), are often used in speech therapy. PECS has been widely used for communication development in children with autism and has proven its efficacy in a large number of studies. PECS is used with people displaying a variety of communication disorders. A review of the literature over the past decade revealed little systematic activity to document or improve PECS intervention services for bilingual children.*

*This study evaluates the effects of PECS intervention with bilingual children from immigrant families in Armenia. PECS could serve as an alternative tool to improve connected speech in bilingual children from immigrant families, thus enhancing their socialization. The study was conducted with nine Armenian children for whom Arabic or Russian was a native language, and Armenian was a second language. These children did not have a good command of the Armenian language. PECS was used to improve their fluency in Armenian. Speech and language therapy sessions using PECS were conducted three times a week for six months. Evaluation of connected speech occurred before the language therapy program was initiated, and three and six months after the intervention. After the completion of the language therapy program, the communication scores improved significantly for all students.*

*PECS has the potential to increase the connected speech level in bilingual children from immigrant families. The method can serve as an option to improve the language skills of immigrant children in Armenia and facilitate their social and academic integration.*

*Keywords: Picture Exchange Communication System (PECS), connected speech development, Armenia, children from immigrant families*

## INTRODUCTION

Population migration has increased worldwide for the last decade, leading to socioeconomic challenges. Children of immigrant families experience immigration-specific issues. The academic future of these children depends on how they experience their early school years. This experience can affect the emotional, cognitive, and social development of immigrant children. Children benefit from a supportive learning environment and such supports can influence personal development and academic trajectories, and in turn, enhance the emotional benefits of early school years (Avagyan & Yesayan, 2015; Elvira, Beusaert, Segers, Imants, & Dankbaar, 2016).

Inclusive education aims to facilitate the social and academic integration of diverse students. Immigrant children are not considered a large population within the Armenian context. Because of this fact, they can often be left out of teachers' and specialists' focus. Children with disabilities remain the main target for inclusion in the mainstream Armenian educational system.

Currently, the state, schools themselves, and specialists are more focused on children with disabilities, because during the Soviet years, they were either educated in segregated schools or remained out of school. According to 2012 UNICEF data, only 63% of children with complex disabilities, 48% of children with intellectual disabilities, 56% of children with auditory impairments, and 69% of children with physical disabilities attended school.

Recent reforms in Armenia reflect worldwide trends in education. Internationally, teachers encounter numerous aspects of diversity in the classroom that include children with different language skills, children with disabilities, gifted children, and children from different social backgrounds. Many teachers are asking for new methodologies and approaches to teach their students (Tichá, Abery, Johnstone, Poghosyan, & Hunt, 2018). In Armenia, teachers are expected to use the latest pedagogical methods of knowledge transfer and child development to equip their students with values to help them become exemplary and productive Armenian citizens (Duda, 2011).

In some countries, children who do not know the official language of their society are both involved in the inclusive education system and enrolled in classes in the official language. In Armenia, the child is directly included in regular classes along with his/her peers. Because of the absence of a systematized approach and legislative support to educate immigrant children, the child does not get additional intensive classes in the official language, Armenian. This factor makes the process of mastering the language more complex. According to Bligh (2014, p. 2), some children have “a time of negotiation, discovery and conflicting tensions,” which she calls “a silent period.” Teachers are often concerned with how to support the learning of bilingual students, especially those who are not proficient in Armenian and cannot communicate with peers and the teacher during the silent period (Bligh, 2014). The silent period is presented as a crucial time for learning, distributed through a synthesis of close observation and intense listening (Lai & Wang, 2015).

In addition, immigrant children struggle with integration, socialization, and psychological problems caused by the language barrier (Çaglar, 2007; Kulkarni & Parmar, 2017); thus, the Armenian language development support they receive from the speech-language therapist becomes vital and substantial.

The researchers enrolled such children in language therapy due to the students’ inability to express themselves competently, as evidenced by poor vocabulary, grammatical errors, and delayed speech and language development. Having a successful past experience of PECS usage for connected speech development (44 children with autism, aged 2.5–8 years) (Avagyan, 2011b), the researchers decided to try this methodology with immigrant children. In the period 2012–2014, the researchers worked with nine immigrant children from Russia and Syria. These children were sociable, but had difficulties with communication; specifically, they lacked fluency in Armenian.

Recent reviews have documented the effectiveness of one type of augmentative and alternative (AAC) system, the Picture Exchange Communication System (PECS; Bondy & Frost, 1994), for individuals with autism spectrum disorders (ASD) (Flippin, Reszka, & Watson, 2010). Subsequently this methodology was used with people of different ages having communicative difficulties of various etiologies. Today, PECS is successfully used in Europe, USA, Canada, Japan, Australia, Armenia, and other countries (Avagyan, 2011a, 2011b; Ganz, Davis, Lund, Goodwyn, & Simpson, 2012; Miller, 2018). The primary goal of this methodology is

functional communication skill development, speech initiation, and spontaneous speech formation. With the help of PECS, the child learns to express his or her wishes, thoughts, and in the course of time, also emotions, using pictures.

The present study aims to evaluate whether PECS may improve the speech and language skills in Armenian immigrant children. The Armenian version of PECS was translated by the academic staff of the special education faculty at Armenian State Pedagogical University. The translated version has been used in previous studies conducted by the faculty (Avagyan, 2011a, 2011b; Avagyan, Mkrtchyan, & Petrosyan, 2018). In combination with other methods, PECS could be an effective alternative tool to improve connected speech in bilingual children from immigrant families, thereby enhancing their socialization. Other researchers have applied PECS as a remedial method to support communication in children from immigrant families (Cohen & Miguel, 2018).

### **Research Question**

The study set to answer the following research question: Is there a significant improvement in speech development of children in Armenia, whose native language is not Armenian, using the PECS intervention?

## **METHODS**

### **Participants and Setting**

The nine participants were 7–10 years old. The dominant language of four participants was Arabic, and for five of them, it was Russian. Because the researchers spoke Russian, they could evaluate the speech and language skills of children whose dominant language was Russian. Families of all participants lived in Yerevan and had immigrated to Armenia 16–18 months prior to the study. For assessing the connected speech level of the children speaking Arabic, the researchers asked parents about their child’s speech and to translate his/her speech. Refer to the section below about assessment of connected speech. Three of nine children were at the fifth level (i.e., absence of connected speech). Those children had extremely limited vocabulary, including mainly household words. In their dominant language, the children had the first level of connected speech. Four children were at the fourth (low) level, and two of them were at the third (medium) level of connected speech in their dominant language. These six children had high levels of connected speech in their mother tongue; hence, their problem is not the result of a speech disorder, rather it is a lack of fluency in Armenian. The

low level of connected speech in the dominant language of three children reveals possible speech and language delays or disorders, as evidenced by poor vocabulary and grammatical errors.

The nine participants were enrolled in private speech therapy sessions at the local health care center. The children also attended inclusive schools and their schools' multidisciplinary teams considered them children with temporary special educational needs according to their language abilities.

### **Procedure**

Several factors explain the effectiveness of the PECS method in improving connected speech in Armenian for immigrant children. During their therapy sessions, the children hear only Armenian; word translation is unnecessary, since the child sees pictures of objects, actions, and emotions. With the help of pictures, the specialist can develop the child's connected speech even if the specialist does not master the language of the immigrant child. Visualization of words and sentences increases information perception and memorization. PECS becomes a starting mechanism of language development, from the child's connected speech can be further developed during Armenian language classes at school. PECS is easily used everywhere, with everybody.

The researchers' limited experience of using PECS with immigrant children has shown that it accelerates vocabulary enrichment, the children learn grammatical constructions easier, and express themselves more freely, which makes them self-confident.

Before using PECS to develop the connected speech of the nine immigrant children, the researchers evaluated the children's speech and language skills in the immigrants' dominant language.

The same therapist conducted language therapy sessions using PECS three times a week for six months, 30–40 minutes per session. The researchers used a translated version of PECS by the academic staff of the special education faculty at Armenian State Pedagogical University (Avagyan, 2011a, 2011b; Avagyan et al., 2018), where the characteristics of grammar, syntax, and flexibility of the Armenian language were taken into consideration. The researchers modified PECS for this purpose: separate cards were created for auxiliary verbs. Since PECS is a methodology based in the English language, it has to be adapted to the Armenian one. The two languages have syntactic differences; in Armenian, the auxiliary verb goes at the end of the sentence. Sometimes a supplementary card is needed

for the language adaptation, e.g. when using the English card "it is," a separate Armenian card is needed for the auxiliary verb. As for English prepositions, Armenian does not have an equivalent. While a preposition is used in English, a word has an ending or is transformed in Armenian. This specification was taken into account in the process of adapting PECS to the Armenian language for connected speech development.

In order to ensure the child's engagement and motivation, topics for sessions were chosen taking into consideration the learner's interests. They were encouraged to use PECS in everyday life.

### **Ethical Approval**

The study was approved by an institutional review board, the Ethics Committee of the Faculty of Special Education of Armenian State Pedagogical University.

### **Assessment of Connected Speech**

Before initiating language intervention with the immigrant children, the connected speech of the selected group members was examined in Armenian using the following criteria (Zaitseva & Sheptunova, 2012):

1. The ability to dialogue;
2. The description of different subjects;
3. Describing a series of narrative images;
4. Telling a fairy tale/story.

Each of the criteria was evaluated using five levels, with 0–4 points possible at each level (Zaitseva & Sheptunova, 2012). These levels are described in Table 1 below. The first level is the highest level. The second level is considered as above-average. The third level is classified as the medium level. The fourth level is considered the lowest level. The fifth level is characterized as the absence of connected speech.

### **Picture Exchange Communication System (PECS) Intervention**

The work based on PECS methodology consists of six phases (Bondy & Frost, 1994). The first phase involves picture and item exchange. In this phase, the communicative partner (speech therapist) needs an assistant (e.g., child's parent) during the session. A typical situation for the first phase is as follows: The child sits at the table with the assistant behind him/her. The speech therapist sits in front of the child. The child holds a desired object and a picture of the item is placed on the table. The assistant directs the child's hand to the picture, and, if needed, picks up the picture. The child extends his/her hand with the picture to the speech



Table 1  
Levels of Language Proficiency.

Level	Description	Points
1	He/she answers the questions, asks questions, is able to discuss multiple topics, and has a rich vocabulary. The description of a particular thing corresponds to a higher level, if the child can precisely describe different subjects. The series of narrative im-ages and telling a fairy tale/story corresponds to the first level if the child gives a detailed explanation, reflects the basic meaning, maintains the sequence of actions or causal relationships, only skipping insignificant details. At this level the child is able to retell a fairy tale/story.	4
2	He/she answers the questions, but is not always able to form questions. The child has a rich active vocabulary. The description of different subjects corresponds to the second level if the child accurately describes the subject, sometimes mentioning ele-ments that are less important. The series of narrative images and telling a fairy tale/ story corresponds to the second level if the child reproduces the situation in general. In this level, details can be omitted, but the sequence of actions are maintained and not all the causal relationships are reflected.	3
3	He/she answers the questions, but is not able to form questions and does not have rich vocabulary. The description of different subjects corresponds to the third level if the child describes the subject without separating the basic and insignificant details. The series of narrative images and telling a fairy tale/story corresponds to the medium level if the child is able to reproduce separate semantic parts, mixing logical sequence.	2
4	He/she cannot accurately answer questions, sometimes does not understand the meaning of questions, cannot ask questions, and has a poor vocabulary. The descrip-tion of different subjects corresponds to the fourth level if the child cannot describe the subject according to its characteristic features. He/she partly describes the subject, indicating the appearance. The series of narrative images and telling a fairy tale/story corresponds to the low level if the child reproduces the plot with distor-tions, without reflecting time and causal relationships.	1
5	The absence of connected speech	0

therapist. As soon as the therapist has the picture in his hand, he or she pronounces the object’s name and gives it to the child.

In phase two, the space between the child and the picture is increased. The therapist sits or stands a few meters from the child. The child begins to act in-dependently, without the assistant’s help. The child reaches the picture, goes to the communication part-ner, and gets his/her attention. The therapist names the object, takes the picture, and gives the preferred item to the child. This step is important, as the student learns to demonstrate more initiative and activity than in the first phase and acts independently.

By the second phase, the student should already have a communication book where the selected pictures (corresponding to a variety of items) are fixed with fasteners. From the second phase onwards, situations

are created where the child is stimulated to “commu-nicate” with various partners (e.g., therapist, assistant, parent).

In phase three, the child is given a choice between two to three pictures. The student goes to the communi-cation book on the table, selects an appropriate picture from the set, goes to the communication partner and gives it to him or her. For this step, the communication book should comprise of only two/three pictures: one with the preferred item (e.g., cookie), and the second/ third picture with an item that is not preferred/neutral (e.g., sock). This may serve as a stimulus for the child to be attentive towards the pictures and result in him or her giving the image of the preferred item.

In phase four, the focus is on the sentence structure. A strip for sentence formation is added in the com-munication book. The student picks up a picture of “I

want” and puts it on the sentence strip, then picks up the picture of the preferred item and puts it below the “I want” picture (Figure 1). Then the child removes the sentence strip from the communication book, goes to the speech therapist, and gives it to him. The specialist reads the sentence and gives the child the preferred item. Conditioned by the child’s vocabulary enrichment and inclusion of various parts of speech, the sentences become more extensive and the sentence strip is extended accordingly.

In phase five, the child learns to express her/his wishes and answer the question, “What do you want?” The goal of this phase is the spontaneous choice of the preferred item from among the other items. The child selects the corresponding picture from a set, in response to the therapist’s question, and gets the desired item from the therapist.

Phase six, the final phase, can be described as answers to the questions: “What is it?”, “What do you see?”, “What do you like?”, “What don’t you like?”, “What kind of weather is outside?”, and “What do you hear?” The child begins to comment spontaneously about the events taking place around him/her. The communication book contains a large variety of pictures (sets of pictures grouped by themes) and the child has to select the appropriate picture/answer and present it to the therapist. Taking into consideration the characteristics of grammar, syntax, and flexibility of the Armenian language, the researchers in this study modified PECS by creating separate cards for auxiliary verbs, endings, conjunctions, and so on (Avagyan, 2011, b).

Figure 1  
*Communication Book (Pictures with Titles in Armenian) with the Sentence Strip.*



Since immigrant children typically already have functional vocabulary, and they usually do not display speech disorders, language intervention typically begins at the 4th phase of PECS. It is directed to maximum vocabulary enrichment, correct sentence formation, and gradually extending the use of various parts of speech. After the 4th phase, the 5th phase is perceived quickly and without difficulties.

In phase six, the child learns to spontaneously comment on events taking place and answer questions. In this phase, the child already forms grammatically-correct sentences. Since the names of the objects and actions are written on all the pictures, the potential for developing reading skills in Armenian is encouraged along with the development of connected speech during the six-month period. An increase in connected speech was observed in all children (according to the 0–4 point scale).

The researchers created a work plan for each child, taking into consideration the individual level of intellectual and speech development. Class topics were chosen according to the child’s interests.

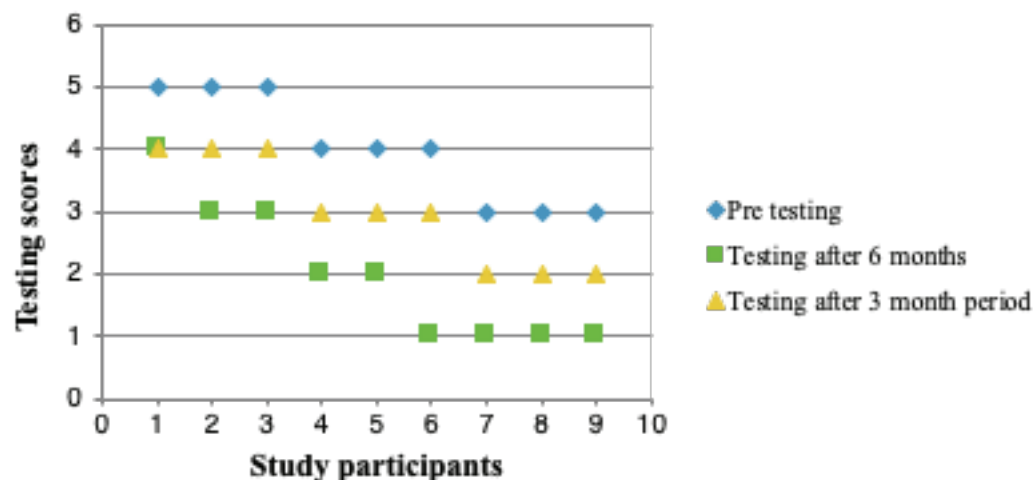
### Data Analysis

The results were analyzed descriptively and by using one-way split-half repeated measures analysis of variance (ANOVA) across different time intervals (before the intervention, after three months and after the intervention program was completed—after six months). The critical value for statistical significance was set at  $p = 0.05$ .

## RESULTS

Figure 2 presents the dynamics of connected speech development in nine children from immigrant families. In a three-month period, six out of nine children improved their communication skills to the next level. Initially, three children displayed communication skills below level four. After completion of the speech intervention program (after a six-month period), the communication scores for the children were as follows: Four children were rated as 1, two children were rated as 2, two children were rated as 3, and one child was rated as a 4. Table 2 provides a summary of language scores at pre-test, three-month follow up and a post-test after six months for all nine participants. Tables 3 provides results of change in language of participating students using split half-repeated-measures ANOVA. There was an overall significant improvement in speech development in the Armenia language across the nine participating students.

Figure 2  
Dynamics of Connected Language Development in Nine Children from Immigrant Families.



Note: Connected speech is evaluated using 1–4 levels (scores), where 1 is the highest score, 4 the lowest level, and 5 falls below the initial level of rating.

## DISCUSSION

After three months of speech and language therapy using PECS, the first re-evaluation of children and comparative analyses of data was conducted. During this time period, three of the children did not display much progress in connected speech; however, their vocabulary was enriched. They began to form sentences with the help of pictures from PECS and express their wishes and make comments. When trying to dialogue or to make stories, the child automatically switched to the dominant language and sometimes tried to translate something in his/her mind, while still making grammatical mistakes in the sentences. The remaining six children progressed by one level. After six months of speech and language therapy, it was clear that two of three children without connected speech had progressed, they displayed a medium level of connected speech. For example, one child demonstrated vocabulary enrichment, used adjectives and verbs, and formed long sentences. It is noteworthy that the sentences were grammatically correct. In addition, the statistical analysis revealed significant overall difference between the pre-intervention and post-intervention test results ( $F=7.71$ ), whereas the difference within the group (between the individual scores of students)

was insignificant ( $F=0.79$ ). Therefore, the adaptation of PECS cards to Armenian grammar appeared to positively impact the speech and language skills of these children.

The examination of the mother tongue of the children during the research showed that two of three children, having below-average ability in their mother tongue, demonstrated gains in speech. The remaining six children advanced one level to above-average. For these children, speech and language therapy were stopped because their speech and language skills were deemed sufficient to attend classes and communicate with

their Armenian-speaking peers. The teachers indicated that for children who did not receive intervention, the development of speech and language skills was challenging.

Thus, in this research a creative approach to PECS has been applied. First, taking into consideration the characteristics of grammar, syntax, and flexibility of the Armenian language, the researchers in this study modified PECS, created separate cards for auxiliary verbs, endings, conjunctions, and so on. Second, PECS was not used with children with disabilities; rather, PECS was used with children who lacked knowledge of the Armenian language and had connected speech difficulties.

Table 2  
Mean Values and Standard Deviations for the Three Measurements.

Time	Pre-, Midterm, and Post-intervention Testing			
	1	2	3	Total
N (number of participants)	9	9	9	27
$\sum x$ (sum of scores)	36	27	18	81
Mean	4	3	2	3
$\sum x^2$	150	87	46	283
Std. Dev.	0.866	0.866	1.118	1.2403

Table 3

*Between-intervention/Within-intervention Effectiveness of PECS, Assessed by Repeated-measures ANOVA.*

Source	SS (Sum of Squares)	Degree of Freedom	MS (Mean Squares)	
Between-test	18	2	9	$F = 7.71^*$
Within-interventions (between students)	22	24	0.9167	$F = 0.79$
Error	18.6667	16	1.1667	

Note: \* = the result is significant at  $p < .01$ .

At the time of this study, the lead researcher had almost nine years of therapy experience of using PECS with children with autism. That background allowed her to see differences between using PECS with children with autism compared to using PECS with immigrant children. In this study, working as a therapist with children from immigrant families, she found: (1) it is easier to find reinforcers; (2) reinforcers are varied by the therapist from the very beginning; (3) there is no need to encourage children to communicate because they are interested in it themselves; and (4) work starts from the 4th phase of PECS (Avagyan, 2011b).

Based on the findings, the researcher made three recommendations:

1. Follow the PECS protocol, even when taking a creative approach to PECS (e.g., use sentence strip, follow steps of teaching phases).
2. Encourage children to use alternative communication everywhere, in different settings.
3. Take into account the interests of children.

In conclusion, PECS appeared to positively impact the speech and language levels of bilingual children from immigrant families in Armenia. It appears that PECS can be a useful tool in improving the speech and language skills of immigrant children in Armenian and facilitate their social and academic integration. More research needs to be conducted to expand on the findings of this study in Armenia and worldwide.

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# Perception of Self-competence and Social Acceptance of Street Children in India

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## Abstract

*Street children are defined as, “those for whom the street more than their real family has become their real home, a situation in which there is no protection, supervision or direction from responsible adults” (Ennew, 1994, p. 15). The purpose of the present study is to evaluate the perception of self-competence and social acceptance of street children in India. Twenty-six street children ranging in age from 5–9 years participated in the study. The children attended an educational training program at the Salaam Baalak Trust in Mumbai, India. The children’s social-emotional competence and perception of self-competence was measured using the Pictorial Scale of Perceived Competence and Social Acceptance (Harter & Pike, 1984). Descriptive analysis of each of the subscales of the test demonstrated that the children had high perception of self-competence in three of the four subscales. The results showed that the perception of self-competence of street children is high. This finding is very positive, given the circumstances in which these children live and the uncertainty of their future. Their strong sense of self raises the question of what really influences perception of self-competence.*

**Keywords:** *street children, India, self-competence, social acceptance*

## INTRODUCTION

The Inter-NGO Programme for Street Children and Street Youth has defined street children as, “those for whom the street more than their real family has become their real home, a situation in which there is no protection, supervision or direction from responsible adults” (Ennew, 1994, p. 15). Stephens (1995) and Hecht (1998) define street children as those “living, working, playing and sleeping on the street and who are deprived of basic rights” (pp. 8–9, 72–73). UNICEF (1984) distinguishes street children in three categories:

1. *Children on the street.* These are children who work on the street with moderate ties to their families and mostly return home at the end of the day.
2. *Children of the street.* These children have minimal relations with their family, and they perceive the street as their home and they live on the streets.
3. *Abandoned children.* These children are similar to the children on the street category, but have severed all ties to their families.

Street children are also viewed as those children who typically fend for themselves without any type of adult supervision or help, and in some instances a group of children band together to form a support system (Parveen, 2014). Street children are a transient

population and it is hard to have an estimate accurately estimate many of them there are in India. UNICEF has assessed that there are about 80 million street children across the world, of whom 20 million are in Asia (Pietkiewicz-Pareek, 2012). There are many reasons why these children live on the streets. Globally, the most prevalent reasons are financial, running away from home due to abuse inflicted on them by their parents/step parents, not doing well in school, escaping problems at home (e.g., alcoholism, abuse), migrating to urban areas from rural areas in pursuit of a better life, and in some cases the children were kidnapped and left on the streets (Kebede, 2015; Kopaka, 2000; Maposa, 2013; McAlpine, Henley, Mueller, & Vetter, 2010; Whitehead & Hashim, 2005; Young, 2004). Most street children attended school when they lived with their families. About a quarter of street children are either illiterate or have minimal education (Epstein, 1996). Street children do many types of odd jobs (e.g., washing cars, begging, scavenging, paper and rag picking, shoe-shining) to sustain themselves (Swart-Kruger & Richter, 1997). In many cases, street children are part of the “unorganized labor market” and work for minimal wages in such places as hotels, gas stations, and mechanic repair shops (Chande, 2015; Mukherjee, 2014; Ribeiro & Trench Ciampone, 2001). The average daily minimum wage of the street children is about 3.80

rupees (about 5 U.S. cents) per day (Pietkiewicz-Pareek, 2012). Younger children spent their money on food and movies, while the older children spent their money on drugs, tobacco, and alcohol. Research has also shown that these children often engage in risky behaviors, such as taking drugs, smoking, and drinking to relax and to deal with the stress in their lives (Asante, Meyer-Weitz, & Petersen, 2014; Bal, Mitra, Mallick, Chakraborti, & Sarkar, 2010; Gaidhane et al., 2008; Mathur, 2009; Sherman, Plitt, ul Hassan, Cheng, & Zafar, 2005). This is a problem for street children all over the world.

The report about the health status of street children in many countries is not very positive. Most were malnourished, had respiratory infections, skin infections, gastrointestinal issues, dental and mental problems (Asante et al., 2014; Ayaya & Esamai, 2001; Berti, Zylbert, & Rolnitzky, 2001; Nigam, 1994; Nzimakwe & Brookes, 1994; Senanayake, Ranasinghe, & Balasurya, 1994; Wright, Kaminsky, & Wittig, 1993). Street children lack basic health care, nutritious food, and a safe living environment. Sustained living in an unhygienic and usually hazardous environment seems to perpetuate health problems among this population (Gupta, 2012). Researchers have demonstrated that living in conditions that are not conducive to their social-emotional wellbeing, and that being under constant stress has a profound impact on the psychological wellbeing of street children (Thatiseti & Raj, 2013). Besides environmental threats, street children are also under constant threat of abuse (physical and sexual) and neglect inflicted upon them by the adults in their lives, such as the owners of shops where they work, police, older street children, and bosses (Ganesan, 1996; Association for Development, Delhi, 2002). Street children seemed to rely on their peer support system to help them through difficult times. They felt that their peers and social workers were reliable, dependable, and supportive, in comparison to the police (Baker, 1997; Gupta, 2000; Rohde, Ferreira, Zomer, Forster, & Zimmermann, 1998).

Despite the odds stacked against them, street children seem to have a remarkable ability to cope with the stressors in their lives (Kellett & Moore, 2003; Verma, 1999). There is contradicting information about the mental and social-emotional health of street children. Early research about the social-emotional development of street children all over the world showed that the mental health of street children in Kenya, South Africa, and Sudan was comparable to that of children living at home (Aptekar, 1993; Kopaka, 2000; Mulugeta, 2005; Richter, 1989, 1991; Sorsa, Kidanemariam, & Erosie,

2002; Veale, 1992). Researchers have also found that street children manifest many characteristics typical of resilient children, i.e., very intelligent, being empathetic, having high self-esteem, were very independent, enterprising, and had a wide support network (Lusk, 1992; De Oliveira, Baizerman, & Pellet, 1992; Ekpiken-Ekanem, Ayuk, & Adadu, 2014; Mulugeta, 2005; Tyler, Holliday, Tyler, Echeverry, & Zea, 1987; Tyler, Tyler, Echeverry, & Zea, 1991; Tyler, Tyler, Tommasello, & Zhang, 1992). In Pakistan, positive early familial interactions seemed to play an important role in street children's self-confidence, aggressive behavior, relationship with peers, and independence (Rana & Chaudhary, 2011).

Living on the streets seemed to also have a profound negative impact on the mental health of street children (Shanthi & Jeryda, 2014; Thatiseti & Raj, 2013). Street children with a history of being abused early in life seemed to be at a higher risk for emotional and behavioral disorders (Smith, 2010). In their work with street children in Brazil, Rohde et al., (1998) found that street children had lower scores on developmental appropriateness, self-esteem, and social skills. Similarly, Thatiseti and Raj (2013) found that street children in southern India demonstrated higher levels of depression, antisocial behavior, anxiety disorders, frustration, and low attention span.

These children engage in menial labor for survival, subsistence, and carve a safe space for themselves. However, our society does not view the street children with empathy. Most often, society views them as a dangerous nuisance (McFadyen, 2004; Panicker, 2003). This makes it hard for these children to find permanent and safe jobs. This negative perception and frequent abuse by society perpetuates a vicious cycle of negativity and a burning desire to achieve a positive identity at any cost among street children.

Several social service agencies in India try to cater to the educational needs of street children. However, research (Saini & Vakil, 2002) has noted that lack of consistency in the training offered to these children may be a critical factor in the lack of success of such programs. Most importantly, research needs to be done to identify the needs of these children (e.g., social-emotional development, self-esteem issues), and then training programs need to be created. Research also needs to be conducted in developing appropriate modules to train teachers and social workers so they, in turn, train children according to their individual needs.

Harter & Pike (1983) defines self-competence as the "feeling of confidence in achieving certain tasks." Perception of self-competence is multidimensional

and it evolves as children become more adept at physical skills, achieve cognitive and social competence, and gain a greater understanding of their skills and limitations. Research has demonstrated a relationship between self-concept and social competence, adjustment and success in school, and self-concept at later ages (Downs, 1989; Hubbard & Coie, 1994). Perception of self-competence is influenced by several factors. Some of these influential factors include age, developmentally appropriate practices, and parenting attitudes (Gottschalk, 1993; Harter & Pike, 1983; Jambunathan, Burts, & Pierce, 1999; Jambunathan & Hurlbut, 2000; Warash & Markstrom, 2001).

The purpose of the present study is to evaluate the perception of self-competence and social acceptance of street children in India. There is scant literature looking at the perception of self-competence among the vulnerable population of street children. Information from this study will be useful in developing programs that address all areas of development for the street children.

## METHODS

### Participants

Twenty-six street children (14 male and 12 female), ranging in age from 5–9 years, participated in the study. The children attended an educational training program at the Salaam Baalak Trust in Mumbai, India. They came to the center on a drop-in basis and were not obligated to come to the center regularly.

### Instruments

The children's social-emotional competence and perception of self-competence was measured using the Pictorial Scale of Perceived Competence and Social Acceptance (Harter & Pike, 1983). The scale consists of four subscales, each composed of six items. The subscales are: (a) cognitive competence (e.g., "This boy is good at picking out the first letter of his name" versus "This boy has trouble picking out the first letter of his name"), (b) physical competence (e.g., "This boy is very good at tying his shoes" versus "This boy cannot tie his shoes"), (c) peer acceptance (e.g., "This boy has lots of friends to play with" versus "This boy does not have many friends to play with"), and (d) maternal acceptance (e.g., "This boy's mother cooks a lot of the food he likes" versus "This boy's mother does not cook a lot of the food he likes"). The questions were presented in a "structured alternative format," in which each child was presented with descriptions

and pictures of two different "kinds of children," one of whom was competent and the other was not. There are different picture plates for each gender. The child was first asked to point to which of the two depicted children was most like him/her (e.g., "This girl can point to the first letter of her name" versus "This boy cannot point to the first letter of his name"). The child was then asked whether this is only "sort of true" or "really true" by pointing to one of two circles beneath the picture (e.g., "Can you really point to the first letter of your name?" pointing to a large circle versus "Can you sort of point to the first letter of your name?" pointing to a small circle). Each item was scored on a Likert-type scale ranging from 4 (highest level of perceived self-competence) to 1 (lowest level of perceived self-competence). The internal consistency of all scales combined was found to be .89 (Harter & Pike, 1983). A mean score was calculated for each of the subscales. The internal consistency reliabilities for the preschool children were: Cognitive competence .71, physical competence .66, peer acceptance .74, and maternal acceptance .85 (Harter & Pike, 1983). Harter and Pike (1983) also did correlations between children's scores of cognitive and physical competence with that of the teachers' scores and found it to be .37 and .30 respectively. The children were evaluated in a quiet setting in the center. The evaluation lasted about 15–20 minutes for each child.

### Procedure

The researcher worked with the administration of the Salaam Balak Trust in Mumbai to assess the children. A trained data collector tested the children in the resource room in each center. The researcher and the data collector had an inter-rated reliability of .89. The children were informed that there was no negative ramification for non-participation and no remuneration was given for participation. The children were also informed that they could stop the testing if they were uncomfortable or tired, or simply did not want to participate anymore.

Table 1  
*Descriptive Statistics of Street Children's Perceived Self-Competence.*

Subscale	Min	Max	Mean	SD
Cognitive competence	2.8	4.0	3.45	.59
Physical competence	3.12	4.0	3.68	.64
Peer acceptance	3.4	4.0	3.82	.67
Maternal acceptance	2.46	3.72	2.88	.69



## Analysis

Since this was an exploratory study investigating the perception of self-competence of street children, it was deemed appropriate to analyze the data for descriptive statistics (see Table 1). Descriptive analysis of each of the subscales of the test showed that the children scored in the range of 2.8–4.0 for cognitive competence, 3.12–4.0 for physical competence, 3.4–4.0 for peer acceptance, and 2.46–3.72 for maternal acceptance. Children had high perception of self-competence in three of the four subscales. The children did not have high perception of self-competence in the maternal acceptance subscale. The mean scores for the children in the four subscales are as follows: Cognitive competence = 3.45, physical competence = 3.68, peer acceptance = 3.82, and maternal acceptance = 2.88.

## DISCUSSION

The above results indicate that the perception of self-competence of street children in Mumbai, India, is high—close to the maximum score possible. This is very positive, given the circumstances in which these children live, and the uncertainty of their future. These children have suffered losses, been abused, have been abandoned by their families, or are living on the streets with their families. Despite these negative experiences, the street children seemed to have a positive sense of their physical competence, cognitive competence, and peer acceptance. These children live in unhygienic, hazardous and dangerous environments, without regular access to nutritious food and medical resources. Very often, they do not have consistent shelters to protect them against the elements of nature and predators. Research has shown that street children are chronically malnourished and unhealthy (Asante et al., 2014; Ayaya & Esamai, 2001; Berti et al., 2001; Gupta, 2000; Nigam, 1994; Nzimakwe & Brookes, 1994; Senanayake et al., 1994; Wright et al., 1993). The street children in the current sample had a superior sense of physical competence despite all the threats with which they lived. As research has shown, street children are chronically under some form of threat either from adults in their lives, adults in their places of work, police or older street children (Ganesan, 1996; Association for Development, Delhi, 2002). Perhaps being vigilant all the time and being in a constant state of “fight or flight” gives these children a sense of having superior physical competence.

Similarly, the street children in the current sample had high perception of cognitive competence, despite having limited or no access to formal education on

a regular basis. Research has shown that most street children had some form of education when they lived with their families (Epstein, 1996). Street children are constantly alert and make life-altering decisions in split seconds. Providing educational opportunities for these children has been an important task for many NGOs and governmental agencies (Al-Dien, 2009). Living in an environment where they need to constantly strive for survival enables them to practice a variety of cognitive skills to negotiate the best monetary or social outcome for them. They face new challenges every day and must reflect, revise, and implement their cognitive decisions. These experiences gave these children plenty of opportunities to improve their cognitive abilities in the real world, without formal education. In fact, there is evidence that street children are prepared for college education (Nieuwenhuys, 1996).

High scores on peer acceptance among the street children in this study showed that they perceived that their peers liked and accepted them and wanted to spend time with them. These results are not surprising because research has indicated that street children rely on their vast network of other street dwellers for support and bonding (Baker, 1997; Gupta, 2000; Rana & Choudhary, 2011; Rohde et al., 1998). Street children consider their friends a very important source of financial and emotional help. Their friends were the only constant source of stress relief and emotional outlet in their otherwise unstable lives (Gupta, 2000).

The children scored relatively low on the maternal acceptance subscale. The questions in this subscale measured how the children perceived their mothers’ demonstrated love and affection for them. Since the street children in this sample had little or no contact with their mothers, it is not surprising that they did not perceive that their mothers had overwhelming affection for them. The younger children in this sample seemed to have higher scores than the older ones, the reason being the older children had been living on the streets for a much longer time than the younger children, and therefore might not view their mothers’ affection for them positively. Research has also shown that one of the reasons children run away from home is because parents/step parents abuse them (McAlpine et al., 2010; Whitehead & Hashim, 2005; Young, 2004). In many cases when the children were abused by the step parent, their biological parent did little or nothing to stop the abuse. This resulted in the children resenting their biological parent (Joshi, Visaria, & Bhat, 2006; Maran, 1997; Shweta, 1999).

Traditionally, perception of self-competence has been documented as influenced by parenting and classroom environment and practices (Jambunathan, 2006; Jambunathan, Burts, & Pierce, 1999; Jambunathan & Hurlbut, 2000). The strong sense of self of the participating street children raises the question of what really influences perception of self-competence. More research needs to be done on studying the influence of internal and external factors on the development of perception of self-competence among street children. There are some critical factors both internally and externally that these children have been influenced by in order to have a high perception of self-competence and social acceptance. These results also seemed to highlight the importance of providing appropriate support to the children so they can maintain their high perception of self-competence and reach their full potential to succeed in life.

### CONCLUSION

This is one of the first studies of street children's perception of self-competence. The study results demonstrated that all agencies working with street children should collaborate to meet the children's needs effectively. Street children's belief in their self-competence implies that this positive perception can be the foundation for all their services. Research has shown that when children have a positive self-perception, they continue to have positive self-competence in later ages as well (Bosacki, 2014). Organizations can develop educational and psychological wellbeing programs in an integrated manner for the street children. These programs should strive to sustain the positive perception of self-competence and teach children other skills that enable them to become confident, competent, and productive members of their community.

### LIMITATIONS

The small sample in this study may have resulted in findings that are not representative of street children in India or even in Mumbai. The information is, however, needed and highlights the importance of studying the social-emotional development of street children. More research needs to be done with a larger sample of street children, including research on the effectiveness of different types of intervention programs for street children in India and other countries.

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# Inclusion, Disability, and Schooling in India: A Qualitative Exploration of Select Programs

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## Abstract

*This qualitative study explores the landscape of inclusive education in India today, specifically asking the question, “What are the competing ideologies and narratives around inclusive education and disability that drive policy and practice in India, as positioned against the United Nations’ worldwide goal of inclusion?” An understanding of the contextualized realities in policy and implementation enables programs to offer professional development to faculty and to increase their capacity for inclusion, and encourages governmental policymakers to create culturally responsive policies and accountability systems for both access and outcomes. After extensive interviews with administrators at eleven special programs, primarily centered in Delhi, the researchers found several paradoxes or tensions that emerged. Furthermore, they suggest recommendations based on these interviews.*

Keywords: *disability, inclusion, special education, Critical Disability Studies, India*

## INTRODUCTION

In India, there is an urgent need for better access and quality of education for students with disabilities and for better understanding of the landscape of inclusive education, as the imperative of a socially-just education system rubs up against pragmatic and ideological realities. Daunting obstacles to educational inclusion in India include poverty, a lack of binding laws and accountability systems, insufficient resources, and India’s “unique cultural and social background” (Das & Shah, 2014, p. 574). There is a compelling need to bring new light to the journey toward educational inclusion for Indian children, and to provide clarity around both the current state of inclusive practices and a vision of possibility to stakeholders across India, including school administrators, educators, families, and government policymakers.

### Overview of Literature

#### Disability and Schooling in India

The first challenge in this work is understanding terms in relation to the Indian context.

*Disability statistics.* India, with a reported 2011 disability rate of 2.21% of the population and only 1% of school-aged children, has “far lower reported instances of disability than most other places in the world” (Mampatta, 2015, para. 3), with worldwide estimates around 15.3%. Indian data “systematically underestimate

prevalence of disability” (Bakhshi, Babulal, & Trani, 2017, p. 2); thus, policy is “effectively running blind” (Mampatta, 2015, para. 4).

*Disability definition.* The United Nations, in its Convention on the Rights of Persons with Disabilities, describes disability as long-term impairment across physical, mental, intellectual or sensory domains which interferes with participation in society (United Nations, 2006). Indian law, under the Persons with Disabilities Act (Ministry of Law and Justice, 2016), states that the person must be “suffering” from 40% or more of the disability “as certified” by medical authorities (p.41), framing disability through a lens of deficit and medical deviation.

A government scheme known as Sarva Shiksha Abhiyan (SSA), or Education for All, aims to implement a “multi-option model of educating Children with Special Needs” (*Ministry of Human Resource Development Annual Report, 2015*, p. 210), including school settings, home-based education, remediation, rehabilitation, and vocational education, among other possibilities. Such a sweeping range of settings permits traditional schools to defer to specially-designed—largely segregated—programs, leading to complacency and lack of inclusive opportunities, relegating populations with special needs populations to marginal contexts.

*Divyaang.* In 2015, the Indian government led by Shri Narendra Modi introduced a new term for people with disabilities which was adopted into official

communications and policies. Intended as a strength-based response to the deep-rooted deficit thinking, the term “divyang” translates roughly to mean “those whose bodies have divine power.” Despite the intent of acceptance, disability rights groups raised objections to the use of the term as “patronizing” (National Platform for the Rights of the Disabled, 2016, p. 1).

*Inclusive education.* Lastly, “inclusion” in India means something broader in scope than a global North perception of the term which tends to be synonymous with the Special Education concept of Least Restrictive Environment (Individuals with Disabilities Education Act, 2004). As India aims to increase diversity in classrooms, broad integration encapsulates acceptance of a variety of historically marginalized groups. The Indian National Council for Teacher Education (2009) detailed an “insidious pattern” of the “social exclusion of children who come from socially and economically deprived backgrounds, Scheduled Castes (SCs), Scheduled Tribes (STs), minority and other communities, girls and children with diverse learning needs” (p. 13). This source describes inclusive education as both a “philosophical position” and an arrangement of facilities and processes to ensure “conditions of success” for all. The Right to Education Act (Ministry of Law and Justice, 2009) mandates educational inclusion of subgroups, including Scheduled Castes, Scheduled Tribes, Other Backward Castes, and girls.

Singh (2009) explains that, in India, “innumerable definitions and interpretations of inclusion exist,” encompassing conflicting ideologies and practices (p. 13). With more than 20% of school-aged children out of school, “the ‘special needs’ version of inclusion is irrelevant” (p. 14). The challenges across Indian society to combat exclusionary practices are formidable (Kumar, Ahmed, & Singh, 2010), and there is an urgent need for research on inclusive education (Bakhshi, Babulal, & Trani, 2017; Singal, 2008).

### **Ideological Stance**

The ideology of inclusion supports the education of children with disabilities alongside their non-disabled peers in general education classrooms and is grounded in principles of social justice, equal opportunity, and ethics (Elshabrawy & Hassanein, 2015; Obiakor, Harris, Mutua, Rotatori, & Algozzine, 2012). Global policy statements unequivocally promote the goal of inclusion in regular schools for children with disabilities (UNESCO, 2003). The United Nations Convention on the Rights of Persons with Disabilities, ensuring an inclusive education system (United Nations, 2006), was

ratified by India in 2007. Building on historic global declarations of human rights (United Nations, 1948), children’s rights (United Nations General Assembly, 1989), and education for all (World Conference, 1990), the first World Conference on Special Needs Education issued the Salamanca Statement, a pivotal document in full support of “building an inclusive society and achieving education for all” (UNESCO, 1994, p. ix). Research suggests many benefits from inclusion of children with disabilities into regular classrooms (Bui, Quirk, Almazan, & Valenti, 2010; Whitbread, n.d.; Willis, 1994) for children with and without disabilities. The regular classroom environment “bolsters [the] academic progress” of children with disabilities, by holding them to higher standards, exposing them to challenging content, and modeling behaviors of nondisabled peers. Likewise, inclusive classrooms benefit children without disabilities by helping them “become more tolerant and learn to appreciate human differences” (Willis, 1994, pp. 2–3). With effective implementation of inclusive practices and mandated compliance with national policies to secure the rights of all children, all students gain from inclusion of students with disabilities in regular classrooms, including academic, social, and behavioral benefits (Whitbread, n.d.). While there is national support for this stance (National Council of Educational Research and Training, 2006), inclusion remains a “contestable term” (Clough & Corbett, 2012, p. 6) molded by competing rhetoric, interests, beliefs, and definitions (Allan, 2014), perhaps especially in developing countries (Das & Shah, 2014; Catholic Relief Services—Vietnam, 2007; Juma & Lehtomäki, 2016).

In India, several laws mandate progression toward inclusive classrooms (Das & Shah, 2014; Ministry of Law and Justice, 2009), although educational settings continue to create segregated realities. The Right to Education Act declares that children with disabilities have a right to “pursue free and compulsory elementary education” (Ministry of Law and Justice, 2009, p. 3), but the reality is that most children with disabilities either do not attend school, or attend specialized schools or programs distinct from regular settings (National Council of Educational Research and Training, 2006). Furthermore, the process of inclusion is not solely about access to and placement in regular schools, but also about quality and experiences in schools (Das & Shah, 2014; Elshabrawy & Hassanein, 2015).

Historically in India, disability has been viewed through a progression of limiting lenses, including the charity model, where the individual, largely isolated, is to be pitied and cared for; the moral or religious model,

where the disability is viewed as an act of God; and the medical or bio-centric model, viewing the disability as inherently bad and in need of fixing (Clough & Corbett, 2012; Ghai, 2015; Goodley, 2013; Kamboj, 2016; Retief & Letšosa, 2018). More recent paradigms include the social model, where the disability is seen as a product of environmental or contextual conditions; and the human rights model which affirms the basic human rights of all people and focuses on a social justice commitment (National Council of Educational Research and Training, 2006; Retief & Letšosa, 2018).

### **Objectives and Research Questions**

In this study, the central research question is, “What are the competing ideologies and narratives around inclusive education and disability that drive policy and practice in India, as positioned against the United Nations’ worldwide goal of inclusion?” Specifically, the researchers ask: (a) How are these terms—Inclusion and Disability—defined and understood in India? (b) What are the points of convergence and divergence between Indian realities and the India-ratified U.N. Convention on the Rights of Persons with Disabilities? and (c) What are the challenges and what possibilities are emerging from the journey toward inclusive education in the country?

This project explores ideological and pragmatic considerations around disability and inclusion in K–12 education systems in India. This study focuses on the education of children with developmental disabilities, specifically cognitive, orthopedic, and sensory impairments arising from neurological and non-neurological conditions. An understanding of the contextualized realities in policy and implementation will enable programs to offer professional development to faculty and to increase their capacity for inclusion, and will encourage policymakers to create culturally-responsive policies and accountability systems for both access and outcomes.

## **METHODS**

### **Theoretical Framework: Critical Disability Studies**

The theoretical framework applied to this research is that of Critical Disability Studies, which takes its lead from other Critical Studies perspectives (Ghai, 2015; Liasidou, 2014). A paradigm shift in the 1980s and 1990s framed disability as a social construction, evolving from structural and cultural barriers and inequities (Clough & Corbett, 2012; Ghai, 2015), but recent theorists stress the need for a framework that values

a realistic portrayal, recognition, and experience of impairment (Liasidou, 2014; Goodley, 2013). Critical Disability Studies examines the relationship between sociocultural factors and biological differences (Ghai, 2015), a vital consideration of the interplay between individuals with disabilities and larger contextual and structural realities in Indian school settings. Scholars further argue for engaging in critical theory that, while evolving from global North theory, must embrace cross-cultural perspectives from non-Western cultures, in order to acknowledge aspects of survival, oppression, and indigenous modes of living (Goodley, 2013; Mee-Kosha & Shuttleworth, 2009).

### **Research Method: Applied Ethnography**

Ethnography describes a culture from the perspective of the participants, based on elements of history, environment, social processes, and beliefs. Applied ethnography goes beyond description with the intention to be useful to the local culture, such as through problem-solving, program development or exploration, fresh perspectives, policy recommendations, or resource assistance (Garson, 2015). The researchers held interviews at schools and studied their programs; collected artifacts such as pamphlets, online information, workshop materials, and handbooks; and were given tours at all the places they visited. They took field notes and debriefed together after every visit. Each visit lasted two to three hours.

Their selection of eleven schools and programs was through convenience sampling, located by familiarity, recommendation from others, and geographic proximity. They contacted one government school whose principal declined to be interviewed. Gaining permission for research at government schools has additional layers of challenge as compared to private schools or nongovernmental organizations, as school heads cannot be directly approached; a permission letter from the directorate of education (under the education ministry of the applicable government) is required. Most government schools tend to be bureaucratic in their organization and management, and due process to gain entry is tedious and seldom smooth.

The researchers collected data using semi-structured interviews and observation field notes. Interviews were coded and the two researchers counter-checked each for credibility. Interviews were primarily conducted with school administrative leaders, in order to focus on the aforementioned specific research questions around intent and ideology, programming, and structure of each site.



In every case of contacting a particular program, the researchers aimed to locate a variety of educational settings, including specialized Special Education Needs (SEN) programs within larger school structures, fully integrated schools, or segregated programs established to meet the needs of children with special needs. Of the eleven programs, one was focused on adult vocational skills and one was an organization within a basti [slum] government school that aimed to empower poor communities. However, neither of these were well-suited to the researchers' specific purposes, as the first was

not within the K–12 domain, and the second did not aim to create inclusion for children with disabilities. The remaining nine special schools—eight situated in Delhi and one in the northern state of Uttarakhand—catered to children with developmental and neurological disabilities, including intellectual disability, autism, cerebral palsy, multiple disabilities, or a combination of these differences. These nine schools form the basis of this study's findings and conclusions. Table 1 summarizes these programs.

Table 1  
*Program Characteristics.*

Program	Location	Year established	Run As	Assessment Recognition <sup>1</sup>	Nature	Student Composition	Interviewees
A	New Delhi	1981	Charitable Private Trust	CBSE + NIOS	Inclusive	Majority with disabilities	Principal (Founder)
B	New Delhi	1987	Charitable Private Trust	NIOS + IGNOU	Inclusive	Majority with disabilities	Principal (Founder)
C	Dehra dun	1996	Charitable Private Trust	Activity-based curriculum	Special School	All students with disabilities	Principal (Founder) + 2 teachers
D	New Delhi	1988	Private School	CBSE + NIOS	Integrated (Special Needs Unit)	Majority without disabilities	Principal
E	New Delhi	1991	Charitable Private Trust	Activity-based curriculum	Special School	All students with disabilities	Program Coordinator
F	New Delhi	1990	Private School	CBSE	Integrated (Special Needs Unit)	Majority without disabilities	Program Coordinator
G	New Delhi	1984	Charitable Private Trust	Activity-based curriculum	Special School, integration of basti children	Majority with disabilities	Program Coordinator
H	New Delhi	1992	Private School	CBSE	Inclusive	Majority without disabilities	Program Coordinator
I	New Delhi	1966	Charitable Private Trust	CBSE + NIOS	Inclusive	Majority without disabilities	Principal (Founder)

Note: <sup>1</sup> CBSE, the Central Board of Secondary Education, sets mandates for curriculum and assessment; NIOS, the National Institute of Open Schooling, facilitates testing for students who are unable to pursue regular studies; IGNOU, Indira Gandhi National Open University, provides online university courses; activity-based curriculum allows for flexible programming and vocational skill development for children and youth, not aligned with national testing.

This qualitative research, while providing rich description and direction for future study, is not intended to be generalizable beyond the given context and the group of participating programs. As noted by Ulin, Robinson, and Tolley (2005), “Lessons learned from qualitative studies can be applied to other contexts if samples have been carefully selected to represent viewpoints and experiences that reflect key issues in the research problem. Our goal is to produce data that are conceptually, not statistically, representative of people in a specific context” (p. 27). The researchers believe their research has credibility and transferability, as it is replicable in additional contexts that may be studied to create additional confirmation of findings.

## RESULTS

Several themes emerged as the researchers considered their data. All programs discussed their origins and impetus for their work, expressing strong philosophical stances grounded in social justice. Program leaders spoke of the belief in inclusion and the deeply-entrenched societal stigma toward disability. They detailed their intensive work with parents and the barriers and challenges in the work toward inclusion and effective education for children and youth with significant disabilities. This section delves into each of these themes.

### History of Programs Visited

Each of the leaders of these educational programs told their program’s origin story. Each spoke of an original female principal with a passionate and unwavering belief that children with differences deserved an education, and who took it in hand to fill an obvious gap. Most of the programs began in the 1980s or 1990s from humble beginnings, often due to the founder herself having a child with special needs. At one place, the beginnings were “a result of an experiment” to take equal numbers of able and disabled children. Another program originated in “five huts” and responded organically as children’s needs arose. All program leaders attested to a large gap in India in services throughout those decades to educate children with disabilities. At vastly different places, the researchers heard the same lament about the stark lack of programming during the late 20th century, that “there was a great need for inclusive education.” “There was nothing here in India at that time.” Because of this lack of information, awareness, and policy, many of the founders had no clear direction; thus, they looked internationally, or reached out to agencies who specialized in specific disabilities such

as the Blind Association and the Spastic Society. As one school was being constructed, an inclusive expectation was “built into the architecture of the building” with ramps. From the start—and to this day—the programs affirm that they have “huge waiting lists.” These schools fill a vital niche for inclusive education.

### Philosophical Stance of Programs Visited

Globally, inclusion as a social justice initiative has been a priority for years. In India, given the complications of inclusion for various marginalized groups—based on gender, caste, and economic realities—as well as the structure and types of school systems, these school leaders were asked what ideologies drove their inclusion work for children with disabilities. The answer was an underlying belief in the human capacity and worth of people with disabilities. All programs recognized a common humanity across differences, with a passion for social justice and action permeating the school culture. One administrator noted, “You have the whole soul invested. So I guess it’s in our spirit and action and words and thoughts. When you are talking and walking that language, I guess people get it. We weren’t very consciously attending to it; we are just like that.” Another spoke of “every individual as a dignified human being.” Yet another said, “It’s about embracing diversity, it’s not only children with special needs.”

The programs approached disability from a belief in strengths. One administrator stated, “We just talk about respecting differences and [that] everybody’s unique and everybody comes with their own qualities and we should just appreciate and learn from others.” Another said, “We don’t go around saying, ‘Oh you poor thing, you have autism.’ We don’t think of it as we’re going to get rid of autism; we talk about embracing it. It’s just another difference in our personalities. And of course it needs support, but then who doesn’t need support? You’re just as meaningful and your real feeling is just as valid as my real feeling.” One leader said, “Your children are your strengths, not your challenge.”

Administrators supported a self-reflective mindfulness grounded in humility, with an expectation for continuous learning on the job. Said one, “All members of the school are always learning and growing.” Others noted, “We learn from the children—they are our biggest teachers,” and “Whatever we do, also we grow from it.” Several described a spiritual journey. For example: “It was as if destiny had decided I need to be equipped to deal with people with disabilities because it was going to happen in my own home. God said, ‘Get ready, this is what’s going to happen to you.’ So it was

just by accident, or maybe some divine hand pushed me.” To these leaders, inclusion and education are one and the same. In the words of one director, “What is education if it is not inclusive? What is special about understanding the child? You’re an educator. If you’re not understanding your child, how will you ever teach?”

### **Belief in the Benefits of Inclusion**

Despite having emerged from decades of exclusion of people with disabilities, these programs envision an inclusive society. In addition to filling a void for children with significant challenges, these programs also strive for integration with non-disabled children, and several programs have a commitment to children from economically weaker sections (EWS). Study participants extolled the benefits of inclusive schools and classrooms.

Administrators spoke of the innocence of children, suggesting an idealistic, unbiased, and untainted acceptance of difference. They used terms such as “accepting,” “friendly,” “innocent,” and “sensitive” to describe non-disabled peers’ acceptance of children with disabilities. One administrator said, “They don’t know; they are young. They just take [the disabled children] into the fold... as a friend. They just learn to be empathetic, by having them there.” Another program administrator said that this type of acceptance is “just beautiful to see.” These remarks suggested that children are inherently free from bias when growing up in inclusive settings.

Social learning happens for all children, thereby breaking down barriers that exist in the broader Indian society. In one school, children from a nearby basti learned etiquette and hygiene together with children with disabilities, taking these lessons back into their community which “triggers a kind of change also.” Several programs had integrated sports programs, allowing children with disabilities such as blindness or orthopedic disabilities to thrive. As one leader noted, “Very clearly, [we] feel that to have children in the class with additional needs is going to help the mainstream, the neurotypical children. It works both ways. To be more empathetic, to be just more accepting. So the other children also stand to gain far more.” Although further exploration reveals more complex realities, including over-protective enabling, “innocent cruelty,” and children who are “mean” to those with disabilities, the programs do deliberate work around sensitivity and acceptance with all children, beginning when the children are very young. Regardless, the pervading attitude exemplified in action across these programs is that “no skills are learned in isolation... Let children interact

with each other” in inclusive classrooms, sports, and other activities, to create understanding that can reach beyond the school walls.

Even within these interviews, the benefits discussed are social in nature, not academic. In the social benefits, it was discussed as peer-to-peer relationships, not as caregiver relationships.

### **Issues of Stigma**

Despite intent, stigma around disability is strong in India, creeping into the classrooms and halls of these programs in ways that must be continually addressed. This stigma is based in sociocultural, religious, historical, and political factors that lead to marginalization. One principal said, “If you look at [autism] historically, religiously, spiritually, which is very prevalent in India, we label it as, ‘Oh this family, it’s your past Karma, past sins.’” Our interviewees reflected on stigma, but believed that society is slowly changing for the better.

The charity model around disability, a pervasive reality across India, has disadvantages and advantages. To view children with challenges as needing charity diminishes the dignity of that person; however, it may also be a source of funding for these specialized schools. As one principal stated, paraphrasing the thought process of a potential funder, “One way to elevate my spiritual status is if I do something for these lowly kids.” Another one said, “In the Indian context, people still look at the disability sector with pity... You just probably end up thinking, ‘This is charity; my goodwill that I’m doing, supporting the person.’ That still exists, hugely.”

In India, poverty is a significant barrier to schooling for children with and without disabilities. Given the governmental priority to minimize exclusion of children on the basis of caste, tribe, gender, and economics, children with disabilities are only one of the subgroups needing support. Families with multiple children find themselves facing the same need to prioritize their children’s schooling. As an administrator said, reflecting the thought process of one such hypothetical family, “I don’t have money to feed my absolutely able boy child, and you want me to start to think about this girl child who is challenged. Wouldn’t it be better to finish her off now?” Another captured this point even more succinctly. In regard to the poorest kids with disabilities, “They’re at home and they die young,” she said. The government’s encouragement to use the term *divyang* paradoxically further creates a stigma. As one leader noted in reference to the term, “You’ve taken them away from help, from being another human being.”

To address such systemic biases against disability, these programs begin by sensitizing their own teachers to a more strengths-based understanding of these children. Administrators discussed professional development, emotional support, and funded opportunities intended to build sensitivity. In some schools, sensitivity training for teachers focused on keeping children in mainstreamed classrooms, maximizing time with non-disabled peers. One principal said, “[The teachers] get to learn so many things when you work with children, when you have diversity in the class; it’s how you look at diversity, how you appreciate [it].” Another explained that the expectation of inclusion was built into the fabric of the structure of the school itself, as the founder made a policy decision not to have a school counselor. “Because when you have a school counselor, with a little office of hers, with some stuffed toys and some alphabets and the magnetic board, it is very tempting at the least sign of things not running perfectly, this one has to go to the counselor. So the philosophy of the management was, ‘You are mother, you are counselor, you are teacher, you are disciplinarian—deal with it.’”

These programs also did extensive sensitivity work with the children, using spontaneous teachable moments as well as planned curricular decisions to educate students and to encourage social inclusion, even when academic barriers required more restrictive environments for some children. An administrator explained, “We don’t take the term special needs. We just talk about respecting differences and everybody’s unique and everybody comes with their own qualities and we should just appreciate and learn from others.”

Even with early integration and ongoing sensitivity education, negative views of differences may develop, and social exclusion becomes a daunting challenge. One administrator explained, “It’s rosy and beautiful until they’re ten years old. [Then] the paths diverge too much.” She said the social exclusion can create a “disaster zone” as children grow. Another principal said, “The story changes after class 2 or 3. The child [with a disability] becomes more and more isolated.” Several mentioned that children can be “cruel,” particularly nondisabled children who have not been in inclusive settings from early in life. Despite the challenges, the programs have had success with socially inclusive education and practices, including sports interactions, special presentations, spontaneous moments of knowledge-building, and other opportunities.

It is often the children themselves who are able to bring their own understanding back to their communities, for broader social impact that is fundamental to

change widespread stigma. A principal explained the benefits of integrating children from the basti into classrooms with children with disabilities:

It’s just amazing if you know the context in the Indian setting, in the way they are working with them. Because those kids, when they go back, they talk to their community. When we have students from the slum societies becoming part of our school, the most interesting thing that I have found is when they work together, they [talk to] each other as if they are of the equal status. That sort of changes the entire mindset of people in the community.

The children from the basti go back and say, “these are my friends,” encouraging acceptance.

Of course, there is more work to do in the broader society. As one principal said, “You need to be really brave.” She told the following story:

Twenty years ago, we used to take our children [with cerebral palsy] on a day out to the zoo. I saw more people around us looking at the children than at the animals, and initially I thought, ‘Gosh, how insensitive and how rude, and how could they do that?’ But then I realized that it’s all ignorance. They don’t know any better. So I started interacting with them. They had questions. And you could see there was some change in the way they started looking at the children, because at the end of the day they’re children, you see?

This principal concluded, “There was no knowledge at that time. Children [with disabilities] were just kept behind doors.” Another program leader reflected, “At a community level, everyone should know these basic things about disability. So when you have to deal with it as a family yourself, you’ve got some idea. It’s not like I’m being initiated into the mysteries now. It should be something we all know about.”

The struggle to educate others is, in the words of another leader, “a continuous challenge, this journey toward acceptance from resistance.” Despite years of effort, as advocates they continue to confront “parents, students, and even staff members who still have that hesitation and really are not comfortable. This can lead to negative feelings and a false belief system. Even now they’ll say, ‘Don’t go down that corridor, the children are mad, don’t interact with those children’... It’s a continuous process.”



## Working with Parents

Parents around the globe struggle to come to terms with raising children with disabilities, a reality that they often have not prepared for and that may radically alter the direction and focus of their family's lives. Parents mourn what might have been, confront their own sense of guilt and powerlessness, and may feel isolated and judged. In India, because of the added layers of historical, sometimes religiously-based, biases against children with disabilities, the challenges of parents become magnified.

Schools that accept students with disabilities provide more than a place where a child can be educated; they provide hope, support, and resources for parents. In a brief interaction with parents at one of the programs, a mother said, "To add to the child's problems, the problems that we as parents had in accepting the situation made everything worse. Our capacity to think and reason had diminished. My thinking and way of processing my child's situation has improved a lot since I came here. Here, along with the child, they work with the parents, too." In every interview, study participants discussed their outreach to, and empathy for, parents. One administrator said, "We're constantly dealing with distraught mothers, hysterically weeping. And what to say to young mothers with their first babies and they don't have a school to go to?"

These school leaders often guide parents through initial stages of grief to help them reach a level of acceptance. One administrator explained that the parents "thought [the children] were nothing, good for nothing." Another mentioned a Hindi expression that translates roughly to mean that "the child has been cursed by the Evil Eye." Yet another said that families have been told to "Forget about the kid, he's a gone case," to focus on their non-disabled children, or to have another child. As one parent shared, "Every school that we approached turned us down. I heard 'No' so many times that it broke me. I couldn't figure out where to take my child." While repeated rejection heightens the parents' anguish, it also increases their frustration, sometimes with the child. One of the administrators mentioned that parents often see a child with a disability as a "wasted investment."

Over and over, the researchers' interactions with administrators and parents revealed the raw pain of parents, with words such as "stigma," "denial," "resistance," "struggle," and "isolation." Thus, the first task of these schools, beyond the initial grief of parents, is in assisting them to reframe how they view their child. As one young mother said during a brief interaction,

"Coming here gave me a reason to live. The teachers here have counseled us parents so well that we now accept things a lot more. The people here have taught us how to cope with painful social situations. I am a lot stronger and more positive now."

The parents' concerns for their children's future was evident across interviews. An administrator said, "The prevailing question of every parent of a special needs child is, 'What is the future of the child after me, when I'm not there?'" Parents want to ensure their children are "not a burden" on anyone in the future. As a parent said, "Through the time we are alive, we will do everything in our capacity for our children. But what [about] after us? At the very least, the children should be self-reliant, so that they are able to lead their own lives or express their needs to those around them and are not dependent on others." Despite these larger unanswered questions, parents advocated for better academic opportunities to be made available for their children. One leader said, "It was a struggle to shift the focus from academics to more of a skill-based training, because, even now, parents feel that academics is the 'be all to end all' of everything." She added, "the vocational offers are block making, printmaking, candle making, and the parents don't really want that for their child. They want an income that's sustainable."

Describing how the enrollment of her child into the program helped her to overcome self-doubt to reach a place of greater self-assurance, one parent said, "I feel so much more strong and positive now. More than my child, I was the troubled one. Coming here gave me a reason to live—attending sessions with my son's teachers, workshops with [the school head], afternoons spent seeing our kids play together, our collective celebrations of small victories, and our holding each other through moments of despair."

These programs encourage parents to develop a strengths-based perspective of their child, and administrators acknowledge that society is slowly changing for the better in terms of acceptance. The places the researchers visited work collaboratively with parents to implement consistent strategies, respite, support groups, and other resources.

## Barriers to Inclusive Settings

At the heart of this inquiry lie the challenges toward inclusion of children with disabilities into mainstream schools, in particular the government, public, and private schools that take non-disabled children. Participants identified the following significant barriers to scaling up inclusion of all children with neurodiverse challenges.

## Most Significant Barriers

(1). **Financial barriers.** With less than 4% allocation in the annual financial budget, the education sector continues to be one of the least valued segments (Peri, 2018). Consequently, there is little directing of funds towards enabling regular school programs to accommodate the diverse needs of learners with disability. This is further complicated by the split in funding for public education between the state and central government, often leading to the involvement of politically-opposed parties.

Insufficient resources have a cascading effect that lead to poor facilities and insufficient accommodations. In a similar vein, lack of resources was identified in interviews as the root cause of poor teacher training and unavailability of teachers trained in special needs education. As one administrator explained, “It’s not that the intent is not there [in government schools]. It’s just a lack of resources, lack of awareness, lack of training.” Another said, “Government schools have their own set of challenges. We have so much poverty. A lot of children don’t have the advantage of going to school, so special needs is probably last on their list. First, the teachers need to be there. First, the resources need to be there. And children need to come. It’s very depressing.”

(2). **Lack of infrastructure.** Inadequate resources naturally leads to poor infrastructure. Despite considerable improvement in physical accessibility in schools, the lack of facilities frequently impeded learning for children with disabilities. One principal said, “In the government school, to get that child to move who needs a two-foot-long ramp, would have taken a year.” Another one said, “They don’t have the infrastructure, so there’s no point [in inclusion].” Notwithstanding the fact that “government schools” in India encompass a range of models, including some that are spearheading new initiatives in inclusive school designs, these statements reflect a certain reality. School buildings are predominantly not accessible to people with disabilities. Only 18% of Sarva Siksha Abhiyaan (SSA) schools (those targeted for improvements) were barrier-free, and the numbers in some states were as low as 2% and 6% (Kohama, 2012). Suggesting developments, one administrator said, “The new schools are trying. Older ones are not asked to make changes to make them disability-friendly. But new ones are. There is a rule and the new buildings that are coming, they have to do it.”

(3). **Issues pertaining to teachers.** Gaps in teacher education, lack of specialized training, student-teacher ratio, and professional development of in-service

teachers were identified as key barriers by the administrators interviewed. The general teacher education programs such as B.Ed (Bachelors in Education) and B.El.Ed (Bachelors in Elementary Education) have a very small component of teaching for inclusion, and differentiated instruction is not prominent in the curriculum. Thus, most teachers in mainstream classrooms do not possess the knowledge and skills to respond to the needs of learners with disabilities. As shared by one of the administrators, “Teacher training is a huge gap. It’s just not covered in any significant or practical way. The idea of differentiated learning is so anathema within the system, it can’t be covered.” Another one said, “The way the B.Ed. courses are constructed, there should be a module on special education. In fact, if the whole thing was special education-centered, that would work best. Because that applies to everybody.”

A student aiming to be a teacher must choose a general education track or a special education track. With general education having greater employment prospects, far fewer teachers choose special education, leading to a lack of specialized teachers. One participant said, “India is a huge country with very few trained teachers, and even among the trained teachers, the quality training is literally half a drop in an ocean. Not even one full drop.” Suggesting a difference in skill set of mainstream teachers and special educators, one administrator said, “Mainstream teachers [in this school] are not equipped with understanding. Even a simple accommodation, like, ‘After ten minutes allow the child to get up and go’ or something. That is where the special educator will ensure that these accommodations happen.”

(4). **Attitudinal barriers.** While the above issues set up hurdles for inclusion of children with disabilities into mainstream schools, it is the attitudinal barriers that seem to be the most entrenched, pervasive, and damaging. Study participants indicated a pervasive lack of will on the part of mainstream schools. One administrator described facing attitudinal hurdles while advocating for a learner: “I will never forget meeting that principal [of a mainstream school]. She basically said, ‘Look, my hands are tied. I can’t refuse her admission. I have to take her, but it’s not going to work.’ And that was her attitude. ‘It’s not going to work because I’m going to make sure it’s not going to work.’ And she literally went out of her way to make sure it didn’t work.”

These negative attitudes were at the root of systems that remained rigid, despite a push from stakeholders. One leader said, “Apart from all of the physical

barriers—and I think those could be easily solved if there was a will to do it, ramps or toilets, where the class is situated in the school, those kinds of things which are not really major impediments—the system is so rigid and unaccommodating to any kind of difference, that they just don't see how these kids will be able to fit in. And the idea that you can change the system to adjust to the child just doesn't arise for anybody.” This sentiment echoed in the words of another participant who said, “You know, that idea that they can't learn is very fixed. Because they're not learning the same way the other kids are, therefore they're not learning.” Differentiated instruction has yet to make its place in regular classrooms because “it is not a mindset that people appreciate.” A paradigm shift that has only just begun is needed to realize the goal of “sarva shiksha” (education for all).

### Other Challenges

When the researchers dug down into this last barrier—the lack of will to build, sustain, and encourage inclusion—they discovered ideological challenges that resonated with previous points made around stigmatization, biases, and assumptions.

The stigma against disability, arising from long-standing religious, social, cultural, and historical beliefs and values, extends to mainstream school settings, where the prevailing attitude is that, even if other barriers were to be addressed, there is little belief that students with significant differences can or should be educated. Johansson (2016) describes the “hegemonic view about the non-suitability of educating a child with disability in a mainstream school” (p. 116). Jha (2010) suggests that good private schools are highly selective and aim to maintain their “academic standards and position in the public estimation,” thus excluding children with special needs as being unable to “contribut[e] positively to their ‘standards’” (ch 1, para 4).

Administrators discussed the high pressure on academics, specifically in regard to standardized tests that do not allow for easy accommodation of children with cognitive and physical disabilities. If a school system feels pressure to maintain collective rigor, with reputations riding on successful test taking, then it is disinclined to welcome a population of students who need specialized accommodations and modifications in their academic programming. One leader explained, “[Sometimes] it's the educators in schools who are putting value on the academic system and higher marks and telling you if you don't score a 90% at 'A' level, then your child is unable to make it through the system.”

Another director noted, “Academics is the highest priority [in mainstream schools]. So they have to have the capability to retain and sustain them. Some schools, a few of them, are willing. [In nursery], you'll find many of them getting admission because signs [of disability] are not very clear.”

## DISCUSSION

### Existing Tensions

As they explored their data, the researchers uncovered a set of paradoxes—deeply-embedded tensions that exist in the field of inclusive education for children with disabilities that have no ready solution. These tensions represent competing realities and beliefs, some more in line with progressive ideologies around disability and inclusion than others, some that our research suggests are worthy of support and consideration, but none with resolution at hand.

**Tension 1:** Accepting a school's limits so as not to set up a child for failure *versus* expecting them to take some chances to open their doors more widely. As one principal noted, “Sometimes it's a service to deny a student, to say they can't do it. They don't have services, don't have staff, don't have infrastructure, don't have the means. Some schools say, ‘We don't want to take on something that we can't.’” In light of this paradox, this leader said, “It's a double-edged sword. Between the intention and the thing.”

**Tension 2:** Giving time to get more personnel on board in terms of best practices *versus* forcing inclusion now through mandates, knowing that schools are not ready. This tension focuses less on individualized advocacy and more on government-directed systemic change. How might policies create pressure to have schools be ready? What is the timing of these efforts?

**Tension 3:** Inclusion of children with disabilities *versus* inclusion in a broader sense of basic needs for the economically weaker sections, girls, and marginalized castes and tribes. Given the sheer numbers of people in India, focusing on disability may divert resources from other populations.

**Tension 4:** Making inclusion happen in government schools *versus* other types of schools that might be better suited to take on more inclusive practices. Although policies can be directed most readily at government-run schools, these schools have significant barriers to overcome in order to have families view them as viable and equitable options for a decent

education. Without allowing government schools to abdicate responsibility, could some of these specialized programs serve as a template or a model for advocating for necessary resources, training, and implementation of inclusive practices?

**Tension 5:** Conceptualizations from the global North *versus* Indian-specific strengths, beliefs, and ideals. International policy based on global North visions of inclusive practices may disregard or disparage an alternative vision of education founded on India-specific culture, history, and current successes. It's possible that special schools or Special Education Needs units within private and public schools provide the most effective quality programming *at present* for Indian children with disabilities. Given India's ratification of the U.N. Convention for the Rights of Persons with Disabilities, the researchers recognize the problematic consequences of the current largely-segregated system. However, given the numbers of people and the collectivist mindset of interdependence (Chadda & Deb, 2013; Heine, 2010; Markus & Kitayama, 1991), it is vital to consider educational programming within this cultural context.

As noted in the review of literature, definitions of disability and inclusion have contextual specificity in India, not only in regard to existing policies (Ministry of Law and Justice, 2016) and ratification of the international United Nations Convention for the Rights of Persons with Disabilities (United Nations, 2006), but also in light of urgent considerations for inclusion of other marginalized groups (Ministry of Law and Justice, 2009). While the ideology of inclusion is supported, the limitations based on both will and resources are daunting. The researchers support a Critical Disabilities model that values a realistic portrayal, recognition, and experience of impairment (Liasidou, 2014; Goodley, 2013) while recognizing larger contextual and structural realities in Indian school settings (Ghai, 2015).

## RECOMMENDATIONS

The following set of recommendations provide fodder for further research in this arena. Below are the key suggestions that emerged across interviews.

(1). **Leadership is vital.** Administrators spoke of the critical importance of principals who express and expect core values across all members of the community. Effective leaders not only maintain sustainable programming, but build the culture around inclusion (Singal, 2008).

(2). **Parents need to be active and respected participants in planning for their children's education.** All of the programs studied invested great effort in outreach to parents, at every step of the process, from intake to ongoing support, both practical and emotional. Parents were an integral part of decision-making for their children, and they felt empowered to advocate for their children (Johansson, 2016).

(3). **Teacher education must be stronger.** In-service teachers require professional development as a building block for inclusion. Stressing this value, one teacher said, "We go for workshops and (similar) things, so learning is very important." Unless teachers are in the "learning mode," as one participant put it, accommodating diverse needs will remain a distant dream. Additionally, the researchers believe B.Ed. programs for general education must include a *minimum of one full mandated course* in working with children with disabilities, with content that supports efforts toward inclusion, collaboration, and consultation across systems and stakeholders. Interestingly, during the time that the researchers were collecting their data (2017), the National Council for Teacher Education was working on a revised B.Ed. curriculum that now includes a half-credit in "Creating an Inclusive School." The description of this half-course reads, in part:

This course will explore the definition of "disability" and "inclusion" within an educational framework so as to identify the dominating threads that contribute to the psychosocial construct of disability and identity. While analysing the policy and programme initiatives in the area of inclusion, the course will look at models of disability as well as the dominant discourse on "the other" in the narratives of all concerned. (National Council for Teacher Education, n.d., p. 18)

Although norms were developed in 2014, implementation of this curriculum has only just begun and is not reflected in our participants' comments nor in current general education teachers' education.

(4). **Differentiation should be a fundamental teaching methodology across schools.** Differentiated instruction, defined as tailoring instruction to meet individual needs and strengths, is recognized as a cornerstone of effective practice when working across differences in classrooms (Tomlinson, 2014), and should be built into teacher education programs and professional development for in-service teachers.



(5). *Schools must encourage collaboration within a unified team of teachers and specialists.* The need for a multi-professional team to make inclusion a reality was expressed by administrators. One said, “When you start this kind of project (inclusion based), all sorts of professionals are required.” Another one said, “There needs to be collaboration between teachers and special educators.” The researchers recommend strongly that parents also be part of these collaborative teams.

(6). *Specialized schools should work collaboratively with state and national governments to scale up niche programs.* These programs have been doing disability-education properly for the past 30 years and can work with the government to develop wider-scale impact and implement inclusive practices (Singal, 2008). Several administrators noted this point, and mentioned a willingness to make it happen.

(7). *Government subdivisions that manage disability and education—Rehabilitation Council of India, the Ministry of Human Resource Development, and the Ministry of Social Justice and Empowerment—should streamline their efforts under one umbrella.* Such consolidation will strengthen transparency, communication, and action (Kohoma, 2012).

(8). *Encourage a cultural change of mindset in regard to disability.* Program leaders spoke repeatedly of heightening societal visibility, of breaking attitudinal barriers around disability, of encouraging a strengths-based lens that all children bring assets to the classroom and community. As one said, “Education is the key to everything, and it has to be backed up first with feeling... This is all about attitudes. Acceptance.” Another worded it this way: “It’s okay to be who I am—at the end of the day, it’s all about that.”

(9). *Build on the Indian cultural strength of being a collective society.* India is rooted in a collective inter-relational sense of family and community, a fact to build upon as a strength when considering how to support children with disabilities. As one administrator noted, “The whole concept of self-determination, the whole concept of independence, that doesn’t really happen in India. We’re still a very collective society.” She continued: “Still in rural areas they have their extended family, everybody is looking after, it is not only the parent. In smaller towns, the town knows the child.”

## LIMITATIONS

This study is intended to provide descriptive complexity to the Indian landscape of inclusive practices for children with disabilities and is not intended to be generalizable. The researchers visited eleven programs, focusing on urban specialized programs primarily within the city of Delhi. Despite their efforts, their work does not include government schools. Johansson’s (2016) research suggests a possible reason for this struggle to locate a government school willing to talk to researchers about inclusive practices: Despite government mandates, these schools simply do not enroll children with significant developmental disabilities and often claim to be unable to address their needs. In a Catch-22, middle-class parents are reluctant to consider government schools for their children due to the “negative perceptions of these institutions” and, in many schools, their lack of English medium of instruction (p. 102), thereby buying into a societal stigma against government schools that they feel are ill-equipped to accommodate disability.

## CONCLUSION

The researchers hope this work will inform various stakeholders—policymakers, teachers, administrators, and parents—and provide additional support for further research, practice, and policy in regard to inclusive practices for children with disabilities in India. The researchers believe that this study fills an important niche in the literature, and that further exploration can build on this work. They recommend further research that considers both geographical breadth and programmatic depth, extending into other areas of India, particularly rural areas, and into the context of government schools.

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# Benefits of Online Social Support Groups for Chinese-American Parents of Children with Autism Spectrum Disorder

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## Abstract

*Research has shown that online support groups can empower people, particularly those who are handling various types of distress. However, limited investigation has been conducted into whether or not parents of children with disabilities, including Autism Spectrum Disorder (ASD), who come from minority backgrounds, can benefit from participating in virtual community support groups. A pilot survey study was conducted as an exploration into this area. An online support group comprised of Chinese-American parents who have children with ASD was the target audience. Fifty-three Chinese-American parents responded to a 20-question online survey. Findings suggest that participation in an online support group can reduce parental stress for those who have a child with ASD. Insights into the benefits of an online support group for Chinese-American parents with children diagnosed with ASD are discussed.*

Keywords: *autism spectrum disorders, online support groups, parents from minority background*

## INTRODUCTION

Free and asynchronous, semi-synchronous, and synchronous mobile group chat applications (e.g., WhatsApp, WeChat) have become increasingly popular forms of communications over the past 3–5 years due to the support of big data technology. As compared to earlier forms of online communities created by the exchange of discussion forum posting, point-to-point text, or emails at desktop, our modern social network efficiency has been dramatically improved with applications that can process large amounts of text, voice, or video at a group level across the globe. People can be grouped virtually, efficiently, and effectively for various needs or purposes.

These technological and social changes have nurtured the development of online support groups dealing with various types of “distressful situations” to “obtain some emotional relief” (Barak, Boniel-Nissim, & Suler, 2008, p. 1868). Distressful situations can range widely from HIV/AIDS (Mo & Coulson, 2014), domestic violence (Hurley, Sullivan, & McCarthy, 2007), bereaved parents (Scholtes & Browne, 2015), cancer treatment (McLaughlin et al., 2016; Stephen et al., 2014), loneliness management (Carden & Rettew, 2006), sexual life issues (Hucker & McCabe, 2015), suicide prevention

(Barak, 2007), to anxiety, doubt, and stress about academic performance in the early years of medical school (George, 2013).

Although online support groups are increasingly becoming an alternative to traditional face-to-face counseling therapy services, online support groups may never be a “substitute” for professional counseling and therapeutic support services. Rather, they serve to add value and/or supplement traditional counseling practices with a focus on information exchange, non-structured, asynchronized with no time-restraint (Barak et al., 2008). This perspective deserves further investigation.

Parents of children with disabilities have been shown to experience more stress than parents without disabilities, and parental stress levels have a dramatic impact on functioning across family routines (Demarle & Le Roux, 2001). Studies indicate that stress levels of parents are associated with their child’s age, intellectual quotient, severity of autistic symptoms, and adaptive behaviors (Rivard, Terroux, Parent-Boursier, & Mercier, 2014). This stress may be even worse for older parents who have been caring for their children with disabilities for many years and have subsequently developed their own health issues (Dillenburger & McKerr, 2009).



Parents with Asian cultural backgrounds often report internal struggles for their children to meet societal expectations. For example, a Korean mother of a child who has disabilities can experience stress of not being a “good mother” (You & McGraw, 2011). Likewise, in Japanese culture, parents also face social stigma about having a child who is diagnosed with a disability (Kayama & Haight, 2014).

According to the Centers for Disease Control and Prevention (CDC)’s 2012 estimate, the identified prevalence of Autism Spectrum Disorder (ASD) in the United States is “1/68”, which “occurs in all racial, ethnic, and socioeconomic groups,” and “about 4.5 times more common among boys (1 in 42) than among girls (1 in 189).” Parents who are raising children with autism often experience stress or depression associated with their parental duties and need family support.

Limited research has been conducted on whether a specific group, in particular, parents from a Chinese-American background who are experiencing stress from raising children with disabilities, particularly ASD, can benefit from a virtual community support. A pilot survey study was conducted as an exploration in this area by focusing on Chinese-American parents who have participated in social media chat groups with other parents of children with autism spectrum disorders.

### **Related Traditional Stress Coping Strategies**

There are a number of traditional stress management trainings for parents who have children with disabilities. Mindfulness-based stress reducing training with parents who have children with disabilities has shown positive results (Bazzano et al., 2015). Parent training with an Applied Behavior Analysis (ABA) program has also been reported as significantly reducing parental stress for raising children with autism (Lovisotto, Caltabiano, & Hajhashemi, 2015). A training for parents raising children with autism was compared between home-based visiting training versus self-paced training, and findings suggested that the home-based visiting training was more effective (Keen, Couzens, Muspratt, & Rodger, 2010). Parents of children with disabilities reduced marital relationship stress through in-home therapy using Emotionally Focused Therapy (EFT) (Ramisch, Timm, Hock, & Topor, 2013). To develop healthier family systems, functional relationship improvement training for parents who have children with autism also yielded positive results (Karst et al., 2015) for both mothers and fathers (Elfert & Mirenda, 2015).

Moreover, negative outcomes from having a child with a disability, such as depression, social isolation, and spousal relationship problems, can be moderated

by social support groups (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). Boyd (2002) found that informal support (i.e., support from family, friends, neighbors, and other parents of children with disabilities) appeared more effective in managing stress than formal support from related professionals. Informal support can “increase families’ (a) factual knowledge about autism, (b) knowledge of stress and mechanisms for coping with stress, and (c) awareness of social support and advocacy issues” (Boyd, 2002, p. 212).

### **Related Online Stress Coping Strategies**

Compared to traditional parental stress management training, online parental stress management training and virtual support services are far less investigated. However, two online stress management training studies have been documented in the literature.

Clifford and Minnes (2013) reported a well-structured online parental support program for parents of children with ASD. Twenty parents served as the experiment group participants, and 25 parents as a no-treatment control group. Their children’s age ranged from 2 to 22: 17 boys and 3 girls, with ASD at different spectrum levels. They went through 8 sessions over 4 months, 5–10 parents as a group with an average of 3 parents who actually attended each session, bi-weekly, and monitored by a professional facilitator, with various topics, and followed with a short feedback survey. No significant differences (treatment vs. control or pre-treatment vs. post-treatment) were found in stress reduction but participant parents reported that they found “the support group was useful,” and “the most useful aspect of the group was the opportunity to connect with other parents” (Clifford & Minnes, 2013, p. 1670).

Reinke and Solheim (2015) reported a qualitative study on online social support experiences of 14 mothers who had children with ASD and residing in the United States speaking English. Their online social support experiences were non-structured, long-term ongoing, and mainly for information-seeking from a variety of sources. The researchers interviewed the participants individually using open-ended questions, and recorded conversations were analyzed. They found that parents considered online supports beneficial and added value to traditional supports. Parental stress levels or cultural contexts were not reported.

### **Research Questions**

While many traditional in-person types of social support exist, a modern social media-based virtual community, i.e., an online support group, appears to be more flexible and convenient for parents, particularly those

who work full-time. However, more research is needed on the format of online support groups as a platform to reduce parenting stress for parents of children with disabilities, including ASD, as compared to research on traditional types of parent support and parent stress-management interventions. More exploration and further investigation is needed, particularly in the culturally-diverse context with the focus on Chinese-American families.

The first research question aims at determining what primary sources of stress Chinese-American parents experience while raising children with ASD.

The second research question is designed to explore how (to what degree) social media-based chat groups can help minority parents cope with their stress, as well as why this type of support is needed.

## METHODS

### Survey Instrument Design

The survey contains 20 questions in total. The first two questions were constructed to introduce participants to the survey, identify the primary investigator, and obtain participants' consent. The next three questions were related to respondents' demographic information. Eight questions followed that were designed to gather information about their children's diagnosis, number of siblings, and parents' support needs. The last six questions pertained to parents' stress level (pre-/post-comparison). This was a pilot instrument designed for this survey study. The survey link is [https://sjsu.qualtrics.com/jfe/form/SV\\_aWzWb5BqcJLPBgp](https://sjsu.qualtrics.com/jfe/form/SV_aWzWb5BqcJLPBgp)

Published or structured assessment tools were not utilized, due to the special nature of this study. The participants were recruited voluntarily and anonymously from the online chat group while they were chatting online and used the researchers' five-minute quick survey. Respondents used the survey tool to report on changes in their own stress levels, based on stress they felt before versus after participating in the online chat support group.

In short, this survey study is not a typical training or treatment effectiveness study. Rather, this is an opinion survey study about the impact of an online social chat support group via a quick procedure described above. In the future, if sufficient funding is available for the participant recruiting procedure, and if the goal is to assess the treatment effectiveness using an online chat support group as one type of treatment method, more structured assessments and also two separate procedures (pre- and post-assessment) may be considered.

### Survey Deployment Tool

The online survey was deployed via Qualtrics (an online survey tool) for collecting voluntary and anonymous responses.

### Survey Participants and Their Group Size

Participants were Chinese-American parents (either mothers or fathers) who had a child diagnosed with ASD or having other special needs. The children's ages varied. Children's genders were identified by their parents as either male or female. No inclusive or exclusive criteria was used other than each participant self-identified as a parent who has a child with Autism Spectrum Disorder. Participants who participated in the study were concurrently participating in one of two online autism support groups, *Future for Chinese-American Children with Autism*, or *Chinese-American Families Who Have Children with Autism*. Group sizes were 300+ members respectively. There was a total of 53 valid survey responses for this pilot study. No information regarding participants' gender were identified.

### Survey Data Collection Timeframe

The survey was launched online in late fall 2015. The data were collected between December 27, 2015 and February 28, 2016. The data were analyzed between April 2016 and May 2016. The results were finalized in summer 2016, and revisited and analyzed in summer 2017, and again in summer 2018.

### Data Analysis Method

In addition to descriptive analysis of participants' demographic information and their support/training needs, the ordinary least square (OLS) regression was applied to measure the impact of the online support chat group on parents' stress level. Since the researchers could not observe specific evidence of stress change, they adopted the parents' self-reported, stress-reduction change before and after participating in the online chat group through one survey procedure. The targeted factor here is the stress-level reduction, by controlling for other factors such as participants' education level, region, and career through a set of dummy variables.

## RESULTS

### Descriptive Data Analysis

As Table 1 shows, 77% of the participants had higher educational degrees, 17% had educational degrees ranging from high school studies to associate degree studies, and 6% did not disclose this information. Among these respondents, 49% were from the East Coast of the U.S., 40% from California (the West Coast), 4% from the

Table 1  
*Parents' Demographic Information.*

<b>Participants' Location</b>	<b>West Coast</b>		<b>East Coast</b>		<b>Mid-West</b>	<b>South</b>
	21 CA		17 NY 6 NJ 1 PA 1 MA 1 IL (26 Total)		1 MO 1 WI	2 TX 2 SC
<b>Participants' Education Degree</b>	<b>Ph.D.</b>	<b>M.D.</b>	<b>Master</b>	<b>Bachelor</b>	<b>Middle School/ High School/ Associate</b>	<b>N/A</b>
	7	1	21	12	9	3
<b>Participants' Career</b>	20 stay-at-home parents 33 working parents		14 Engineer 3 Bio 4 Social Science 12 Others	<u>Others:</u> Finance, accounting, nurse, business, physician, service, cashier, marketing, management, office, fashion		
Note: Valid samples = 53. The survey began on December 27, 2015 and ended on February 28, 2016.						

Mid-West, and 8% from the South. Also, 38% of them were stay-at-home parents, and 62% were working parents who had careers in engineering (26%), bio-engineering (6%), social sciences (8%), or others (23%) ranging from finance or accounting or business to the medical field or office assistance or fashion.

As Table 2 shows, 43 of the participants disclosed their children's age information, with 14/43 (33%) of the children were 6 years old or younger, 21/43 (49%) were 7–14 years old, and 8/43 (19%) were aged 15–17. More elementary school-age children's parents participated in this survey than Pre-K age children's parents or those whose children were 15–17 years old. Most of the children were officially diagnosed with disabilities in the year of the survey, with ASD/Attention-Deficit/Hyperactivity Disorder (ADHD) as the dominant categories, and coupled with other disabilities as listed. Among 44 children whose parents disclosed their gender information, males who have autism and/or ADHD are dominant (82%, or 36/44). These children all received different types of treatment services, with ABA and speech therapy being most common, plus services of Occupational Therapy (OT), Physical Therapy (PT), Resource Specialist Program (RSP) or special day program. Among these children, 79% have sibling at home... and 14% of their siblings (6/42) suffer from similar disabilities.

As Table 3 shows, participants shared their various training needs. The researchers grouped participants' needs this way: Part I—parenting/school relationship-related, and Part II—children intervention at home-related (Part II (a)—younger-age children, and Part II (b)—older-age children).

In Part I, parenting skills, time management, and stress management were ranked highest. Relationship with schools and accommodation arrangements in school settings were mid-ranked. In Part II, younger children's needs outweigh older children's due to parental participation whose elementary-age children were dominant as the survey participants. Needs in managing their children's attention/focus issues and reducing their speech delay at home were ranked as the highest stressors, and the other related issues were at medium level. Early reading skills were less urgent for this group; participants were more concerned about their children's behavioral and communication challenges.

As Table 4 shows, before the survey participants joined the online support group, 44/53 (83%) claimed that their stress level was high or somewhat high, and only 4/53 (8%) claimed not at all, while 5/53 (9%) chose not to disclose this information. Shame or stigma were not ranked as the highest stressor. About half of the parents (30/53, or 57%) consistently reported a lack of support as a major stress factor. The spousal relationship, along with "other" factors (e.g., lack of parenting skills or being exhausted) were ranked as their second major cause of stress.

Table 2  
*Children Information and Their Sibling Information.*

<b>Child Officially Diagnosed with ASD</b>	<b>No*</b>	<b>Yes</b>	*Concerns: 4 ADHD suspicious of ASD and was being assessed for ASD; 1 ASD by school psychologist/no medical diagnosis; 1 as Developmental disability with suspicious of ASD and was being assessed for ASD				
	6	47					
<b>Child Gender</b>	<b>F</b>	<b>M</b>	<b>N/A</b>				
	8	36	9				
<b>Child Age</b>	<b>Below Age of 6 Years old</b>		<b>At Age of 7–14 Years Old</b>	<b>At Age of 15–17 Years Old</b>	<b>N/A</b>		
	14		21	8	10		
<b>Diagnosed Year</b>	<b>In 2015</b>			<b>2002–2014</b>		<b>N/A</b>	
	3			40		10	
<b>Combined Type of Diagnosis/Symptoms</b> (some more than 1 diagnosis)	<b>ASD</b>	<b>ADHD</b>	<b>Speech Delay</b>	<b>Behavior Disturbance</b>	<b>Reading Disabilities</b>	<b>Others</b>	<b>Others:</b> Tics 2, PDD 1, selective mutism, low muscle tone, ODD, not diagnosed yet
	28	12	12	7	3	7	
<b>Combined Treatment Received</b> (some more than 1 diagnosis)	<b>ABA</b>	<b>SP</b>	<b>OT</b>	<b>PT</b>	<b>RSP</b>	<b>Special Day Class</b>	5 have psychiatrist visit. 10–12: Others (music therapy, riding horse, social worker visits, counseling)
	21	32	16	8	11	10	
<b>Have Sibling?</b>	<b>No</b>	<b>Yes</b>					
	11	42					
<b>Sibling who has Disabilities?</b>	<b>No</b>	<b>Yes</b>	<b>N/A</b>				
	40	6	7				

After the survey participants joined the online chart support group, 48/53 (91%) of them claimed their stress level was reduced, of whom 31% reported their stress levels either “greatly reduced” or even “tremendously reduced,” while 69% reported somewhat reduced stress levels. Five survey participants chose not to disclose this information. No one claimed that this online chat support group had no effect in reducing their stress. Most felt empowered by the online support group, with 22/48 (46%) feeling greatly or tremendously empowered, and

26/48 (54%) feeling somewhat empowered. Among 46/53 (87%) survey respondents who answered the question of whether they do not feel alone after joining the online support chat group, 37/46 (80%) responded as true and 9/46 (20%) as false. Regarding benefits of the online support chat group, 43/53 (81%) of the participants agreed that they can get various kinds of information, 36/53 (68%) agreed that it is convenient, and 28/53 (53%) agreed that they feel connected.



Table 3  
Participant Parents' Training Needs (numbers listed are counts).

Part I	Part II (a)	Part II (b)
<u>Parenting skills related:</u> 31 Parenting skills 28 Time management 25 Stress Management  <u>Relationship with schools related:</u> 23 Communication w/ Public School 19 Politics at Public School 18 Politics at Private School  <u>Accommodations at school related:</u> 18 Accommodation at elementary school 17 Accommodation at middle/High School 10 Accommodation at college 10 Accommodation at vocational school  <u>Getting assessment related:</u> 9 Application for getting assessment	<u>Younger child's intervention skills related:</u> 37 attention/focus issue 23 Speech therapy 18 Memory 18 reading comprehension 17 ABA 16 Behavior Management 9 early literacy	<u>Older child's future arrangement related:</u> 16 Career plan 10 job application 8 College intern

### Inferential Data Analysis

#### *Dependent Variables and Independent Variables.*

Table 5 describes dependent, independent, and control variables used in this study. The study considers a participant's stress level as a relevant dependent variable and the online chat group is the independent variable. The impact of the stress change is calculated as a comparison before and after joining the online support group.

To estimate participants' stress level before joining the online chat group, the researchers used "Stress-Before" as an independent variable. "Stress-Before" provides the degree of stress level before joining the online chat group on a scale from 0 to 10. For example, a higher rating value (e.g., 10) represents a higher stress level. See below for scale details before joining the online support group.

#### Before joining the Online Chat Group, the stress rating and its values:

- Not stressful (0)
- Somewhat stressful (4)
- Stressful (6)
- Very stressful (8)
- Extremely stressful (10)

"StressAfter" is an ordinal variable for the effectiveness of the "Online Chat Group" (scale of 0–6). For example, if a participant responded that his or her stress level is tremendously reduced after joining the online chat group, then his or her "StressAfter" would be 6 points less. See below for scale details after joining the online support group.

#### After joining the Online Chat Group, the stress reduction rating values:

- Somewhat = reduced by 2 as compared to the level before (2 less)
- Greatly = reduced by 4 as compared to the level before (4 less)
- Tremendously = reduced by 6 as compared to the level before (6 less)

**Descriptive Analysis.** Table 6 provides descriptive statistics for the data from the valid 53 participant surveys. The stress level change was calculated as a comparison before and after joining the online support group. For example, a participant would be assigned a value of 10 if that person was rated as "extremely stressful" before joining the online support group. If, after joining the online support group, the stress of the

Table 4

*Stress Level, Stress Coping and Benefits of Having Online Chat Group Support (numbers listed are counts).*

<b>Stress Level Before Joining the Online Chat Group</b> (5-scaled)	5 – extremely stressful 19 – very stressful 10 – stressful 10 – somewhat stressful (subtotal: 44)  4 – not stressful 5 – Didn't share this info	
<b>Why stressful?</b> (Each selected more than one option)	5 – shame 8 – stigma 13 – spouse relationship 30 – lack of support 15 – others	<u>Others (12/15):</u> 5 – worry about child's future 2 – lack of method/parenting skills for special kids 1 – Can't keep up daily schedule 2 – exhausted 2 – lost direction
<b>Stress Level Reduced After Joining the Online Chat Group?</b>	2 – tremendously reduced 13 – greatly reduced 33 – somewhat reduced 5 – no answer	
<b>Feel Empowered Afterwards?</b>	3 – tremendously empowered 19 – greatly empowered 26 – somehow empowered 5 – no answer	
<b>Don't Feel Alone Afterwards?</b>	37 – true 8 – false 8 – Didn't choose to answer this question	
<b>Benefits of Online Chat Support Group?</b> (Each selected more than one option)	43 – to get various info 36 – convenient 28 – feel connected 15 – no GEO Limit 9 – privacy 2 – others	2 others One parent: "words of encouragement mean a lot when feeling hopeless."

same participant is rated as "tremendously reduced," which is equivalent to a value of 6, then the reduced value is 4 points (10-6=4). These rating value comparisons before and after joining the online support group were calculated to show how significantly the online support group helped to reduce each participant's stress level based on their reporting in the survey.

**Control Variables.** The researchers considered several control variables in their model. These control variables include participants' region, education level, and career information (e.g., engineering field). With sublevels

of control variables, these control variables became 12 dummies in the analysis. See Table 5: Variable Construction for related details.

**Inferential Findings.** To examine the association between parents' stress level change and the effect of the online chat group, the researchers ran the ordinary least square (OLS) regression estimation that includes "StressAfter" as a dependent variable and "StressBefore" as an independent variable. They also included "Region", "Education", and "Career" as control variables. In other words, the researchers want to explore

Table 5  
Variable Construction.

Variable	Units or values	Description
<b>Dependent Variables</b>		
StressAfter	0 to 6	Effectiveness after joining the Online Chat Group
<b>Independent Variable</b>		
StressBefore	0 to 10	Stress level that parents have from their children
<b>Control Variables</b>		
Region	0/1	Dummy variables for CA, NY, and other state
Education	0/1	Dummy variables for Bachelor, Master, PhD, and Others
Career	0/1	Dummy variables for parents' career information, such as fulltime, engineering, bioscience, social science, and others

this model:  $StressAfter = \beta_0 + \beta_1 StressBefore + \lambda Region + \nu Education + \eta Career$ . They estimated the model via Stata (StataCorp, 2015). The result shows that  $StressAfter = -3.56 + 0.958 StressBefore$ , with  $R^2$  as 0.76 and degrees of freedom as 10. The coefficient of independent variable (i.e., "StressBefore" = 0.958) is significant at  $p < 0.01$  level.

Thus, the empirical evidence suggests that participation in the online support group can reduce parenting stress, particularly for parents whose child was newly diagnosed with ASD. Furthermore, the more stress the

parenting, the more helpful the online chat group. For example, when other things are held equal, a parent with a very stressful rating (i.e., 8) is more likely to reduce stress by joining the online chat group than a parent with a less stressful rating (i.e., 6).

In summary, findings indicate that primary sources of stress for Chinese-American parents raising children with ASD can stem from a lack of support from school settings and partners. Findings also suggest that online support groups can potentially reduce stress levels for these parents.

## DISCUSSION

Our world is culturally-diverse and community-based (Dukes & Lamar-Dukes, 2009). The effectiveness of special education services should be examined within the context of the clients' cultural background (Curtis & Singh, 1996; Danseco, 1997; Lamorey, 2002). Limited research on Asian-American parents, particularly the Chinese-American sub-group has been conducted (Parette, Chuang, & Huer, 2004). Little research has explored how modern online support groups can reduce the stress associated with parenting children with ASD. Understanding parents' stress within their cultural context and helping them with appropriate stress management strategies deserve closer attention. Further research can impact the design and implementation of effective strategies in online support groups for culturally-diverse populations.

This pilot survey study explored this area and provided evidence. The overall results of the pilot survey study are statistically positive

Table 6  
Descriptive Statistics.

Variable	Mean	SD	N	Min	Max
1. StressAfter	4.04	2.09	42	0	8
2. StressBefore	6.80	1.97	42	4	10
3. Region (CA)	0.43	0.50	42	0	1
4. Region (NY)	0.36	0.48	42	0	1
5. Region (OtherState)	0.21	0.42	38	0	1
6. Education (Bachelor)	0.24	0.43	42	0	1
7. Education (Master)	0.43	0.50	42	0	1
8. Education (Ph.D.)	0.14	0.35	42	0	1
9. Education (Other)	0.19	0.40	42	0	1
10. Career (Fulltime)	0.31	0.47	42	0	1
11. Career (Engineering)	0.21	0.42	42	0	1
12. Career (Bio Science)	0.10	0.30	42	0	1
13. Career (Social Science)	0.29	0.46	42	0	1
14. Career (Other)	0.10	0.30	42	0	1
* Coefficients are significant at the $p < 0.05$ level					

in reducing the parental stress of Chinese-American participants who had children with ASD. This mode of support can empower parents with valuable information to share and learn from each other. The pilot survey also showed that participants deeply appreciated the benefits of joining such a modern online support group and felt very comfortable with this mode of support. One possible reason is that people are becoming familiar with using technology to interact with others and are becoming well versed in interacting with online communities. As a result of advancing technology, people are utilizing online social supports in the mental health industry. More investigation about such social support deserves attention.

Findings from this pilot survey study conclude that the major source of stress for parents of children with ASD is the lack of social support, rather than cultural factors of shame or stigma due to having children with disabilities. In addition to lack of social support, participants also felt that stress was related to their skills in managing their child's behavior at home, such as attention/focus issues, or their child's speech and language skills. Further, the majority of participating families had access to special education services (e.g., ABA intervention, speech therapy service, OT/PT service) when they took this survey and were receiving support for their children through formal school settings. However, the survey revealed that parents needed skills training in managing their relationship with school personnel and getting accommodations for their children. Thus, parents experienced stress in understanding school-provided services, and how to utilize such services. Finally, while parents were getting school-based services, they experienced stress in accessing further services, such as "social support services" which were related to the improvement of family communication systems, or spousal relationships (\*see the data for "Others" in Table 4). However, it is not clear what detailed social support services these parents wanted through their unique cultural context, as well as how this social support may be related to their cultural context. Further investigation is needed.

## CONCLUSION

Overall, this pilot survey study has enriched the research on how online social support groups can help reduce the stress experienced by Chinese-American parents who raise children with disabilities, such as ASD. The overall results are statistically positive, indicating that the online support group (an informal social support service) can potentially reduce parental stress

among Chinese-American parents of children with ASD by empowering them with useful information and peer support. Parents felt connected with other parents going through similar experiences and were able to help address each others' needs. This pilot survey study also found that the major source of stress for Chinese-American parents of children with ASD is the lack of social support, rather than cultural factors of shame or stigma due to having children with disabilities. The results of this study may have valuable and broader implications on alternative ways that parents of children with ASD from minority groups can connect, learn, and support each other. The study deserves further investigation and follow-up.

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# Conducting a Trial-Based Functional Analysis in the Classroom

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## Abstract

*Many individuals with autism display behavior that may interfere with the acquisition of new skills within the classroom. Due to the rising rates of autism, it is likely that many teachers will encounter students with autism and behavioral difficulties within their classrooms. Current behavior interventions are typically designed by specialists within local school districts. However, as the rates of autism within the classroom increase, this may no longer be a sustainable model. By applying practical and accessible behavior functional analysis procedures, such as a trial-based functional analysis (TBFA), for the classroom, teachers can analyze and intervene with unwanted behaviors as soon as they become present. This decrease in time delay from behavior identification to intervention may increase a teacher's sense of efficacy and minimize overall classroom disruption. The following tutorial provides teachers with a step-by-step guide to implementing TBFAs in the classroom. Resources for creating function-based behavior intervention plans are provided and lasting effects of behavior interventions on teacher efficacy in the classroom are discussed.*

Keywords: *autism, classroom functional analysis, teacher intervention, trial-based functional analysis*

## INTRODUCTION

Within the United States, 1 in 6 children, or nearly 17% of children were diagnosed with a developmental disability between 2006 and 2008 (Boyle et al., 2011). In a 2011 World Health Organization (WHO) report, the rising prevalence of disabilities amongst children was highlighted, but exact figures could not be determined. Impediments, such as a lack of resources or idiosyncratic methods of data collection, were reported. Despite these barriers, disabilities, developmental or otherwise, were suggested to have lasting effects on an individual's ability to lead a productive and independent life if not supported and educated from birth (WHO, 2011).

The term *developmental disability* is inclusive of a group of pervasive impairments that originate at birth or during childhood, and substantially impacts an individual's ability to navigate their environment (Developmental Disabilities and Bill of Rights Act, 2000). Within the United States, children under the umbrella term of developmental disabilities typically have autism, behavior disorders, brain injury, cerebral palsy, Down syndrome, fetal alcohol syndrome, intellectual disability, or spina bifida. Although no precise data exists regarding international rates, behavioral excesses such as aggression are reported in 53% of all individuals with autism in the United States, with the two-to-four-year-old group displaying the highest levels of aggression

at 54.6% (Mazurek, Kanne, & Wodka, 2013). Mazurek and colleagues (2013) noted that although the rate at which physical aggression occurs decreases among adolescents, the severity or intensity of aggression from 14- to 17-year-olds makes aggressive behaviors pertinent to all stages of childhood. This link between frequency of behavior (early in life) and intensity of behavior (later in life), lays the groundwork for behavioral excesses such as physical aggression to be a pervasive lifelong impediment if not intervened with early in life. Kanne and Mazurek (2011) stated that behavior excesses such as aggression have the potential to affect immediate (physical harm) and long-term (family stress, out-of-home placements, and decreased independence) implications for individuals with autism and their caretakers. It has also been reported that teacher efficacy and increased rates of burnout due to behavior excess of challenging behavior impact the educational opportunities for students with ASD (Kanne & Mazurek, 2011).

Within the field of applied behavior analysis, behavior is described as a function of the environmental contingencies that may be present. The function, or why a behavior may occur, can be investigated using a functional behavior assessment to provide teachers specific information to intervene on behavior. Cooper, Heron, and Heward (2007) categorized functional behavior assessments into three groups: functional analysis, descriptive assessment, and indirect assessments.

## Functional Analysis

Functional analysis is an established and effective method for analyzing the environmental reinforcement for problem behavior (Hanley, Iwata, & McCord, 2003). Hanley and colleagues reviewed 277 studies that used functional analyses and found that 95% were successful in identifying the function of the problem behavior. Despite these promising findings, Asmus, Vollmer, and Borrero (2002) noted that traditional functional analyses are infrequently used within schools. They list several factors that may contribute to the lack of practical application within the classroom setting, such as lack of training and lack of time. As described by Iwata, Dorsey, Slifer, Bauman, and Richman (1994), functional analyses use contrived settings to manipulate antecedents (what happened before the maladaptive behavior) and consequences (what happened after the maladaptive behavior) repeatedly until a common trend becomes present. To be implemented, teachers or school personnel would have to create an alternative setting and change the school schedule. Once the setting and schedule had been altered, this process on average could take six-and-a-half hours, excluding additional time to interview stakeholders and train staff, over a week or two (Iwata et al., 1994; Tincani, Castrogiovanni, & Axelrod, 1999). These factors alone make traditional functional analyses impractical within the school setting.

Several alternative methods of conducting a functional analysis have been created to capture the effectiveness of traditional functional analysis procedures in a more time- and resource-effective manner. In a recent systematic review of functional analysis procedures, Lydon, Healy, O'Reilly, and Lang (2012) described five alternative methods to conduct functional analyses: brief functional analysis, latency functional analysis, precursor functional analysis, protective equipment and functional analysis, and trial-based functional analysis (TBFA).

Although more research needs to be conducted to be considered evidence-based, TBFAs are a promising practice that use existing trials within ongoing activities or daily routines in which antecedent variables may already be present (Lydon et al., 2012). Whereas typical functional analyses remove the student from the environment, TBFAs measure student behavior within the environment based on a naturally-occurring presentation of antecedents and consequences. This version of the functional analysis allows teachers to minimize the time and artificial space needed to evaluate behavior.

The results of the trials are recorded as an occurrence or non-occurrence of behavior, which is then analyzed to develop a hypothesis for why the behavior may occur (functional hypothesis).

## Implementing the TBFA

Each student will be evaluated in three conditions within the TBFA: (1) tangible (wanting an item), (2) escape (wanting to get away from someone or something), and (3) attention (wanting to gain the attention of an adult or peers). Nine (three trials per condition), four-minute evaluation sessions, embedded into typical daily activities, are conducted over two consecutive days (McDonald, Moore, & Anderson, 2012). Evaluation sessions consist of one, two-minute control session, followed by a two-minute testing interval. Each testing interval ends as soon as the student displays the target behavior.

## Preparing for the TBFA

The TBFA helps teachers identify why a behavior may occur so they can create a specific intervention plan. The first step in the process is to define the interfering behavior(s). Multiple behaviors may occur for the same reason (or function) while other times a student may have multiple maladaptive behaviors that occur at different times and serve different functions (Cooper et al., 2007). Define each potential maladaptive behavior in observable and measurable terms. The definition should be clear enough so anyone can identify the behavior when it occurs. For example, the term "hitting" can be defined as "using a closed or open hand to strike another's body." Knowledge of a student's preferences is also important when starting the assessment. Da Fonte et al. (2016) guide readers through a three-step preference assessment that can be implemented within a classroom setting. Prior to starting the assessment, review the typical classroom schedule and make a list of the times the student is likely to naturally experience removed attention, demands, or is told "no" regarding a preferred item.

**Tangible condition.** During the tangible condition, the teacher provides access to a highly-preferred item for two minutes during the control condition. During the test condition, the item is removed, but remains within view. If the student reaches for the item, the teacher moves the item away from the student and says, "You can't have that." If the student engages in the maladaptive behavior, the teacher gives the student the item and the session ends (see Figure 1).



Figure 1  
*Description of Trial-based Functional Analysis Steps Within the Classroom.*

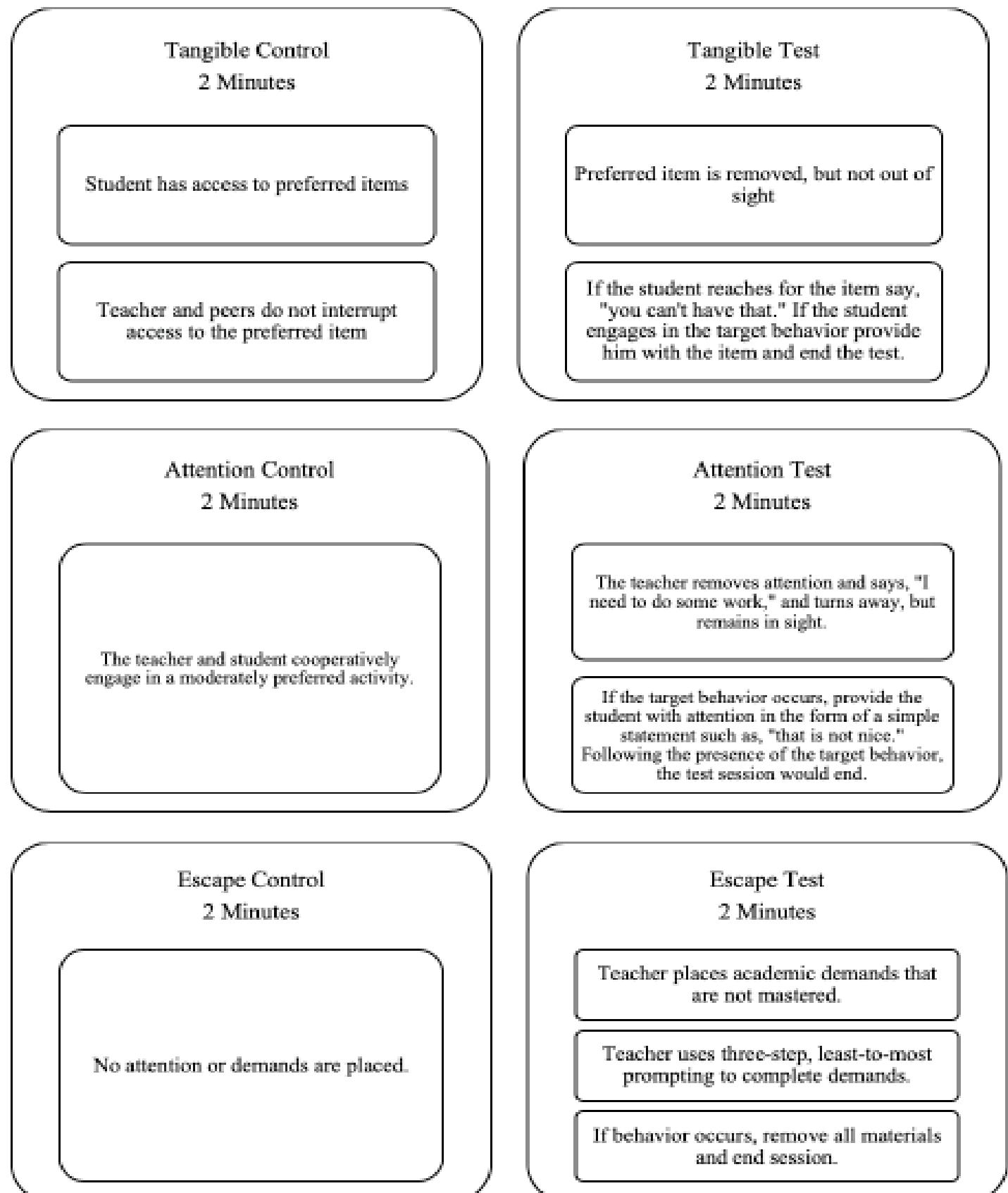


Table 1  
*Error Correction Procedure.*

<b>Teacher Action</b>	<b>Response to Student Action</b>
Teacher places demand. “Touch the number 13.”	Student does not respond—continue to next step. Student engages in target behavior—discontinue trial and record the behavior on the data sheet.
Teacher says, “Touch the number 13” and says, “it’s the one with the 1 and 3.”	Student does not respond—continue to next step. Student engages in target behavior—discontinue trial and record the behavior on the data sheet.
Teacher says, “Touch the number 13” and models by pointing to 13.	Student does not respond—continue to next step. Student engages in target behavior—discontinue trial and record the behavior on the data sheet.
Teacher says, “Touch the number 13” and uses hand-over-hand prompting to touch the number 13.	Student does not respond—continue to next demand with same 3-step prompting schedule. Student engages in target behavior—discontinue trial and record the behavior on the data sheet.

**Escape condition.** During the escape control condition, the teacher does not provide any attention or demands on the student. During the escape test condition, the teacher places academic demands that have not been mastered. To complete the task, the teacher uses a 10-second, least-to-most, three-step prompt (verbal, model, full-physical prompt) when placing demands (Rispoli, Ninci, Neely, & Zaini, 2014) (see Table 1). Upon the completion of the task, regardless of the level of prompting required, the student receives social praise. If the student engages in the maladaptive behavior, the teacher immediately removes all of the materials from the table.

**Attention condition.** Control sessions for attention consist of the teacher and student taking part in a moderately-reinforcing activity as determined from a preference assessment. The teacher engages with the student and provides verbal praise such as “great job,” or “I really like what you are doing!” During the test condition, the teacher removes his/her attention and says, “I’m going to do some work” and then directs their attention away from the student. If the student engages in the maladaptive behavior, the teacher says, “That’s not nice” or “Remember we have nice behavior at school.”

### **Collecting Data and Interpreting Results**

Following each trial, record the occurrence or non-occurrence of the target behavior. Figure 2 provides an example of a simple data sheet. Each box represents a trial. If the behavior is present during the control or

test condition, place a check in the corresponding box. If the behavior is not present during the control or test condition, leave the box blank.

When analyzing the TBFA results, start by looking at trials that had the behavior present during the control condition. It is likely that these sessions did not yield valid results because the behavior was occurring before the assessment occurred. Less emphasis should be placed on these sessions (Hanley et al., 2003). Next, look at the sessions that had the lowest number of behaviors present. In the example illustrated in Figure 2, tangible and attention fall in this category. Based on these data, it can be hypothesized that the student likely does not engage in the problem behavior to gain someone’s attention or access an item. Finally, look at the conditions that had the highest levels of behavior. Based on Figure 2, the escape condition had the highest likelihood of eliciting behavior. Based on this information, we can hypothesize why the maladaptive behavior is occurring. Thus, a hypothesis statement should say, “When Sally engages in screaming behavior, she is able to escape demands.”

Identifying the function of a maladaptive behavior is an essential component of creating a clear and effective behavior intervention plan. Without knowledge of a behavior’s function, a teacher may inadvertently reinforce, or increase, the inappropriate behavior when trying to decrease the behavior. Following the identification of the behavior function, the teacher would then identify a replacement behavior to teach that serves the same function as the inappropriate behavior (Cooper et

Figure 2  
Completed Example of the Data Sheet.

**Student Name:** Sample Sally

**Observer:** Teacher 1

**Behavior:** Screaming – Yelling inaudible words and/or sounds above the speaking volume of the room.

**Instructions:** Place an **X** in each box in which the behavior occurs. Use a different data sheet for each behavior. If the behaviors have similar results, they may have the same function and may benefit from the same (or similar) intervention.

**Attention**

	Control	Test	Control	Test	Control	Test
		X				
Date:	10/1/19		10/1/19		10/2/19	

Rank the Behavior Functions

1. **Escape**
2. **Access**
3. **Attention**

**Escape**

	Control	Test	Control	Test	Control	Test
		X		X		X
Date:	10/1/19		10/1/19		10/2/19	

**Access**

	Control	Test	Control	Test	Control	Test
			X	X		
Date:	10/1/19		10/1/19		10/2/19	

Notes:

al., 2007). For example, if the student’s maladaptive behavior serves an escape function from a non-preferred classroom task, the teacher can create an intervention plan that targets appropriate ways for the student to communicate a desire to escape from a task other than using screaming behavior. Identifying a clear behavior function allows the teacher to know what replacement behavior needs to be taught in place of the maladaptive behavior. In our example, the teacher would use the escape function to identify the need to teach the student to request, “All done,” or “I need a break.” For more information regarding function-based interventions, please visit <http://afirm.fpg.unc.edu/afirm-modules>, [www.pbisworld.org](http://www.pbisworld.org), <http://www.intensiveintervention.org>, and <https://iris.peabody.vanderbilt.edu/>

**CONCLUSION**

The presence of behavioral excesses, such as aggression, within the classroom can have a lasting effect on a teacher’s sense of self-efficacy, decreasing school personnel’s belief that they may effect change (Kanne & Mazurek, 2011). This decreased sense of self-efficacy was highlighted in a critical analysis of the factors that influence special education teacher attrition within the United States. Billingsley (2004) identified a need for the creation of a collaborative environment that decreases the potential for teacher burnout and increases a teacher’s sense of self-efficacy while building a broader base of knowledge to take on the unique challenges within a special education classroom. This teacher attrition variable illustrates the need to develop

effective assessment methods for teachers to evaluate and intervene on behavior within the classroom. Often teachers wait for district resources to support behavior intervention, thus creating a delay in intervention and an opportunity for a student to practice unwanted behavior. By applying practical and accessible behavior functional analysis procedures, such as the TBFA, for the classroom, teachers can analyze and intervene with unwanted behaviors as soon as they are present. This decrease in time delay from behavior identification to intervention may increase a teacher's sense of efficacy and minimize overall classroom disruption.

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