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# The Journal of the International Association of Special Education

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## CONTENTS

# Editor's Message

Greetings to all members and friends of the **International Association of Special Education** (IASE). I am very pleased to provide the IASE readership another quality publication focused on the broad range of issues concerning students and individuals with special needs around the world.

The mission of the ***Journal of the International Association of Special Education*** (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 in our mission is a commitment to cultivating international authors, reviewers, and readers to become skilled and creative writers, critics, and consumers of international special and inclusive education research and innovative teaching practices.

In this 2017 issue of JIASE, articles represent studies and practical applications carried out in several different countries, including Nigeria, Kenya, Tanzania, and the United States. Topics covered in the articles include stigmatization of persons with disabilities, situational analysis of inclusive education, job-related goals of a young adult with ASD, health-care experience of children with disabilities, and more.

This publication would not be possible without the dedication, inspiration, and hard work of IASE past president, Dr. Iris Drower; associate editors, Dr. Britt Ferguson, Associate Professor of Special Education for National University in California and Dr. Malgorzata Sekulowicz, of the University of Lower Silesia, Wroclaw, Poland; managing editor, Thomas J. Donaghy of the Institute on Community Integration at the University of Minnesota; and our wonderful team of 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 consideration. Publication submission guidelines are located on the IASE website at http://www.iase.org/ as well as at the end of this journal issue. We hope that you will find this issue to be interesting and professionally engaging. Hope to see you all in Magamba, Tanzania, East Africa, on July 15-17, 2019, for our 16th Biennial IASE Conference.

Sincerely,
Renáta Tichá, PhD, Editor of JIASE

# Stigmatization of Persons with Disabilities: The Role of Gender, Knowledge, and Attitude Towards Disabilities in Nigeria

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## Abstract

*This study focuses on the influence of gender, knowledge of, and attitude towards, disabilities on the stigmatization of persons with disabilities. The research design employed was a descriptive survey research design. The population of the study was civil servants in Ibadan, Oyo State, Nigeria. The sample was made up of 250 civil servants, using a multistage random sampling technique. Three instruments, the Knowledge of Disability Scale (KDS), Attitude Towards People with Disability Scale (ATPDS) and Stigmatization of People with Disability Scale (SPDS) were administered to the participants. Data collected were analyzed using the Pearson product-moment correlation and multiple regression analysis. The result revealed that there is a significant joint effect of gender, knowledge, and attitude on the stigmatization of people with disabilities in Oyo State, Nigeria. There was also relative contribution of all the independent variables, with knowledge and attitudes being the most important. The study recommended that civil servants should make an effort to improve their knowledge and attitude of disability as this will most likely reduce their level of stigmatization of persons with disabilities.*

Keywords: *Stigmatization, gender, knowledge, attitude, disabilities, Nigeria*

## INTRODUCTION

### Background to the Study

The World Health Organization (WHO) observes that disability is a contextual variable that is dynamic over time and is related to circumstances. One is more or less disabled based on the interaction between the person and the individual, institutional, and social environments. The way disability is defined and understood has also changed in the last decade. Disability was once seen as a way to characterize a particular set of largely stable limitations. Now the WHO has moved toward a new international classification system: the International Classification of Functioning, Disability and Health (ICF, WHO, 2001). ICF emphasizes functional status over diagnoses. The new system is not just about people with traditionally-acknowledged disabilities diagnostically categorized, but about all people.

The term "disability" has been used to describe diverse conditions, such as the congenital absence or adventitious loss of a limb, loss of a sensory function; progressive neurological conditions like multiple sclerosis; chronic diseases like arteriosclerosis; inability or limited ability to perform such cognitive functions as remembering faces or calculating sums; and psychiatric disorders like schizophrenia and bipolar disorder (*Stanford Encyclopedia of Philosophy*, 2011). Disability is complex, dynamic, multidimensional, and contested, according to the *World Report on Disability* (WHO, 2011). Disability does not depend solely on the functional limitations relating to an individual's impairment, but also on the environment.

The United Nations' Convention on the Rights of Persons with Disabilities (UN, 2006) defined disability as resulting from "the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others." Many professionals and laymen perceive disability differently, based on their orientation or way of thinking about "differences" (Smith, 2007). Some view disability from a deficit perspective, some have cultural views, while others have sociological perspectives, to mention just a few. Each of these viewpoints affect issues of acceptance, discrimination, and social inclusion or exclusion of persons with disabilities.

Stigmatization is one of the problems that could hinder full participation of persons with disabilities in society. Stigmatization occurs when a negative attitude is adopted with regard to a group in general, as opposed to basing one's judgments on the specific characteristics of individuals within the group (Dovidio, Major, & Crocker, 2000). It has internal, external, and strong negative consequences of importance to public health programs, persons with disabilities, their families, and even practitioners working with persons with disabilities. Idrees and IIyas (2012) reported that the self-concept, cognitive and social development, academic performance and general psychological health of a person with a disability may be largely affected as a result of stigmatization by peers.

Stigmatization has major impacts on the psychosocial life of individuals, families, and communities. It leads to human rights violations of persons with disabilities. It causes stress, anxiety, and further stigma. It reduces acceptance and heightens discrimination, rejection, and social exclusion. It causes label avoidance and makes it difficult to pursue employment or access to services. It can result in a lowering of self-esteem and self-efficacy (Nolan, McCarron, McCallion, & Murphy-Lawless, 2006).

People who perceive themselves as stigmatized may internalize stigmatizing ideas (Graham et al., 2003, cited by Nolan et al., 2006). To most people with disabilities, stigma is a significant barrier to mainstream social participation. Therefore, it is necessary to understand stigmatization factors in any society seeking equity and inclusion of all persons. Moreover, stigmatization occurs on societal, interpersonal, and individual levels, and various individuals describe stigma differently. For example, from a social psychological perspective, stigma is not considered to reside in the person, but rather in the social context (Crocker, Major, & Steele, 1998; Hebl & Dovidio, 2005). What is stigmatizing in one social context may not be stigmatizing in another situation (Crocker, Major, & Steele, 1998).

Stigma is a powerful phenomenon that is often linked to the understanding of lay people about a disability and their perceptions of the condition. For instance, Lisle (2011) argued that it is a lack of knowledge that often leads people to define a learning disability incorrectly. This statement is supported by Duchane, Leung, and Coulter-Kern's study (2008), which examined teachers' attitudes towards students with learning disabilities and revealed that less-favorable attitudes towards teaching students receiving special education services were related to misunderstanding or lack of knowledge of disabilities. Ignorance and misinformed beliefs about the condition or its causes may lead to stigma, prejudice, and discrimination and can have negative consequences for seeking help. Similarly, Rao (2004) showed that individuals who reported a better knowledge of the legislation associated with learning disabilities had a more positive attitude toward those who had learning disabilities.

Bedini (2000) examined the effects of perceived stigma on the recreation participation of persons with disabilities and found that study participants clearly believed that persons with disabilities were stigmatized by others in the community. Responses to perceived stigma included feeling demeaned, helpless, intimidated, and disempowered. Bedini suggested that attitudes of persons were as essential as accessible environments. Whether held by people with or without disabilities, Bedini argued that attitudes would benefit from further examination in order to enhance understanding and would provide welcoming environments for those with disabilities, facilitated by those without disabilities.

Human attitudes are expressions of their level of preference or dis-preference for things, organisms or phenomenon. Lucas (1999) stated that attitude is a favorable or unfavorable evaluative reaction toward something or someone, and is exhibited in one's beliefs, feelings or intended behavior. Attitudes are comprised of three components: affective, cognitive, and behavioral (Lucas, 1999; Myers, 2008). The affective component represents the emotional portion of an attitude, whereas the cognitive component refers to ideas, beliefs, and opinions (Antonak & Livneh, 1988). The behavioral component describes a person's willingness to interact with the subject at hand and the manner in which they do so (Cook, 1992). It is important to understand the components of attitudes, since understanding attitudes should help predict behavior toward persons with disabilities. Furthermore, the relationship between attitudes and behavior is complex, and attitudes only account for a small part of behavior.

Perry, Ivy, Conner, and Shelar (2008) investigated the attitudes of college students, as pre-professionals, towards persons with disabilities. An initial step was taken to establish a normative attitude mean for this population using the Attitudes Toward Disabled Persons (ATDP) scale, Form B (Yuker & Block, 1986). In addition, data were collected from 298 undergraduate students on the frequency of their interaction with persons with disabilities. Respondents' gender and frequency of interaction with persons with disabilities (ranging from daily to less than six times a year) significantly accounted for differences in mean ATDP scores, while age, specialization, and program accreditation were found to have no significant impact on mean attitude scores. Moore (1998) and Lucas (1999) also addressed the linkage between attitudes and people with disabilities. Perry et al. (2008) concluded that existing literature indicated that most persons with disabilities, like other minorities, desire to achieve acceptance and integration in society.

Studies have shown that the image of disability may be intensified by gender. For women, it is a sense of intensified passivity and helplessness, a corrupted masculinity generated by enforced dependence (Meekosha, 2004). It is also customary that in most African societies—which are also mainly patriarchal—a man is expected to have more than one wife. This, in turn, implies that the women would bear him many children—further evidence of a man's virility. In fact, the powerlessness of women may be exaggerated when individuals speak about what it means to be a man (Oluwole, 2008). These images have implications in terms of education, employment, living arrangements, personal relationships, victimization, and abuse that then, in turn, reinforce the images in the public sphere.

The gendered experience of disability illuminates sustained patterns of difference between men and women (Gerschick, 2000). Women with disability experience more extreme social categorization than men, being more likely to be seen either as hypersexual and uncontrollable or de-sexualized and inert (Abu-Habib, 1997) and there is evidence that women with disabilities experience major psychosocial problems that remain largely neglected, including depression, stress, lowered self-esteem, stigmatization, and social isolation (Nosek & Hughes, 2003).

Girls with disabilities suffer a double discrimination, facing not only stigma, prejudice, and inequities encountered by many persons with disabilities, but also exclusion as a consequence of gender discrimination (WHO, 2010). This makes them less likely than either boys with disabilities or girls without disabilities to obtain healthcare, get an education, receive vocational training, find employment or benefit from inclusion in the social, political or economic lives of their families (Groce, 2004). A study of young Jamaicans found that females have a stronger perspective that mental illness is due to a failure of will while males hold more benevolent opinions. However, no differences were reported for social restrictiveness (Jackson & Heatherington, 2006). Therefore, this study considered the relationship between factors like gender, knowledge of disability, and attitude towards people with disabilities on the one hand, and the stigmatization of individuals with disabilities on the other.

## Objectives of the Study

This study investigated the relationship among gender, knowledge of disability, attitude towards individuals living with disabilities, and the stigmatization of people with disabilities among civil servants in Ibadan. Under British colonial rule, Ibadan was the center of administration of Nigeria's old Western Region and the Ibadan area, with a population of 120,000, became a British Protectorate in 1893. The principal inhabitants of the city are the Yorùbá. The British developed the new colony to facilitate their commercial activities in the area, and Ibadan soon grew into the major trading center that it remains today. Nigeria gained its independence in 1960. Ibadan became the capital of Oyo State in 1976. The city is located in south-western Nigeria, 78 miles inland from Lagos and it is a prominent transit point between the coastal region and the areas to the north. Its population is estimated to be about 3,800,000, according to the 2006 national population estimates.

As an ancient town, the Yorùbá traditions, culture, and belief system are deep rooted in the inhabitants, including the civil servants. Despite their level of education, most civil servants seem uncomfortable talking to people with disabilities. Civil servants in Idaban also tend to think of people with disabilities as less productive than everyone else. This has implications for social interaction with people with disabilities.

## Research Questions

1. What is the relationship among the independent variables (gender, knowledge of disability, and attitude towards individuals with disabilities) and the dependent variable (stigmatization of individuals with disabilities) among civil servants in Ibadan, Oyo State?

2. What is the joint contribution of the independent variables (gender, knowledge of disability, and attitude towards individuals with disabilities) to the dependent variable (stigmatization of individuals with disabilities) among civil servants in Ibadan, Oyo State?

3. What is the separate contribution of the independent variables (gender, knowledge of disability, and attitude towards individuals with disabilities) to the dependent variable (stigmatization of individuals with disabilities) among civil servants in Ibadan, Oyo State?

## METHODS

### Research Design

The study is a descriptive research of correlational type. This design was chosen because it suited the variables of interest in this study.

### Population

The target population for this study was made up of all civil servants in Oyo State ministries of education, finance, agriculture, health, lands and housing who reside in Ibadan, Oyo State. A civil servant is a public sector employee who works for a government ministry, department or agency. Civil servants in Nigeria majorly assist the executive arm in planning and executing government policies.

### Sample and Sampling Technique

The sample for this study was drawn from the target population. The sample was made up of 250 civil servants in Ibadan, Oyo State who were randomly selected from the core ministries in the state secretariat. The sampled civil servants consist of 136 males and 114 females. Their age ranged between 23 and 58 years. Participants' length of service is between less than a year and 20 years.

### Instrumentation

The instruments for the study were three different instruments. These instruments were:

***The Knowledge of Disability Scale (KDS).*** The Knowledge of Disability Scale was developed by the researchers (Lazarus and Oluwole) and used to measure the knowledge of disability of the participants. An 8-item scale with a 5-point scale ranging from 1 to 5 was used for all items, with higher numbers representing greater perceived amounts of knowledge of disability. An example of the items include, "I do not believe that government has any legislation on protection of disabled individuals." The highest score obtainable is 40 while the lowest is 8. A test-retest reliability coefficient of 0.78 was found.

***Attitude Towards People with Disability Scale (ATPDS).*** The Attitude Towards People with Disability Scale (ATPDS) was developed by the researchers and used to measure participants' attitudes towards people with disability. Items include "I dislike disabled people, generally speaking" and "I just do not like relating with people with disability." A 10-item scale with a 5-point scale ranging from 1 to 5 was used for all items, with higher numbers representing greater perceived amounts of attitude towards people with disabilities. A test-retest reliability coefficient of 0.78 was found.

***Stigmatization of People with Disability Scale (SPDS).*** The stigmatization of people with disabilities was assessed with Stigmatization of People with Disability Scale (SPDS). All items were rated on a five-point Likert scale, namely, 1=strongly disagree, 2=disagree, 3=not sure, 4=agree, 5=strongly agree. An example of the items include, "I am scared of becoming disabled when interacting with people with disability." To determine the score of this scale, ratings within each scale are summed up. Negative statement items on the instrument were reverse-coded so that a high score on the instrument indicates a high degree of stigmatization of people with disabilities. A test-retest reliability coefficient of 0.69 was found.

***Administration of the Instruments.*** The researchers visited the ministries in the Oyo Government secretariat and physically distributed the main instruments and collected them after respondents completed them. It took about three weeks for the civil servants to complete the questionnaires. Out of 300 questionnaires administered, 250 were retrieved, translating to an 83.3% retrieval rate.

### Data Analysis

Product-moment correlation and multiple regression analyzes were used to analyze the data collected. The dependent variable was stigmatization of people with disabilities, while the predictor variables were gender, knowledge of disability, and attitude towards people with disabilities.

## RESULTS

### Research Question 1

What is the relationship among the independent variables (gender, knowledge of disability, and attitude towards disability) and the dependent variable (stigmatization of people with disabilities) among civil servants in Ibadan, Oyo State?

Table 1 contains descriptive statistics and inter-correlations among the study variables. As shown in Table 1, stigmatization of people with disabilities has a significant positive correlation with gender ($r = .213$; $p<.05$) and significantly high correlation with knowledge of disability ($r = -.700$; $p<.05$), and attitude towards people with disabilities ($r = -.822$; $p<.05$). The gender of participants was coded as follows: Male = 1; Female= 2.

Table 1

*Descriptive Statistics and Inter-correlations Among the Variables.*

| **Variables** | **Mean** | **Standard** | **1** | **2** | **3** | **4** |
|---|---|---|---|---|---|---|
| Stigmatization | 23.62 | 5.90 | 1.000 | | | |
| Gender | – | – | .213* | 1.000 | | |
| Knowledge | 29.95 | 5.69 | -.700* | -.047* | 1.000 | |
| Attitude | 27.62 | 3.76 | -.822* | .232* | -.705 | 1.000 |

Table 2 indicated that males ($\bar{x}$ =31.62) have negative attitude towards disability and people with disability, while the attitude of females towards disability ($\bar{x}$ = 23.15) is somewhat better than that of males. A majority of the inexperienced workers ($\bar{x}$ = 33.16) exhibited negative attitude towards disability and people with disabilities when compared to experienced workers. More young workers ($\bar{x}$ = 37.32) displayed a negative attitude towards disability and people with disabilities than older workers, with a mean score of 29.33.

**Research Question 2**

What is the joint contribution of the independent variables (gender, knowledge of disability, and attitude towards disability) to the dependent variable (stigmatization of people with disabilities) among civil servants in Ibadan, Oyo State?

Regression analysis of variance demonstrates a significant joint contribution of the independent variables to the stigmatization of people with disabilities (F (3, 246) = 198.08, $p<.05$). The linear regression coefficient is R=.841, R Square=.707, Adjusted R Square=.704, and Std. Error=3.211. The three predictors jointly accounted for 70.4% (Adjusted $R^2$=.704) variation in the prediction of stigmatization of people with disabilities. The remaining percentage not accounted for could be a result of extraneous variables not addressed in this study.

**Research Question 3**

What is the relative contribution of each of the independent variables (gender, knowledge of disability, and attitude towards disability) to the dependent variable (stigmatization of people with disabilities) among civil servants in Oyo State?

The strongest and largest contribution is from attitude to disability, ($\beta$ =.632, t=-12.476, $p<0.05$), followed by knowledge of disability ($\beta$ =-.251, t=-5.088, $p<0.05$). However, gender does not significantly predict stigmatization of people with disabilities ($\beta$ = .055, t= 1.521, $p>0.05$).

## DISCUSSION

The first research question was designed to test for the relationship among the independent variables (gender, knowledge of disability, and attitude towards disability) and the dependent variable (stigmatization of people with disabilities among civil servants in Ibadan, Oyo State). The study found different results for each independent variable. In the first instance, there was a significant positive relationship between gender and attitude of participants towards people with disabilities. Results indicated that more males ($\bar{x}$ = 31.62) have negative attitudes towards disability and people with disabilities. A majority of the inexperienced workers ($\bar{x}$ = 33.16) exhibited negative attitudes towards disabil-

Table 2

*Attitude Towards Disability Among Civil Servants in Idaban, Oyo State.*

| **Attitude Towards Disability** | **No.** | **Mean** | **Std. Dev.** |
|---|---|---|---|
| Males | 136 | 31.62 | 3.12 |
| Females | 114 | 23.15 | 2.03 |
| Experienced workers (10 years and above) | 126 | 28.19 | 3.06 |
| Inexperienced workers (< than a year to 9 years) | 124 | 33.16 | 2.98 |
| Young workers (23-39 years) | 136 | 37.32 | 3.71 |
| Older workers (40-60 years) | 114 | 29.33 | 2.97 |

ity and people with disabilities when compared to the experienced workers. Also, more young workers ($\bar{x}$ =37.32) displayed negative attitudes towards disability and people with disabilities.

The study also found a significant negative relationship between knowledge of disability and stigmatization of people with disabilities. This result is consistent with researchers (Duchane, Leung, & Coulter-Kern, 2008) who have found a significant relationship between knowledge of disability and stigmatization of people with disabilities. This also corroborates previous findings by other researchers (Bedini, 2000; Perry et al., 2008). The low level of knowledge of disability leads to an increase in stigmatization. The more people know about disability, the less they are prone to stigmatize people with disabilities. This is because knowledge of disability stimulates an empathetic view of people with disabilities (Crocker et al., 1998), which prevents stigmatization.

The result of the second research question revealed that the independent variables—gender, knowledge of disability, and attitude towards disability—when combined, have significant effects on the stigmatization of people with disabilities. Thus, the results indicate that the independent variables' capacity to predict stigmatization of people with disabilities could not have happened by chance. This finding is consonant with previous research (Lucas, 1999; Myers, 2008; Duchane et al., 2008; Rao, 2004; Moore, 1998). Also, Rao (2004) showed that there is a relationship among knowledge of disabilities, attitude towards disabilities, and stigmatization of individuals with disabilities. This large body of empirical evidence demonstrates that knowledge, attitude, and gender influence stigmatization of individuals with disabilities.

The result of the third research question revealed that knowledge of disabilities and attitude towards disabilities made significant negative contributions to the prediction of stigmatization of people with disabilities, but gender did not contribute to the prediction. In terms of magnitude of contribution of predicting variables, attitude towards disabilities contributed the most, followed by knowledge. This is consistent with previous research. For example, a large body of empirical evidence has demonstrated that attitude influences stigmatization (Lucas, 1999; Myers, 2008; Duchane et al., 2008; Rao, 2004).

Gender not making an independent contribution is also consistent with previous research (Jackson & Heatherington, 2006). This can be explained by the fact that both men and women are equally influenced by the values of their society. They all possess the same societal beliefs and attitudes; this influences their attitude and gender does not change it.

## CONCLUSIONS

This study found a significant relationship among the independent variables of gender, knowledge of disability, and attitude towards individuals with disabilities, on the one hand, and the resulting stigmatization of people with disabilities on the other. There was also a significant relationship among the above-mentioned variables. This study found that the three independent variables jointly predict stigmatization of people with disabilities. Separately, however, gender did not significantly predict stigmatization, while knowledge of disability and attitude towards people with disabilities did. The finding implies that poor knowledge and negative attitude towards persons with disabilities tend to negatively influence the stigmatization of people with disability.

This study showed that civil servants in Ibadan, Oyo State who are supposed to interpret and execute government welfare policies for people with disabilities, have apathy towards these individuals. To reduce stigmatization of people with disabilities, there is a need to re-educate the civil servants about disability. There is also a need to remind civil servants of their obligation to enforce the National Policy on Education Act (2004), which stresses respect for individuals, irrespective of orientation, physical fitness or mental state.

## RECOMMENDATIONS

Based on the study findings, the following is recommended:

1. Civil servants should work toward improving their knowledge of disability. This will likely reduce stigmatization of people with disabilities.

2. Organizations should encourage their employees to improve their attitude towards people with disabilities.

3. Civil servants, especially males, should be exposed to orientation programs to create more awareness about people with disabilities and how to manage disability conditions.

4. There should be regular professional development programs for newly employed and young civil servants in Nigeria, particularly programs that address attitudinal issues towards people with disabilities.

## REFERENCES

Abu-Habib, L. (1997). *Gender and disability: Women's experiences in the Middle East*. Oxford, England: Oxfam.

Antonak, R. F., & Livneh, H. (1988). Measurement of attitudes towards persons with disabilities. *Disability and Rehabilitation, 22*, 211–224.

Bedini, L. A. (2000). Just sit down so we can talk: Perceived stigma and community recreation. *Therapeutic Recreation Journal, 34*(1), 55–68.

Cook, D. (1992). Psychological impact of disability. In R. M. Parker & E. M. Szymanski (Eds.), *Rehabilitation counseling basics and beyond* (pp. 249–272). Austin, TX: PRO-ED.

Crocker, J., Major, B., & Steele, C. (1998). Social stigma. In D. T. Gilbert, S. T. Fiske, & G. Lindzey (Eds.), *The handbook of social psychology* (4th ed., Vol. 2, pp. 504–553). Boston, MA: McGraw-Hill.

Dovidio, J. F., Major, B., & Crocker, J. (2000). Stigma: Introduction and overview. In T. F. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull (Eds.), *The social psychology of stigma* (pp. 1–30). New York, NY: Guilford Press.

Duchane, K., Leung, R., & Coulter-Kern, R. (2008). Preservice physical educator attitude toward teaching students with disabilities. *Clinical Kinesiology (Online) 62*(3), 16–20. Retrieved from ProQuest Central. (Document ID:1584154781).

Gerschick, T. J. (2000). Towards a theory with disability and gender. *Signs, 25*(4), 1263–1268.

Groce, N. (2004). Adolescents and youth with disabilities: Issues and challenges. *Asia Pacific Disability Rehabilitation Journal, 15*(2), 13–32. http://www.aifo.it/english/resources/online/apdrj/apdrj204/adolescent.pdf 3

Hebl, M. R., & Dovidio, J. F. (2005). Promoting the "social" in the examination of social stigmas. *Personality and Social Psychology Review, 9*, 156–182.

Idrees, B., & Ilyas, R. (2012). Discrimination and stigmatization of physically disabled students in a general educational environment in Pakistan: A case study, *Academic Research International, 2*(2), 622–626.

Jackson, D., & Heatherington, L. (2006). Young Jamaicans' attitudes toward mental illness: Experimental and demographic factors associated with social distance and stigmatizing opinions. *Journal of Community Psychology, 34*, 563–576.

Lisle, K. (2011). Identifying the negative stigma associated with having a learning disability. *Honours Theses*, Paper 22.

Lucas, K. M. (1999). *Non-handicapped students' attitudes toward physically handicapped individuals*. Retrieved from http://clearinghouse.mwsc.edu/manuscripts/110.asp

Meekosha, H. (2004). *Gender and disability* (Draft entry for the Sage Encyclopedia of Disability).

Moore, D. (1998). Acceptance of disability and its correlates. *The Journal of Social Psychology, 138*(1), 13–25.

Myers, D. G. (2008). *Social psychology* (9th ed.). New York, NY: McGraw-Hill.

Nolan, L., McCarron, M., McCallion, P., & Murphy-Lawless, J. (2006) *Perceptions of stigma in dementia: An exploratory study*. Dublin, Ireland: Alzheimer Society of Ireland.

Nosek, M. A., & Hughes, R. B. (2003). Psychosocial issues of women with physical disabilities: The continuing gender debate. *Rehabilitation Counseling Bulletin, 46*(4): 224–233.

Oluwole, D. A. (2008). Individual, family, school, society and government predictors of scholastic achievement among Nigerian university undergraduates. *International Journal of Applied Psychology and Human Performance, 4,* 506–516.

Perry, T. L., Ivy, M. I., Conner, A., & Shelar, D. (2008). Recreation student attitudes towards persons with disabilities: Considerations for future service delivery. *Journal of Hospitality, Leisure, Sport & Tourism Education, 7*(2), 4–14. doi:10.3794/johlste.72.136

Phelan, J. C., Link, B. G., & Dovidio, J. F. (2008). Stigma and prejudice: One animal or two? *Social Science & Medicine, 67*(3), 358-367. doi:10.1016/j.socscimed.2008.03.022

Rao, S. (2004). Faculty attitudes and students with disabilities in higher education: A literature review. *College Student Journal, 38*(2), 191–198. Retrieved from ProQuest Psychology Journals. (Document ID: 669335921).

Smith, D. D. (2007). *Introduction to special education: Making a difference* (6th ed.). Boston, MA: Allyn & Bacon.

Stanford Encyclopedia of Philosophy (2011). Disability: Definitions, models, experience. Retrieved from http://plato.stanford.edu/entries/disability/

United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. Geneva, Switzerland: Author. Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

World Health Organization. (2010). *Community-based rehabilitation guidelines*. Geneva, Switzerland: Author. Retrieved from http://www.who.int/disabilities/cbr/guidelines/en/index.html

World Health Organization. (2001). International Classification of Functioning, Disability and Health (ICF). Retrieved from http://www.who.int/classifications/icf/en/

World Health Organization and the World Bank. (2011). *World Report on Disability*. Geneva, Switzerland: Author. Retrieved from www.who.int/disabilities/world_report/2011/chapter1.pdf

Yuker, H. E., & Block, J. R. (1986). *Research with the Attitudes Towards Disabled Persons Scales (ATDP) 1960–1985*. Hempstead, NY: Hofstra University.

# Situational Analysis and Development of Inclusive Education in Kenya and Tanzania

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## Abstract

*Education for all children is a fundamental right enshrined in national and international regulatory frameworks. Yet, the right to education does not necessarily imply inclusion. According to the United Nations Children's Fund (UNICEF, 2014), a large segment of children are not in school and have long remained invisible, hidden, and forgotten: children with disabilities. The study aimed to identify key challenges and implementation gaps related to inclusive education in Kenya and Tanzania, and to delineate the extent to which these are being addressed through current and/or planned interventions. The study sample comprised 301 respondents (272 teachers, 24 head teachers, and 4 education officers) from the coastal region of Kenya and Tanzania in eastern Africa. Analyses from government policies, status reports, strategies and plans on inclusive education were incorporated to facilitate discussion. The study found that there was an overwhelming challenge of identifying and documenting disability trends in schools. A second challenge was in provision of training to both professionals and paraprofessionals in Tanzania and Kenya. The study recommends that development partners should first commission a study to determine the true demographics of disability in Tanzania and Kenya, in cooperation with nongovernmental organizations (NGOs), universities, and advocacy groups, and then synergize resources and expertise to ensure true implementation of inclusion in accordance with the tenets of the Community Based Rehabilitation model (CBR).*

Keywords: *Inclusive education, situational analysis, practice, policy, Kenya, Tanzania*

## INTRODUCTION

Education for all children is a fundamental right enshrined in national and international regulatory frameworks. Yet the right to education does not necessarily imply inclusion. According to the United Nations Children's Fund (UNICEF, 2012), a large segment of children are not in school and have long remained invisible, hidden, and forgotten: children with disabilities. These children need to be identified and brought into the mainstream in all spheres of life. Further, inclusion must be supported by an intention to provide quality education and educational opportunity for all. Inclusive education involves restructuring of policies, practices, and attitudes so the needs of diverse learners are appropriately addressed. An inclusive education approach can change school culture and the education system so schools can effectively welcome and educate any child. Inclusive education acknowledges that all children can learn, and that they learn at different rates. It encourages flexible teaching, using different methods to suit various learning and social needs. The significance of inclusive education across the world is captured in UNICEF's justification that:

> …ensuring that children with disabilities have access to inclusive and quality education is critical to reverse the cycles of poverty and exclusion. Moreover, the creation of inclusive education systems for all children is fundamental for achieving universal education goals and realizing the human rights of all children.

It is with this background in mind that CBM[1] sought to support a situational analysis on inclusive education in Kenya and Tanzania. This study's purpose was to identify how CBM can best facilitate and support the access for children with disabilities to quality, child-centered education in Kenya and Tanzania. Findings of this study may benefit learners with special needs in Tanzania and Kenya. Other intended beneficiaries include governments, teachers, parents, and all other stakeholders supporting children and youth with disabilities.

### Objectives

The study was guided by the following objectives:

1. Collect and analyze relevant information with regards to government policies, status reports strategies, and plans on inclusive education.

2. Identify actors supporting the implementation of inclusive education in Kenya and Tanzania.

3. Identify key challenges and implementation gaps related to inclusive education in Kenya and Tanzania.

4. Delineate the extent to which implementation challenges are being addressed through current and/or planned interventions.

5. Make recommendations on interventions and types of support which would be suitable to strengthen Inclusive education in Kenya and Tanzania.

### Overview of Literature

This section highlights the various international status reports on inclusive education across the world and also summarizes the legislative frameworks that guide and monitor implementation of inclusive education in Kenya and Tanzania.

### International Frameworks and Reports on Inclusion

In the year 2000, the world's governments adopted the six Education for All goals and the eight Millennium Development Goals (MDGs)—the two most important frameworks in the field of education. The two frameworks validate Article 26 of the 1948 Universal Declaration of Human Rights that states that, "everyone has the right to education." It is implied in the above frameworks that education is not only a right but a passport to human development; it opens doors and expands opportunities and freedoms. It contributes to fostering peace, democracy, and economic growth as well as improving health and reducing poverty. Thus, there is no excuse to having a group of persons systematically denied this fundamental right to development.

The Convention on the Rights of Persons with Disabilities (CRPD) interprets traditional human rights in a manner that specifically addresses particular issues that are faced by persons with disabilities. The CRPD effectuates a paradigm shift in the context of disability by taking to a new height the movement from viewing persons with disabilities as "objects of charity, medical treatment and social protection" towards viewing them as persons with rights, who are capable of claiming those rights and making decisions for their lives based on free and informed consent. Article 4(3) of CRPD stipulates the involvement of persons with disabilities and their representative organizations in decisions on all issues concerning them. Article 54(1)(c) assures accessibility to the physical environment, to transportation, to information and communications, and to facilities and services that are open to the public (Kurumei, 2012).

In support of the CRPD is the *World Report on Disability* (2011), a joint initiative by the World Health Organization (WHO) and the World Bank Group to provide a comprehensive description of the importance of response made to disability issues. The scope of the report elaborates a complexity of measures to improve accessibility and equality of opportunity; promotes

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[1] CBM is an international Christian development organization whose primary purpose is to improve the quality of life of the world's poorest persons with disabilities and those at risk of disability. CBM works with partner organizations in low-income countries to both develop and ensure that persons with disabilities and their families have ready access to affordable and comprehensive healthcare and rehabilitation programs, quality education programs, and livelihood opportunities. Working with persons with disabilities, CBM advocates for their inclusion in all aspects of society, and for the inclusion of disability in international cooperation. Refer to www.cbm.org for more details.

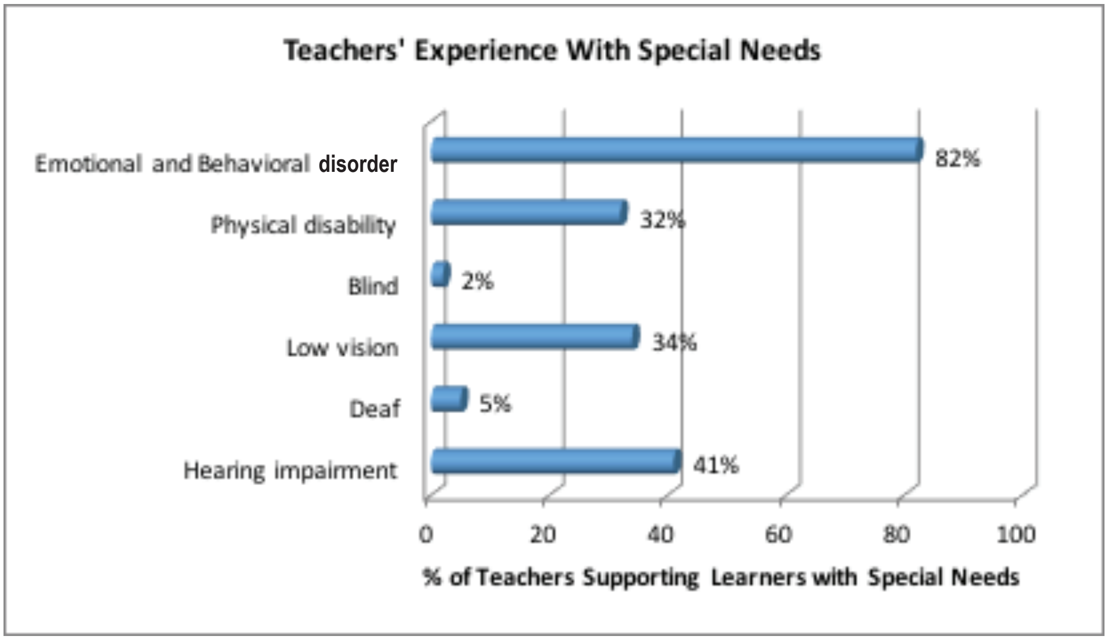
participation and inclusion; and emphasizes respect for the autonomy and dignity of Persons with Disabilities (PWDs). The *World Report on Disability* (2011) estimates the prevalence of disability to be at 15% of the world population. Chapter seven of the report focuses on education and gives key comparative statistics such as the finding that 50.6% of males with disabilities have completed primary school, compared with 61.3% males without disabilities; and 41.7% of females with disabilities having completed primary school, compared with 52.9% of females without disabilities. Such statistics highlight a gap in the enrolment for PWDs in basic education compared to those without disabilities. The African Child Policy Forum (ACPF, 2014) estimates that 75 to 90% of children with special needs in Africa have no access to education. Clearly, there is little empirical information and contradictions of prevalence and access to education for children with disabilities abound through the few studies available in Africa.

***Policy Frameworks on Inclusive Education in Kenya.*** The implementation of inclusive education in Kenya is guided by the above international frameworks as well as by other national frameworks: The National Special Needs Inclusive Education Policy framework; Persons with Disabilities Act, 2003; the Draft National Disability Policy of 2007; the Special Needs Education Policy, 2009; the Constitution of Kenya, 2010; as well as the Education Act, 2013. The 2010 Kenya Constitution, which is the overriding legislative framework in Kenya, commits the government to making sure that people with any sort of disability can access relevant education and training and that all schools are able to include children with disabilities. The Constitution of Kenya has provisions for children's right to free and compulsory basic education, and access to educational institutions and facilities for all persons, including those with disabilities. According to the Constitution, there should be adequate participation and representation of minorities and marginalized groups in all spheres of life. Article 43(1) of the Constitution states that every person has the right to education and Article 53(1)b states that every child has the right to free and compulsory basic education. Article 54(1)b states that a person with any disability is entitled to access educational institutions and facilities for persons with disabilities must be integrated into society to the extent compatible with the interests of the person. Finally, Article 56 on minorities and marginalized groups requires the state to put in place affirmative action programs designed to ensure that minorities and marginalized groups are provided special opportunities in educational and economic fields.

The Draft National Disability Policy of 2007 recognizes disability as a "human rights and a development phenomenon that cuts across all aspects and spheres of society and which requires support from all sectors." One of its aims is to "eliminate disparities in provision of services and ensure that services are available to all citizens with disabilities." The Persons with Disability Act, 2003 recognizes that persons with disabilities face discrimination in various forms and that the government must realize the rights of persons with disabilities as set out in the Act. Article 18 of the Act states that no person or learning institution shall deny admission to a person with disability. The Special Needs Education Policy, 2009, has the mission of creating a conducive environment for learners with disabilities to have equal access to quality and relevant education. Tenets of the above-mentioned guidelines are enshrined in the Education Act (2013), which outlines the need to increase access, enhance retention, improve quality and relevance of education, strengthen early identification and assessment, and ensure equal opportunities in provision of education for children with disabilities. The Education Act (2013), Article 44(4) states that the cabinet secretary will ensure that every special school or educational institution with learners with special needs is provided with appropriately trained teachers and non-teaching staff, infrastructure, learning materials, and equipment suitable for learners with disabilities. Article 46(1) cites the duty of county education boards, in consultation with relevant county government, to provide for Education Assessment and Resource Centers (EARCs), including special needs service clinics to study children with special education needs, advise parents and teachers on appropriate education methods, and advise county education boards on assessing the needs of any child. It is evident that Kenya has all the relevant frameworks to ensure that inclusive education succeeds.

***Policy Frameworks on Inclusive Education in Tanzania.*** Tanzania's implementation of inclusive education is mainly guided by the international frameworks on inclusive education as detailed previously in this section. Implementation is also in line with guidelines detailed in the National Strategy on Inclusive Education (2012). The strategy aims at contributing towards the goals set in line with the Education Sector Development Programme (2008-2017), which emphasizes inclusion as a key strategy to achieve universal and equitable

Figure 1
*Teachers' Experience with Special Needs (Kenya).*



access. The overall goal of the National Strategy on Inclusive Education (2012) is: All children, youth, and adults in Tanzania have equitable access to quality education in inclusive settings.

By implementing the National Strategy on Inclusive Education, it is expected that:

1. Educational policies and programmes are informed by inclusive values and practices.
2. Teaching and learning environments respond to the diverse needs of learners.
3. Educational support is available to all learners.
4. Adaptations, accommodations, and modifications become a norm in inclusive special needs education.
5. Professional capabilities for inclusive education are widened and strengthened.
6. Community ownership of, and participation in, inclusive education is enhanced.

Strategic areas of action that need to be strengthened to boost implementation of inclusive education were highlighted from the above objectives. They include: (i) reinforcing the presence, participation, and learning of all learners in inclusive settings through legislation and policies, (ii) strengthening institutional arrangements for effective implementation of inclusive education, (iii) reviewing and redesigning resourcing and financing for inclusion and educational support, (iv) developing curricula and learning materials that promote differentiation and support learning, and (v) developing an inclusive assessment and evaluation system for learners and teachers. Other strategies include developing institution-based educational support, initiating curriculum revision and teacher (re)training, and developing effective intervention mechanisms for increasing participation of learners with disabilities/vulnerable learners, and establishing educational support resource centers.

## METHODS

### Setting

The present study was carried out between May and June 2015 in both urban and rural areas of Kenya and Tanzania. In Kenya, the study was carried out in Mombasa County, while in Tanzania data was collected in Tanga, Tabora, and Shinyanga Municipalities. Information was sought from respective Ministries of Education at county, regional, and district levels. Specifically, government primary schools and pre-schools with inclusive settings were targeted.

### Target Population and Sample

Teachers, head teachers, and education officers were the key respondents. A total of 386 respondents were targeted to participate in the study. A total of 301 respondents were reached (272 teachers, 24 head teachers, and 4 education officers). This formed a response rate of 78% of the anticipated sample.

### Study Design

The study employed a triangulated methodology that incorporated both qualitative and quantitative techniques. The study commenced with a comprehensive desk review of selected documents to determine duality and/or gaps in regulations between and across Tanzania and Kenya. Further, key informant interviews (KIIs) were conducted to gather information from resourceful persons and questionnaires were filled by teachers across the two countries. The study was also informed by physical observation of inclusive practices within the sampled schools. All tools were structured to address attitudes, perceptions, and experiences in five key areas: curriculum implementation, collaboration, support for inclusive education, attitude towards inclusion, and training in special needs. The teachers' questionnaire was pilot tested in one school in Kenya and one school in Tanzania outside of the study sample.

Data collected in this study was both qualitative and quantitative. Analysis was done within the study thematic areas as envisioned in the objectives of the research. Quantitative data was coded and entered in Excel spreadsheets to allow for computation of descriptive statistics to present trends and patterns of perceptions and practices in inclusive education. Analyses from government policies, status reports, strategies, and plans on inclusive education were incorporated to facilitate the situational analysis of inclusive education. It was not in the interest of this study to carry out a comparative study between Kenya and Tanzania; for this reason, findings from Kenya and Tanzania are presented separately. It was foreseen that such analysis would yield more country-specific interventions to inform decision-making with specific reference to the various contexts in the regions under study. Furthermore, analysis was predominantly based on teachers' responses; however, where interesting trends or discrepancies were noted, insights from head teachers, Ministry of Education officials, and field observations were incorporated.

## FINDINGS AND DISCUSSION

### Situational Analysis of Inclusive Education in Kenya

Data was collected from 2 Ministry of Education officials (County Directors of Education), 157 teachers, and 12 head teachers in selected locales.

### Perspectives from the Ministry of Education

County Directors of Education reported that it is the mandate of the Ministry to ensure education for all children and that the inclusion policy is enforced; they further reported that the Ministry supports inclusion and the need for special needs children to learn with peers in a regular classroom. A major success highlighted was that special needs learners were no longer as stigmatized as they were before. However, not many schools were reported to have the capacity to implement inclusion, especially private schools, which rival public schools in number. Respondents felt that parents were

Figure 2
*Teachers' Attitude Towards Collaborative Teaching (Kenya).*

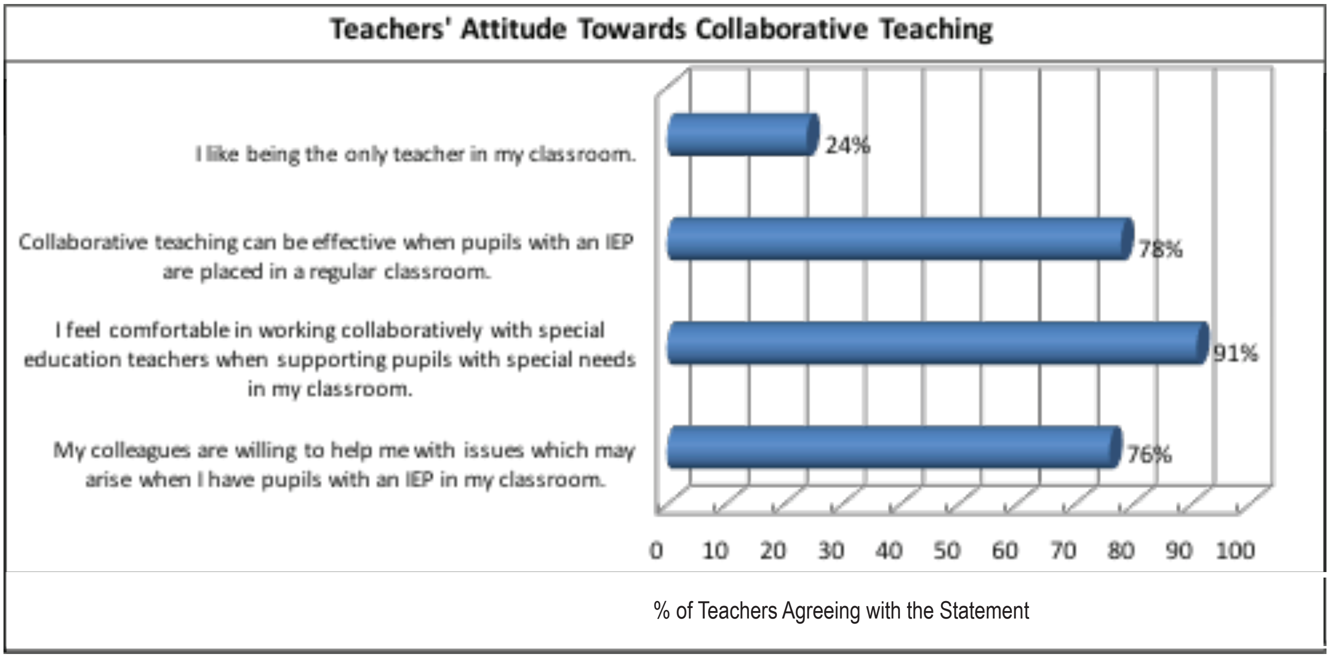
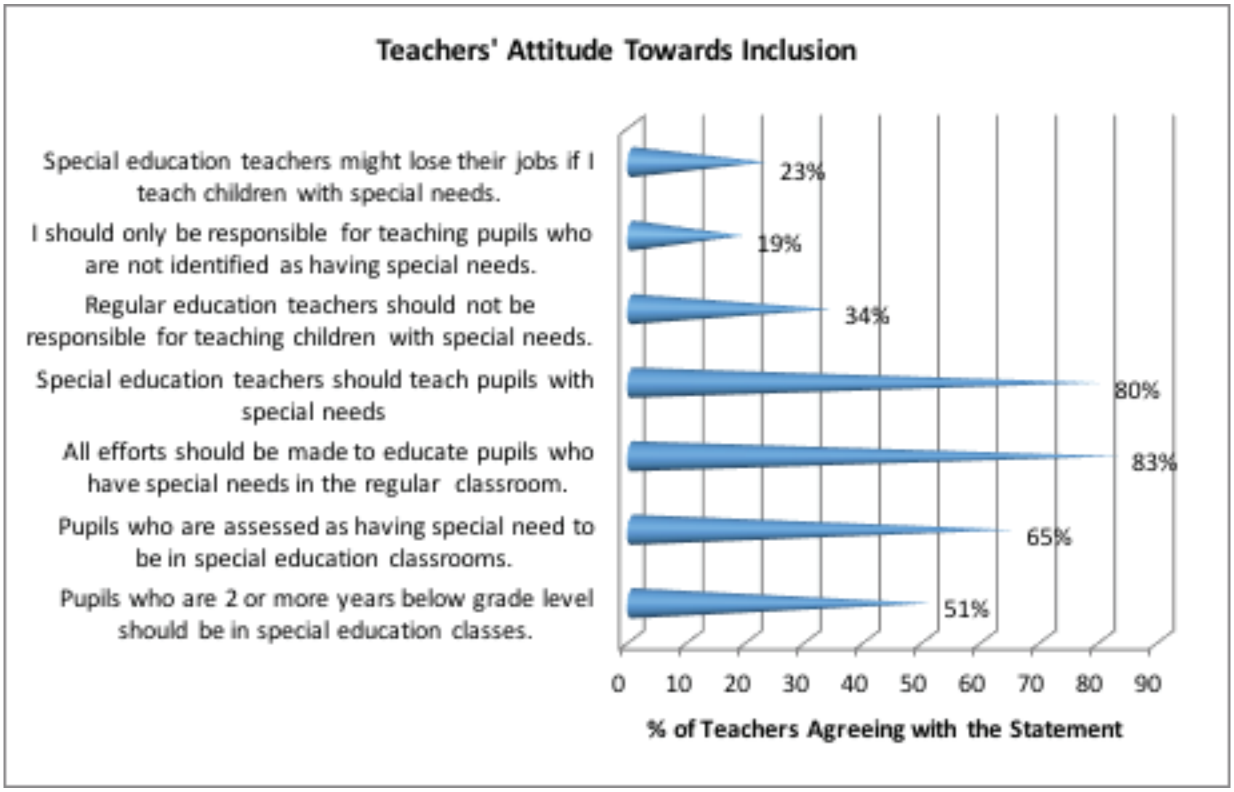


Figure 3
*Teachers' Attitude Towards Inclusion (Kenya).*



supportive of their children as often they took them to school, helped them with homework, and provided learning materials. Major challenges facing inclusion were identified as negative attitudes towards inclusion, poor infrastructure in schools, inadequate number of teachers coupled with high enrollment rates in schools, and lack of personnel trained in special needs. It was felt that more support was needed from nongovernmental organizations (NGOs) and faith-based organizations, as they could engage closely with communities and are able to resolve many deep-seated societal issues from the bottom up.

### Perspectives from Schools

In Kenya, data were collected from schools in Mombasa County. Six of the schools were located in urban/semi-urban areas while the other six were in rural areas. From within the schools, the study determined that in each of the sampled schools, there was an average of 20 teachers; of these about only four were trained as special needs teachers. A majority of the teachers (61%) were female while 39% were male. Further, the teachers were profiled on the basis of their age; it was found that 33% of the teachers were of age 35 years and below, 38% were 36-45 years, and 29% of the teachers were above 46 years. Among the head teachers, 50% were female and 50% were male. They were all above 36 years of age. When asked about their highest level of training, teachers reported that 9% had Ordinary or "O"-level training, 30% had attained a Certificate, 31% were Diploma holders, 9% were degree holders, and 21% had postgraduate training. However, 50% of the head teachers had a training of diploma while the other 50% were trained beyond diploma level. A majority of the teachers (56%) were teaching upper primary school, while 35% were teaching lower primary. Only 8% of the sampled teachers were teaching in pre-school, while 1% of the teachers were teaching learners in Special Units.

One of the study's objectives was to discover stakeholders' experience with special needs. From teachers' perspectives, as depicted in Figure 1, only 2% of the teachers reported that they support learners who are blind, 5% teach learners who are deaf, 32% engage with learners with physical disabilities, while 41% support learners with hearing impairment.

***School Experience with Special Needs.*** An interesting finding of this study was that 82% of teachers supported learners with emotional and behavioral disorders. This fact was echoed by the responses from the head teachers. It is important to note that many stakeholders often overlook behavioral and emotional disabilities and often aim to provide solutions for physical access by removing physical barriers. Considering the changes in educational policies in the recent past (e.g. banning of caning, free primary education, inclusion itself), teachers are now faced with large class sizes and a lack of capacity to control the diverse learners; many teachers also have limited experience with alternative behavior management strategies.

A second significant finding was that in almost all schools, management was unable to give exact statistics of the various disability categories in their schools. The researcher considered this a glaring gap that could delay inclusion implementation, since schools cannot make strategic plans without a situational analysis of their learners' needs. Considering that head teachers reported an average of up to 20 years of work experience with special needs, it is disconcerting that many have not seen the need to plan with statistics.

All the same, 70% of the head teachers responded that their schools can be classified as inclusive, while 30% responded in the negative. Those who termed them as inclusive intimated that teachers have been adequately trained and that learners' individual needs are taken into consideration when teaching. However, head teachers mentioned that they do not get relevant support and this dilutes the effectiveness and practicality of inclusion.

***Attitude Towards Collaborative Teaching***. This study also sought to determine teachers' attitude towards collaborative teaching. Findings (as shown in Figure 2) were all positive, as 91% of the teachers reported that they felt comfortable working collaboratively with special needs education teachers in inclusive classrooms. In addition, 78% felt that collaborative teaching could be effective when pupils with an Individualized Education Plan (IEP) were placed in a regular classroom. And 76% of teachers reported that they got assistance from the special needs teachers in developing an IEP. Such findings are very encouraging as they are an entry point for CBM and other stakeholders to support special needs teachers since they are a solid pillar in supporting inclusion in the school; other teachers look to special needs teachers for guidance and therefore their capacities must be enhanced for inclusion to succeed.

***Attitude Towards Inclusion.*** The role of the contemporary teacher in the classroom is changing drastically, and so must his/her attitude. Teacher attitude towards inclusion is a compounding factor because attitude influences behavior towards, and acceptance of, special needs children in the learning environment. As shown in Figure 4, a large majority of teachers (83%) believed that special needs pupils should be placed in a regular classroom. Yet 80% of the teachers were also of the opinion that special needs teachers should teach learners with special needs. In essence, the message from

Figure 4
*Curriculum Implementation (Kenya).*

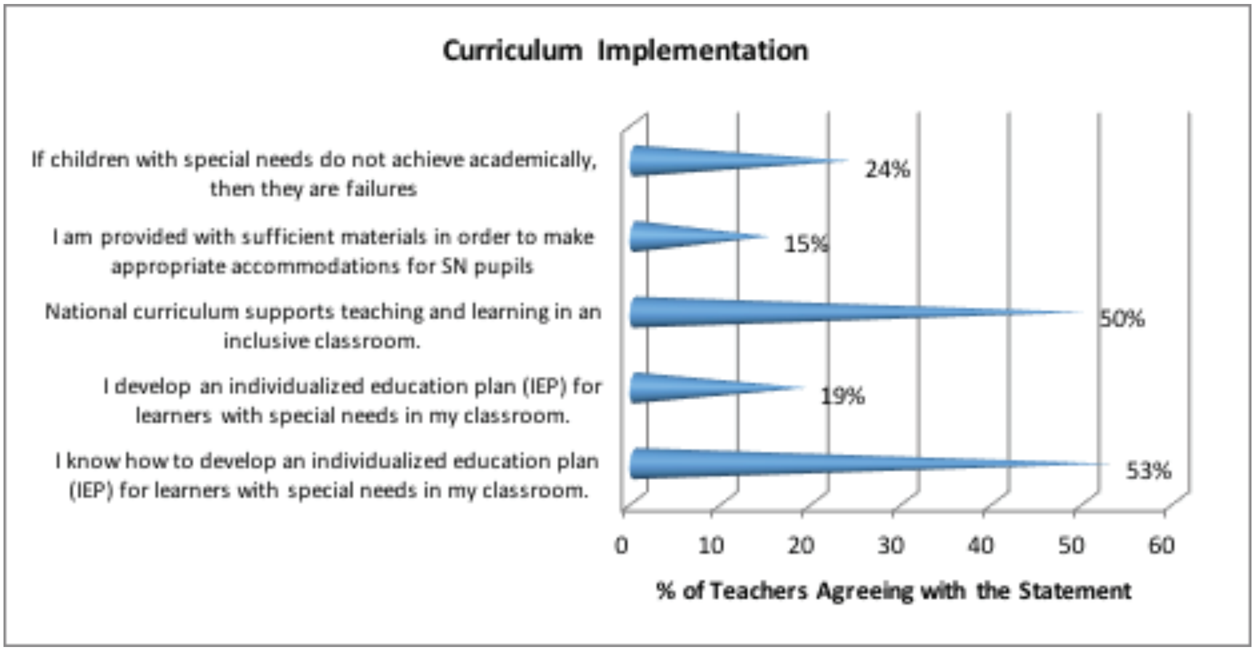
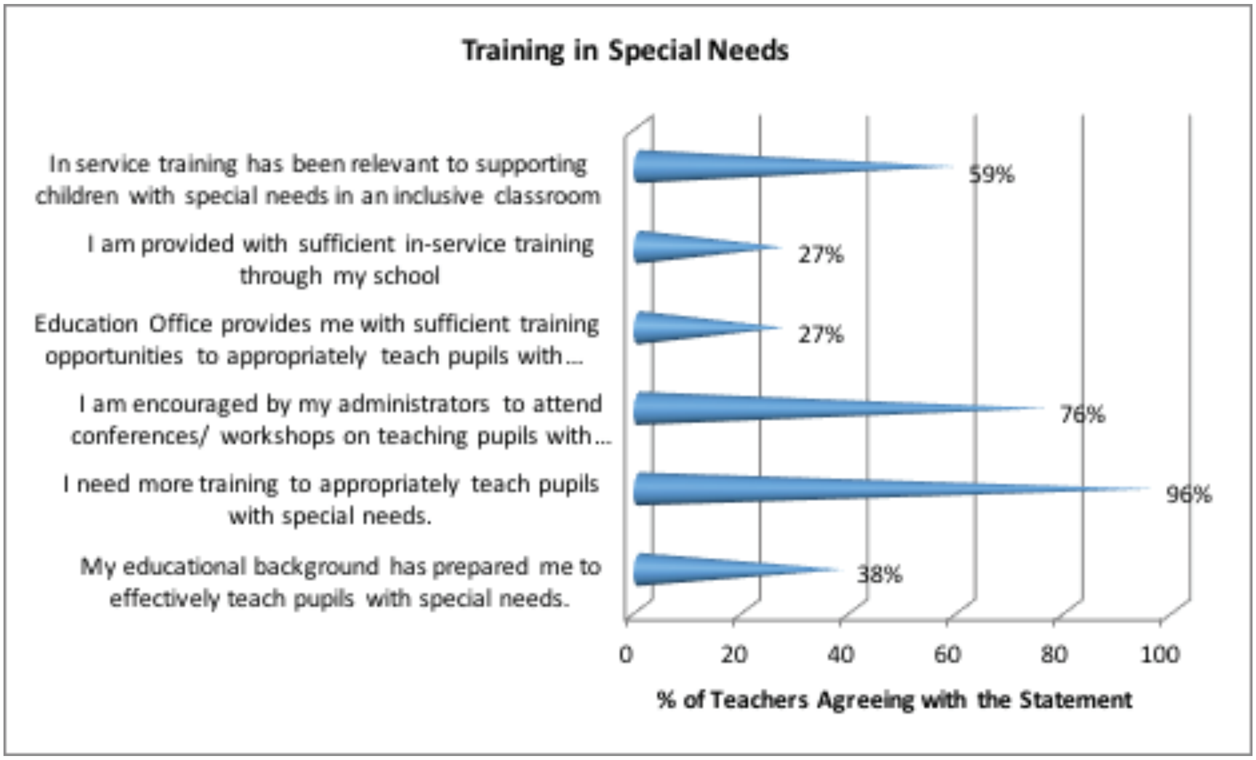


Figure 5
*Training in Special Needs (Kenya).*



respondents is that inclusion is paramount and every teacher should be equipped to support the education of children with special needs. However, 65% of respondents came out clearly to say that learners with special needs should be in special education classrooms, a finding that was corroborated by the 34% of respondents who indicated that regular classroom teachers should not be responsible in teaching learners with special needs. Perhaps equipping all teachers with the relevant skills will placate the 34% who do not support inclusion as a workable solution to education for all. Attitude is the third wheel to social change (the others being experience and perception); teacher attitudes must be taken into serious consideration for them to accept that inclusion is viable.

Head teachers agree that all efforts should be made to ensure that pupils with special needs are in their neighborhood school.

***Curriculum Implementation.*** Curriculum differentiation is one significant key to the success of inclusive education. Teachers must be equipped with the skills and knowledge to adapt the curriculum to the range of learners' needs. A fundamental question posed in this study was whether the national curriculum supported inclusion? Respondents were evenly split as 50% agreed while 50% disagreed (see Figure 6). Among the head teachers, 40% were of the opinion that national curriculum did not support inclusion. Furthermore, only 53% of the teachers responded that they knew how to develop an Individualized Education Plan (IEP) for learners with special needs. A more worrying finding was that although 53% know how to develop IEPs, only 19% of the teachers actually develop IEPs for their learners. It is not surprising then that almost one quarter of the respondents (24%) felt that children with special needs who do not achieve academically are failures.

As aptly captured by one respondent, "… the education system's focus is exam-oriented, dwelling on merit and mean score, and not learners' performance at their level." Among the five aspects of inclusion captioned in this study, the indices on curriculum implementation are the lowest — an indication that the weak link in inclusive education is curriculum implementation. Three terms come to the fore when inclusion and curriculum implementation are mentioned: adaptation, accommodation, and modification. Without exception, all curriculum implementers must understand these terms and know when to apply them to achieve full inclusion.

***Training in Special Needs***. One of the objectives of this study was to investigate the levels of teacher training in special education. Figure 5 depicts that 38% of teachers believed they were adequately prepared to handle learners with special needs. Teachers also intimated that they do not get sufficient in-service training; this, when combined with a previous finding that a certificate was the highest qualification for about 70% of them, shows the dire need for training in these schools.

On the other hand, about 60% of those who received in-service training indicated that the training was relevant to supporting inclusion. The teachers further indicated that their administrators encourage them to attend trainings. And finally, 96% of teachers indicated that they need more training in special needs. The above indices all point to the opportunity presented to policymakers and development partners that most teachers know their skills are lacking, their schools would support them if opportunity arises, they believe training will make them better teachers, and they are willing to take the required training.

***Stakeholder Analysis***. The success of inclusive education lies in partnering and collaboration. Various partners include the Ministry of Education, development partners, teachers, family, and the learners; they must all pull together to acheive the intended goals. For this reason, one of the objectives of this study was to determine the support received in implementation of inclusive practices. From Figure 3, it is evident that 75% of the teachers reported that they receive support from parents of learners with special needs. On the other hand, according to head teachers, parents are only supportive "after intensive follow-up." Parental support is paramount, as their role throughout the child's life cannot be underestimated; the family has a greater understanding of the child's disability and they are the first link to the child's transition back into society when the student leaves school. Further, 87% of the teachers reported being able to approach their school administration about teaching special needs learners. However, only about half (51%) get the support they require from their administrators on challenging issues when teaching learners with special needs. Head teachers also intimated that support from the community was not adequate; although the communities often support the existence of the school in the locality, there have not been opportunities for regular engagement with the school. The schools further reported that they do not get much support, especially for referral systems, resources (e.g. environmental modification, hearing aids, sunscreen, feeding program, equipment that supports curricula activities), and support from paraprofessionals.

The discrepancy in figures for those who are able to raise issues and those who actually get the support is a point for concern as repeated lack of support often leads to frustration and inaction, both of which can kill the concept of inclusion. On the other hand, it is encouraging to note the support given by parents; this is a strength that can be enhanced to enrich the school experience for learners with special needs. An analysis by the head teachers showed that inclusion receives much more support from parents who have children with

Figure 6
*Support Received by Teachers (Kenya).*

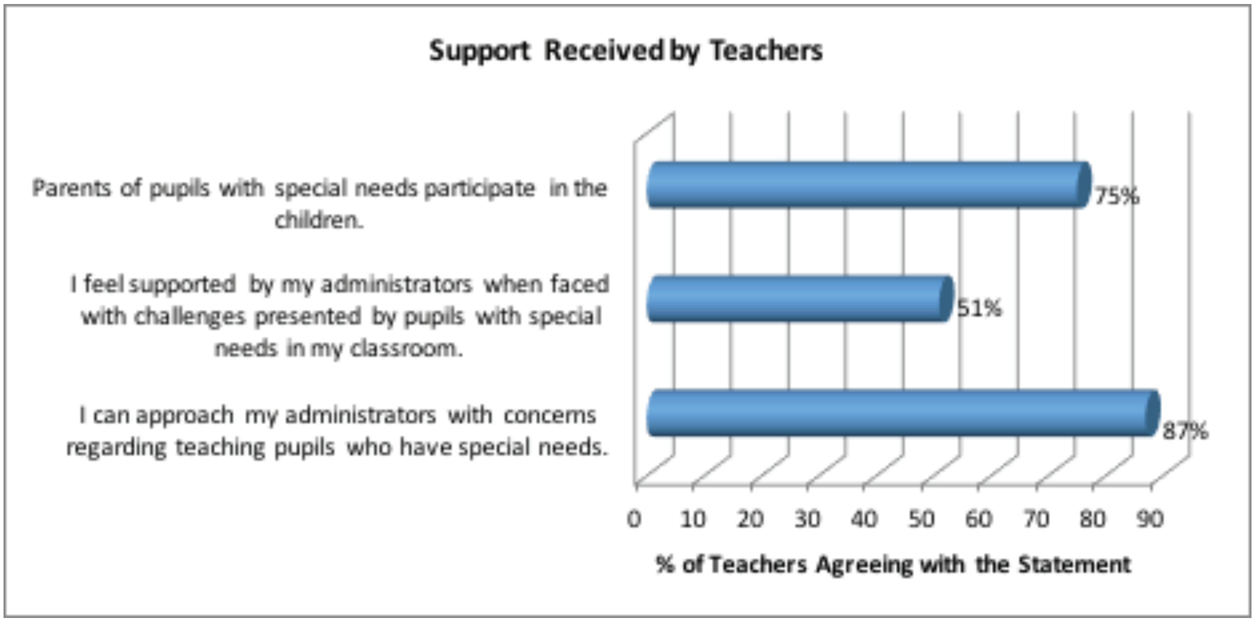
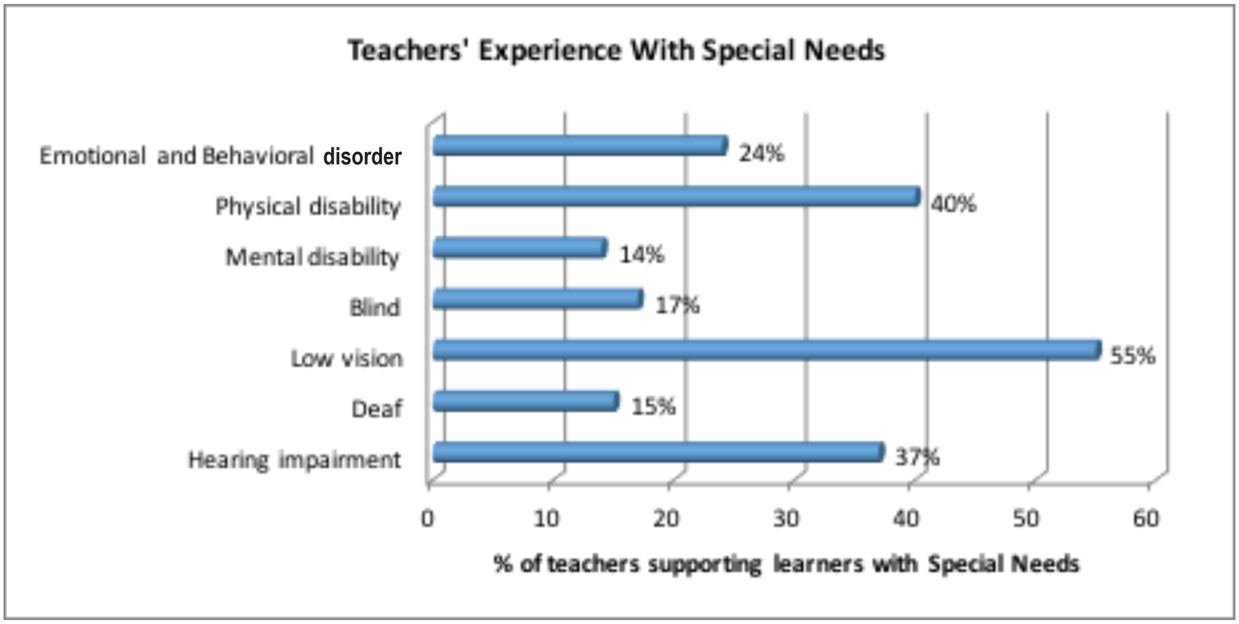


Figure 7
*Teachers' Experience with Special Needs (Tanzania).*



special needs than those who have no special needs children. This again is an entry point for development partners to step in and support schools by providing resources and working towards changing attitudes of the wider community.

### Situational Analysis of Inclusive Education in Tanzania

Tanzania conforms to several national and international instruments that articulate issues and rights of persons with disabilities, such as educational rights as stipulated in the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol from 2006. These instruments are meant to protect the rights of children, who constitute 51% of the total population — 3.5% of whom are children with disabilities. Tanzania has 28 regions (Mikoa). Tanga is located in the northern part of Tanzania while Tabora and Shinyanga are in the west. Tanga has 56 primary public schools; eight of them have an inclusive environment. The study sampled six government inclusive schools in the Tanga Region. Tabora municipality and Shinyanga municipality were also sampled. Tabora region has 78 public primary schools and two special primary schools (one for the deaf and hard-of-hearing and another for the blind and low vision). It has three officially-recognized inclusive primary schools, each with a unit of children with special education needs. Shinyanga region has 577 primary schools and there are 56 schools in Shinyanga Municipality. The municipality has three officially-recognized inclusive schools, two of them have units of children with special needs.

There are other schools with children with special needs. However, given that the numbers of pupils in those schools are small (in many cases less than 10), they are not officially recognized.

### Demographic Profile of Respondents

Respondents in Tanzania were District Education Officers (DEOs), teachers, and head teachers. Four DEOs and 12 head teachers were interviewed. Further, 115 teachers filled the teachers' questionnaire. From the schools the survey reached, 69% of the teachers were female and 31% were male. Their age profiles showed that 31% were aged below 35 years, 69% were between 36 and 55 years while 10% were above 55 years. It was also found that most (70%) teachers in the study had a certificate as their highest level of education. Some 18% had O-level/high school, 9% had a Diploma, 2% had a degree, and 1% had a master's degree as their highest level of education. Concerning the level at which they teach, 18% of the respondents in Tanzania reported teaching at the preschool level, 25% teach lower primary, 46% teach the upper primary level, while 11% teach at the special unit.

**Perspectives from the Ministry of Education**

District officers in Tanzania reported that the Ministry supports inclusion of special needs children in regular classrooms. They agree that the Ministry has a mandate to avail relevant infrastructure, put in place relevant policies, and to rally communities to support special needs children. A major success highlighted was the high number of special needs learners enrolled in schools and the decrease in stigmatization across the entire society. It was felt that parents are supportive of their children as often they take them to school to ensure their safety and security, and parents participate willingly in various school projects proposed for the learners. Major challenges facing inclusion were identified as the high enrollment rates in schools, lack of personnel trained in special needs, and poor infrastructure and resources. It was reported that good support was received from faith-based organizations in the form of food, books, and material supplies. In the DEOs' opinion, the most effective strategy for ensuring effective inclusion is more infrastructure spending (e.g. building of more classrooms, employing more teachers, and sensitizing teachers to train for special needs). Partners reported to be supporting Ministry inclusion in Tanga, Tabora, and Shinyanga were largely the Christian Mission Fellowship that provides food and bedding; YDCP (Youth with Disabilities Community Program) that restructures built-up environments and trains teachers; and PASADIT (A Catholic Church Initiative) that sensitizes communities on child rights.

**Perspectives from Schools**

***Experience with Special Needs***. District Education Officers were certain that inclusion was a positive step, as the numbers of children with special needs have increased significantly over the years. In their view, this showed that parents are finally beginning to trust the education system to improve the lives of children with disabilities. Head teachers reported that, on average, they had 13 years teaching experience with special needs. On average, the schools had about 22 teachers attending to all the learners within the school. Most head teachers reported that none of their teachers had been trained in special needs (with the exception of Pongwe and Kisosoro, which has up to 10 trained teachers). Head teachers also reported that parents are supportive of their children and often provide basic learning materials, despite the poverty that surrounds them. From teachers' perspective, as shown in Figure 7, 55% of all respondents in Tanzania have experience in teaching children with low vision. Some 40% of the teachers have taught learners with physical disability,

Figure 8

*Attitude of Teachers Towards Collaborative Teaching (Tanzania).*

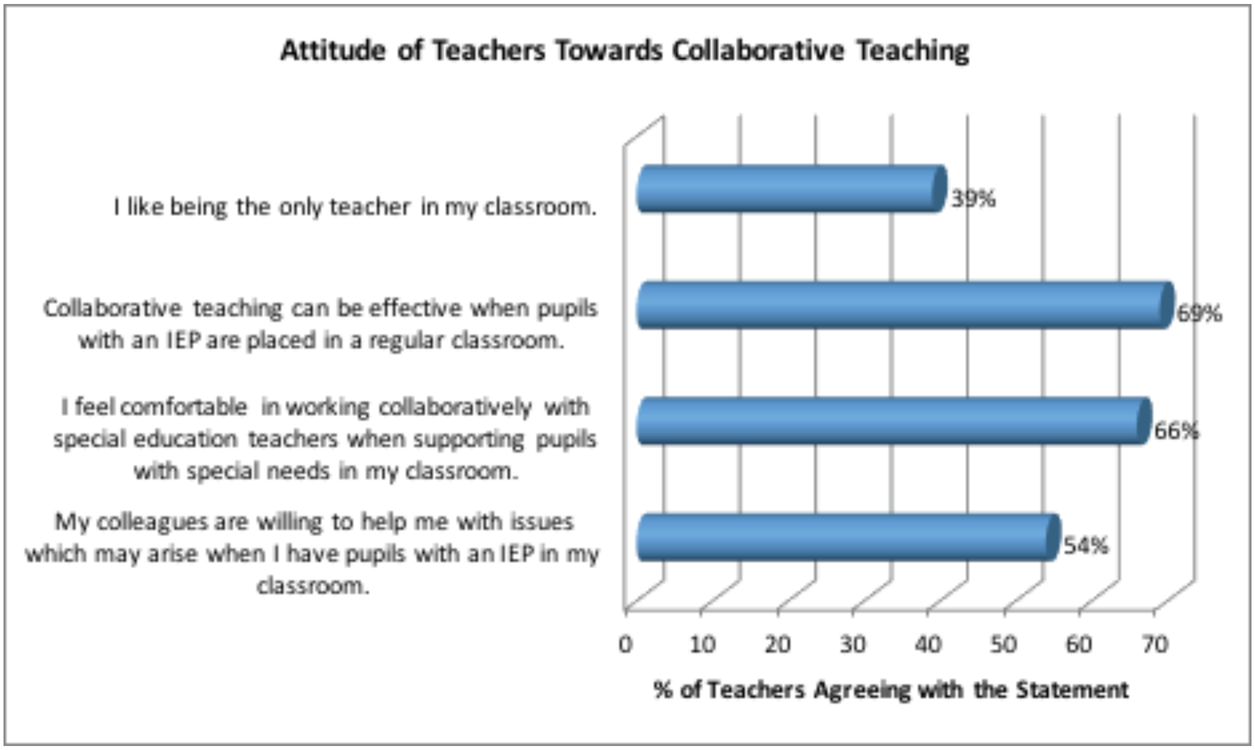
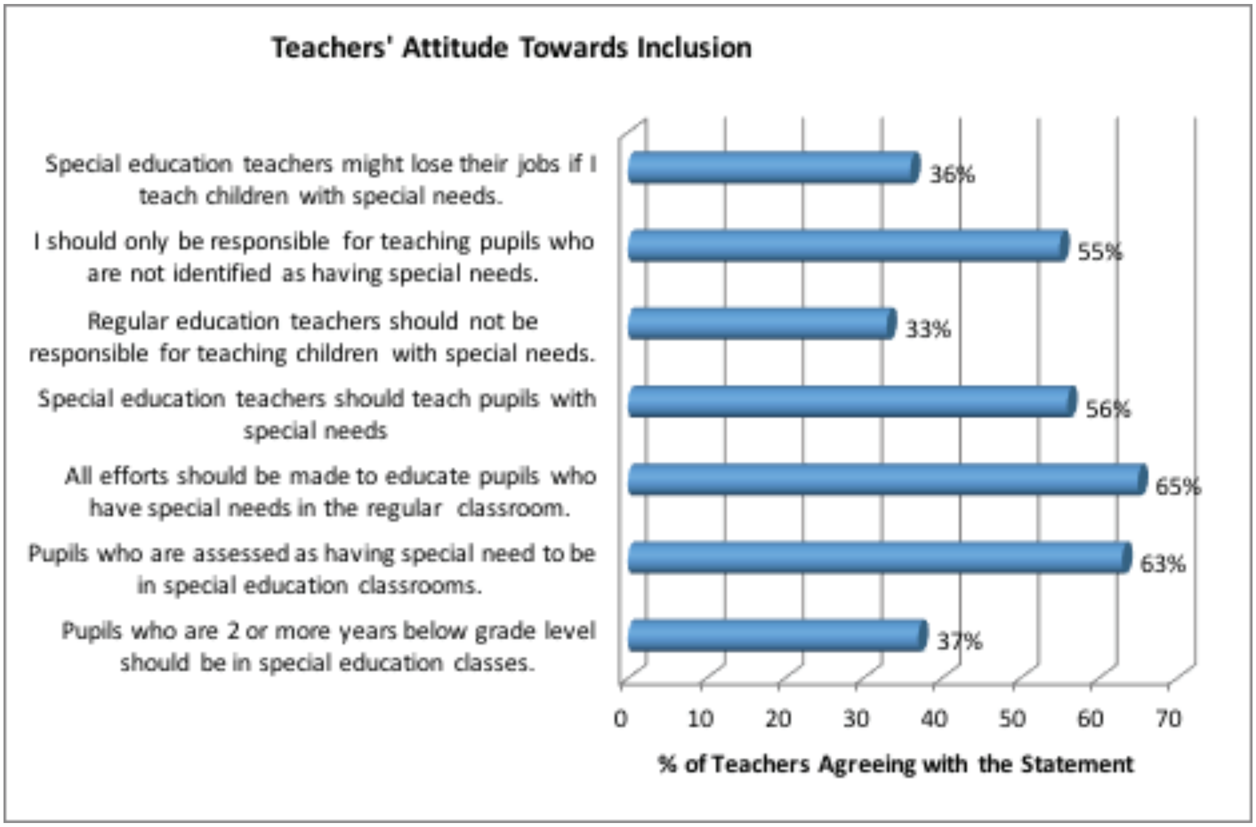


Figure 9
*Teachers' Attitude Towards Inclusion (Tanzania).*



37% of teachers have experience with hearing impairment learners, 24% with emotional and behavioral disorder, 17% with blind learners, 15% with deaf learners, and 14% with mental disabilities. For the Tanzanian teacher, physical impairments seem to be the larger aspect to focus on.

***Attitude Towards Collaborative Teaching***. Head teachers are very positive about collaboration among teachers in teaching inclusive classrooms; none of them responded that collaborative teaching is not effective. With support from Ministry, there seems to be general support for inclusion.

Figure 8 depicts that most teachers (69%) stated that collaborative teaching can be effective when pupils with an IEP are placed in a regular classroom. On the other hand, almost two-fifths (39%) of the respondents reported that they like being the only teacher in the classroom; this is a statistic to be concerned about since effective inclusion requires collaboration. All the same, it is encouraging that 66% of the teachers feel comfortable working collaboratively with special education teachers when supporting pupils with special needs in their classroom. Yet only about half (54%) reported that their colleagues are willing to help them with issues which may arise when they have pupils with an IEP in their classroom. Evidently, from the foregoing indices, there is need to enhance collaborative teaching to synergize existing and potential capacities.

***Attitude Towards Inclusion***. Attitudes in Tanzania were positive, with 65% of teachers in the study agreeing that all efforts should be made to educate pupils who have special needs in the regular classroom; however, almost a similar figure (63%) reported that pupils who are assessed as having special needs need to be in special education classrooms (See Figure 10). In essence, the idea of inclusion seems to split teachers right down the middle. However, when the question was posed about pupils who are 2 or more years below grade level, only 37% of teachers felt that they needed to be placed in special education classrooms. Further, 56% of teachers in the study agree that special education teachers should teach pupils with special needs, while 55% agree that they — regular education teachers — should only be responsible for teaching pupils who are not identified as having special needs. From these responses, it is important that policymakers keep in mind that inclusion is a social movement and that attitude is one of the engines of this movement. Attitudes, misconceptions and perceptions of teachers need to be addressed for inclusion to be fully implemented.

***Curriculum Implementation***. Indices on curriculum implementation, as shown in Figure 11, present an entry point for stakeholders, especially development partners, to engage with teachers. Almost half (48%) of the teachers in the Tanzania study agree that they know how to develop an Individualized Education Plan (IEP) for learners with special needs in their classroom and 43% reported that they do develop IEPs. These statistics imply that more than a large percentage of teachers who know how to develop an IEP actually do prepare such plans. This assertion was supported by 80% of head teachers who said their teachers do prepare IEPs. This finding is important and encouraging, knowing that curriculum differentiation is the key to inclusion. More crucial was the depiction by the larger percentage of respondents (74%) that the national curriculum does not support teaching and learning in an inclusive classroom. Further, the study also found that only 20% of teachers are provided with sufficient materials in order to make appropriate accommodations for pupils with special needs. Given these weaknesses in curriculum implementation, it is not surprising that 46% of teachers agreed that if children with special needs do not achieve academically, then they are failures. Being that the curriculum is not inclusive-friendly, children with special needs are predestined never to realize their potential.

***Training in Special Needs***. Among the head teachers, a majority intimated that they have not been adequately trained to support learners with special needs. Among the teachers, only 39% agreed that their educational background had prepared them to effectively teach pupils with special needs (See Figure 12). Further, only about 40% of teachers in the study agreed that they were provided with sufficient in-service training through their school or by the Ministry. Among those trained, 52% reported that their in-service training had been relevant to supporting inclusive learning. It is a positive finding that 57% of teachers agreed that they were encouraged by their administrators to attend conferences/ workshops on teaching pupils with special needs. And even better is the opportunity presented by the finding that 73% of teachers agreed that they needed more training to appropriately teach pupils with special needs. Generally, teachers in Tanzania reported that their experience with inclusion was positive, especially due to cooperation among teachers and because stigmatization has reduced over the years.

***Stakeholder Analysis***. As highlighted in the section on stakeholder analysis, the success of inclusive education lies in partnering and collaboration. Tanzania's

Figure 10
*Curriculum Implementation (Tanzania).*

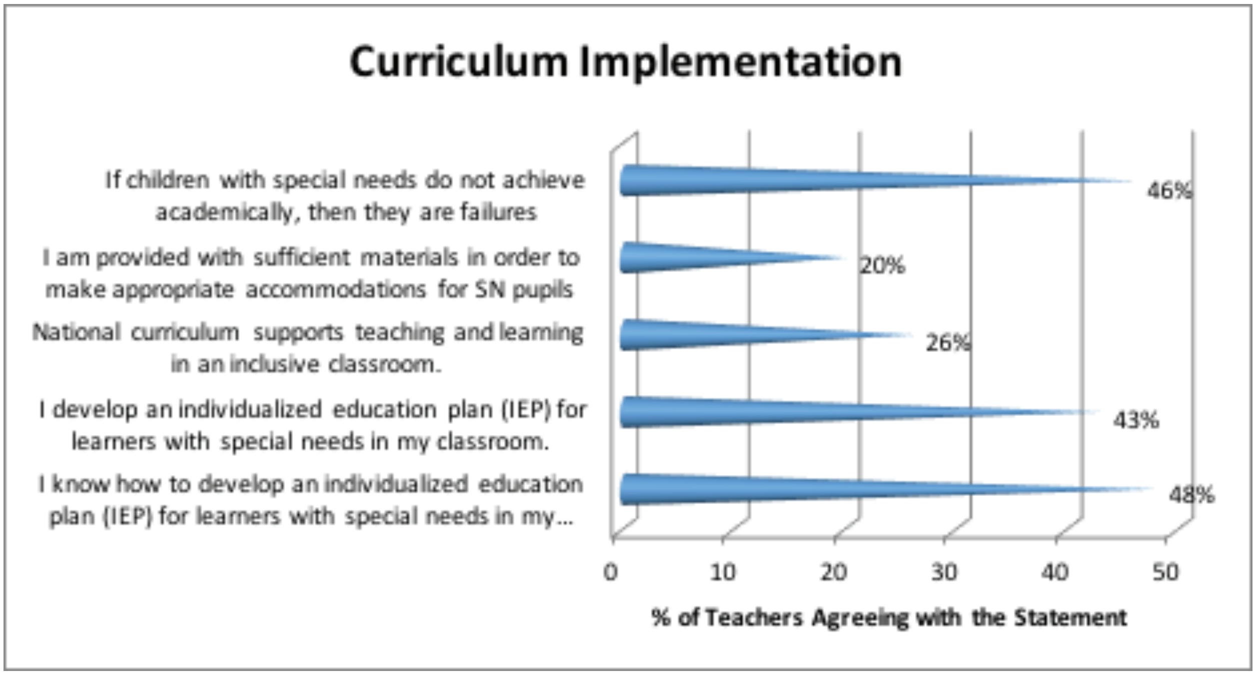
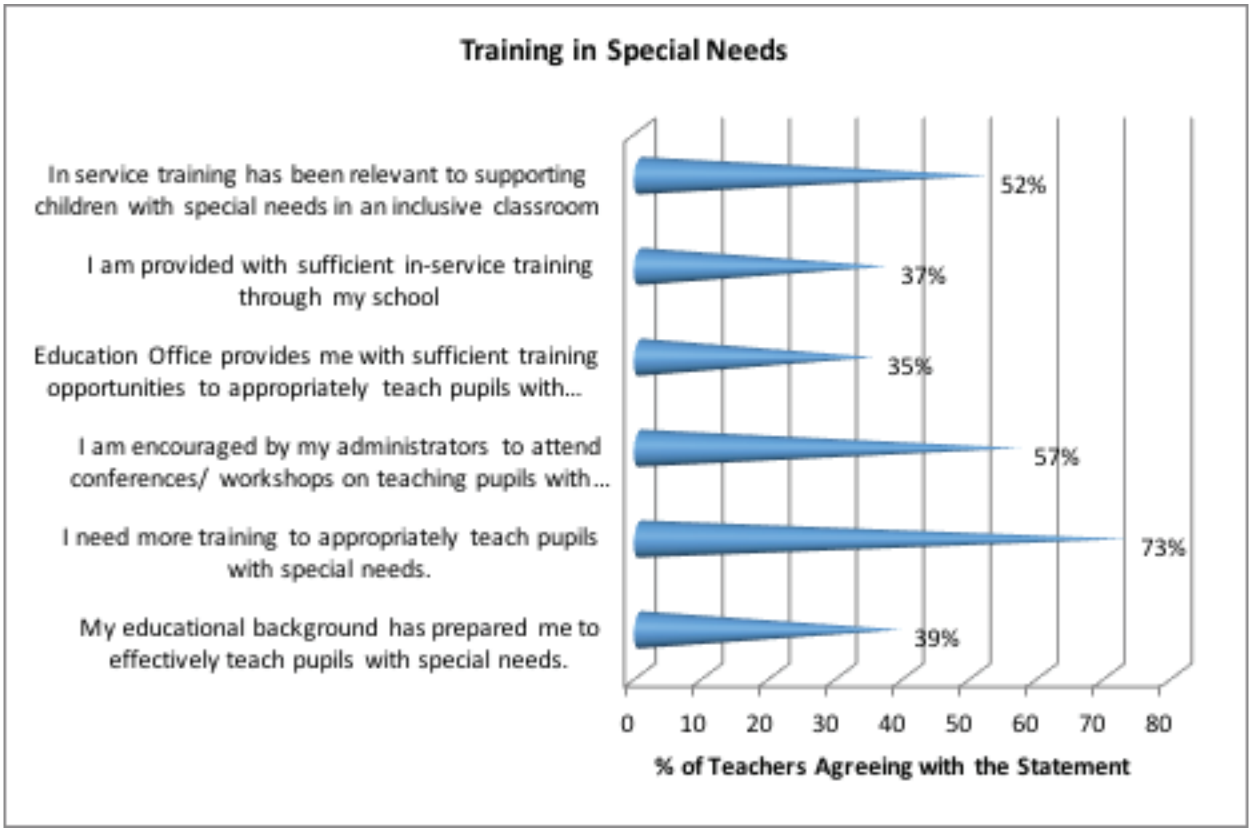


Figure 11

*Training in Special Needs (Tanzania).*



teachers reported that they have a working network of stakeholders that support inclusion. Figure 9 shows that 77% of teachers reported that parents of pupils with special needs participate in their children's learning. A clear majority (64%) of teachers in the study feel supported by their administrators when faced with challenges presented by pupils with special needs in the classroom. And 63% agreed that they can approach their administrators with concerns regarding teaching pupils who have special needs. These are encouraging findings, since it is this kind of support that will ensure successful implementation of planned interventions.

## Recommendations

The following recommendations are based on a synthesis of the current study, policy and practice review, observations in 24 schools, and substantial understanding of the change process in inclusion practices.

*Recommendation 1: Awareness*. Given societies' historical and prevailing attitudes towards disability, a comprehensive campaign of public awareness, identifying the gifts and potential contribution of persons with disabilities to the community, is a good way to start.

a. Persuade organizations to support the development of an awareness program that can provide a basic understanding of disability by airing human interest stories and success stories of persons with disabilities (PWDs) in local newspapers weekly and in key media spots to depict PWDs in a positive light.

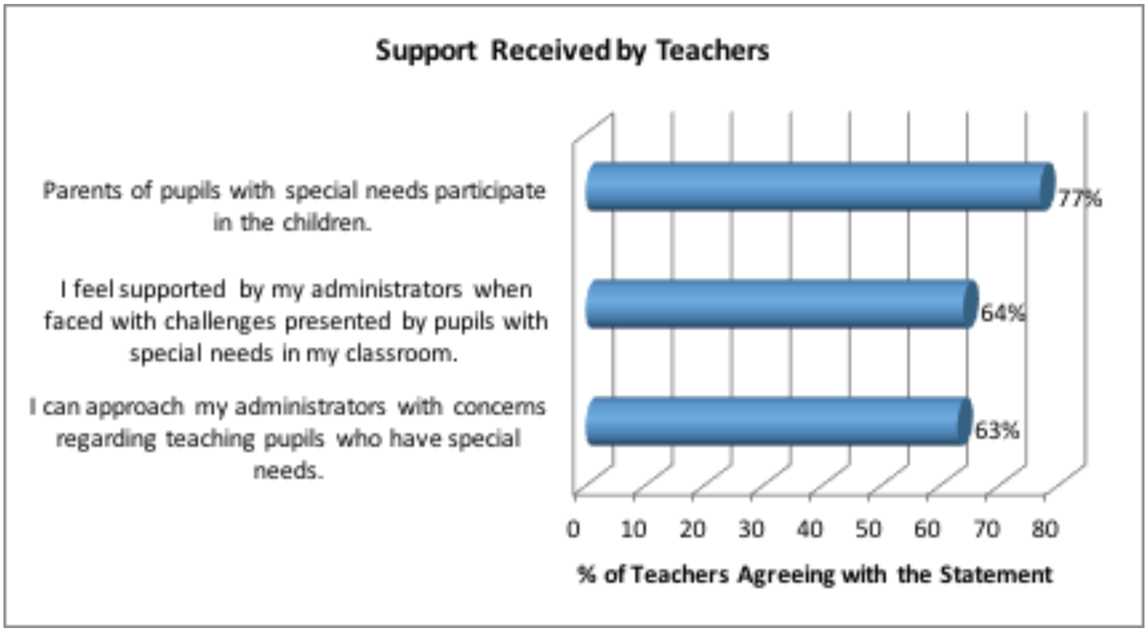
b. Fund universities and other training institutions to hold forums for potential teachers, social workers, and faculty to raise awareness of disability issues, at the national, community, and school levels.

c. Initiate the Burden of Care Model using parent forums in pilot areas in Tanzania and Kenya to encourage parents and caretakers of children living with disability to share their experiences.

d. Ask CBM to sponsor the training of advocacy groups to apply the Community Based Rehabilitation (CBR) Model to ensure the inclusion principle infuses all support given.

*Recommendation 2: Training*. Given the overwhelming challenge of providing training to both professionals and paraprofessionals in Tanzania and Kenya, it is recommended that interested organisations support the development of online training modules to support various aspects of implementation of appropriate inclusive practices in preschools and primary schools.

Figure 12
*Support Received by Teachers (Tanzania).*



*Recommendation 3: Guidelines, Strategic Plan, and Experimental Schools*. Evidence supports the blanket statement that schools will be inclusive is workable in policy, but failing in practice. Therefore, organizations should work jointly with Ministries of Education to develop guidelines and a strategic plan to implement inclusionary practice in phases in educational jurisdictions. Within the guidelines and plan, three preschool/primary schools would be fully supported as experimental schools demonstrating best practices for inclusion, within the context of their cultures, expertise, and infrastructure of exemplary models of practice. This would then be replicated on the basis of successes evidenced and rolled out to the next jurisdiction.

*Recommendation 4: Policy and Regulation*. Following the sequence outlined in Recommendation 3, organizations should translate the goals of the National Strategy on Inclusive education 2009-2017 for Tanzania and the Education Plan 2013-2018 for Kenya into achievable strategic plans in phases that are measurable and replicable.

*Recommendation 5: Data and Statistics*. Organizations should jointly commission a study of the demographics of disability in Tanzania and Kenya. In cooperation with NGOs, universities, and advocacy groups throughout the two countries can then present the governments with an accurate picture of potential pupils with disabilities, showing the scope and enormity of implementing inclusive practices.

*Recommendation 6: Partnering and Collaboration*. Organizations should co-fund and co-manage activities with other major donors to coordinate efforts and share expertise.

**Acknowledgment**

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## REFERENCES

African Child Policy Forum. (2014). *The African report on children with disabilities: Promising starts and persisting challenges*. Addis Ababa, Ethiopia: Author.

Kurumei, W. K. (2012). *Effectiveness of inclusive education in public primary schools in Keiyo District* (Unpublished thesis).

Republic of Kenya. (2003). Persons with Disabilities Act, 2003. Nairobi, Kenya: Author.

Republic of Kenya. (2007). The Draft National Disability Policy of 2007. Nairobi, Kenya: Ministry of Education.

Republic of Kenya. (2009). The National Special Needs Policy Framework. Nairobi, Kenya: Ministry of Education.

Republic of Kenya. (2010). The Constitution of Kenya, 2010. Nairobi, Kenya: Author.

Republic of Kenya. (2013). Education Act 2013, Education Plan 2013-2018. Nairobi, Kenya: Ministry of Education.

UNICEF. (2012). The right of children with disabilities to education: A rights-based approach to inclusive education. Geneva, Switzerland: Author.

United Nations. (2006). Convention on the Rights of Persons with Disabilities. Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

United Republic of Tanzania. (2012). National Strategy on Inclusive Education 2009-2017 (1st ed.). Dar es Salaam, Tanzania: Ministry of Education and Vocational Training.

World Health Organization and the World Bank Group. (2011). *World Report on Disability*. Geneva, Switzerland: Authors.

**Further References**

Republic of Kenya. Special Needs Education Policy 2009.

Education for All and Millennium Development Goals (International Directions).

# The Effects of a Self-Determined Career Development Model with an iPad-based Instruction on Progress Towards Job-Related Goals of a Young Adult with Autism Spectrum Disorder

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## Abstract

*The purpose of this study was to examine the effects of the Self-Determined Career Development Model (SDCDM) on progress towards three goals of a young adult with autism spectrum disorder (ASD), using a multiple probe across goals design. Following the intervention, the young adult made progress towards each of his three goals that exceeded the expectations of his supervisor and behavior specialist. Implications for future research and practice are discussed.*

Keywords: *autism spectrum disorders, employment, technology, self-regulated problem solving, single-subject experimental design*

## INTRODUCTION

Functional independence and employment is one of the main post-school goals for students with ASD and factors into quality of life and contributes to the well-being of the individual and society (Hendricks & Wehman, 2009). When adults with ASD are employed in the community, they generate more money than is spent on them in services (Cimera & Burgess, 2011). Yet, successfully transitioning from school into post-school employment is not typical for young adults with ASD. Nationally representative studies on employment outcomes of young adults with ASD report a grim outcome. For instance, approximately 30% of participants did not work in paid employment or participate in post-secondary education (Shattuck et al., 2012). When considering young adults with ASD within two years of graduation from high school, more than 50% of them had no post-school activity (employment or post-secondary) and continued to live with family or in residential settings (Shattuck et al., 2012). Roux and colleagues (2013) found a similar trend in employment outcomes of young adults with ASD: Only 53.4% had ever held paid employment and those who had worked only earned $8.10 per hour on average.

Self-determination strategies are associated with positive post-school outcomes for young adults with disabilities. Research and practice in teaching self-determination skills to students with disabilities have gained increased attention over the last decade (Lee, Wehmeyer, & Shogren, 2015; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015; Wehmeyer, Palmer, Shogren, Williams-Diehm, & Soukup, 2010). A strategy associated with positive outcomes in self-determination—goal attainment related to academic and vocational, and access to general education curriculum—is a self-determined learning model of instruction (SDLMI; Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000). The SDLMI is a model of instruction that enables teachers to teach students using self-directed and self-regulated learning strategies. Using the SDLMI with the support of a teacher, students engage in a self-regulated problem-solving process to self-set goals, make action plans, self-reflect on progress and goal attainment, and adjust plans to attain a goal. The model has been used effectively in teaching students with a wide range of disabilities across a variety of contexts (Lee et al., 2015). A complete description of the model appears in the Methods section.

While SDLMI was used primarily with students in K-12 settings, the model was adapted for use with adults. The Self-Determined Career Development Model (SDCDM) is a variation of the SDLMI that focuses on adults' job- and career-related goals (Wehmeyer et al., 2003). The SDCDM has been pilot tested with five adults with various disabilities receiving vocational rehabilitation services and seeking employment (Wehmeyer et al., 2003). Other studies examining the effects of SDCDM with adults found that adults with a mild and moderate intellectual disability increased their goal attainment (Dean, Burke, Shogren, & Wehmeyer, 2017; Devlin, 2008). In a recent study using SDCDM with adults with various disabilities, a few adults with ASD were included (Shogren et al., 2016).

While SDLMI and SDCDM offer numerous benefits of self-determination and self-regulated problem-solving for individuals with a variety of disabilities, research that examines the application of these practices to individuals with ASD is limited. In a meta-analysis of studies that used SDLMI, Lee and colleagues (2015) found the use of SDLMI was associated with increased academic and functional performance for students with various disability categories. When examining disability categories, ASD was the least-found disability category across studies. Nonetheless, the mean percentage of non-overlapping data (PND) score for students with ASD was the highest among other disability categories represented in SDLMI studies.

Self-regulated problem-solving and self-management skills should be promoted among individuals with ASD. Due to challenges with executive functioning, people with ASD struggle with self-regulation and problem-solving, and they display a wide range of behavioral and cognitive inflexibility (Leung & Zakzanis, 2014; Tsatsanis, 2005). When asked about the importance of seven skills (choice making, problem solving, decision making, goal setting, self-management and self-regulation, self-advocacy and leadership, self-awareness and self-knowledge) that lead to self-determination among individuals with ASD, parents felt these skills were very important (Carter et al., 2013). Yet, when asked about their children's performance level in each of these seven skills, more than half of the parents noted that their children did not perform well in problem-solving, goal-setting, decision-making, self-regulation and self-management, and self-advocacy and leadership skills.

### Technology-aided Intervention

Previous studies used various strategies that did not include technology to teach students how to use the SDLMI or SDCDM. Yet, technology has become an integral part of the lives of students with ASD. For instance, students with ASD find activities presented via technology more engaging than non-technology activities and spend an average of 4.5 hours per day on technology-based activities compared to an average of 2.8 hours per day spent on non-technology activities (Mazurek, Shattuck, Wagner, & Cooper, 2012). The use of technology in research involving individuals with ASD is expanding rapidly (Shic & Goodwin, 2015). Students with ASD benefit from technology-based strategies from early childhood to adulthood in school, home, and community settings (Fletcher-Watson 2014; Odom et al., 2015). Interventions embedding technology have a positive effect on improving a wide range of skills, such as academic (Knight, McKissick, & Saunders, 2013), employment (Walsh, Holloway, McCoy, & Lydon, 2017), functional (Hong et al., 2016), social, communication, facial recognition, and safety skills of students with ASD (Grynszpan, Weiss, Perez-Diaz, & Gal, 2014).

Recent meta-analysis on technology supports for adults with ASD in employment settings found a variety of approaches (e.g., tablets, iPads, personal digital assistants) used and that technology-aided interventions may be effective (Walsh et al., 2017). However, most of the technology-aided interventions focused on specific "on-the-job" skills. The need to examine the use of technology supports on skills that promote a positive work experience, such as social skills, communication skills, self-advocacy, and problem-solving skills, is as important as specific job-skills (Walsh et al., 2017). Given the limited body of research on instruction in self-regulated problem-solving for individuals with ASD and, particularly, when using the SDCDM, the purpose of this study was to determine the effects of SDCDM instruction delivered via a tablet computer (iPad) on job-related goal attainment of a young adult with ASD.

## METHODS

### Participant

The criteria for participation were: (a) a young adult who was within two years following graduation from high school, (b) receiving vocational rehabilitation or adult services in a post-school adult services program with a goal of obtaining a job in the community, and (c) having a diagnosis of ASD according to the DSM-5 (American Psychiatric Association [APA], 2013).

Paul was a 22-year old, Caucasian male, diagnosed with ASD. Based on the participant profile reports from the center, Paul would complete tasks with the use of directive statements, multiple prompts from staff, and continuous staff support. When frustrated or unsure of how to complete a task, Paul would typically give up and do something else. He was unable to identify and discuss the problems he was having which would lead to frustration and anxiety. In social situations, Paul would typically stand around and observe others; he never initiated a conversation or knew how to properly engage in one. His full-scale IQ was 58 per results from the Wechsler Intelligence Scale for Children—Fourth Edition (WISC-IV) and general adaptive composite score was 63 per the Adaptive Behavior Assessment System – Second Edition (ABAS-II).

### Setting

Paul received services in a customized day program through a non-profit agency that provides lifelong supports for individuals with various disabilities. Supports at the center ranged from early intervention services to transition services for local school districts and job training for adults with disabilities. He received individualized vocational skills training in a customized day program. Customized day program services included skill training in a variety of areas through community outings, guest speakers, vocational opportunities via volunteering, and community-based employment.

When Paul worked on his goals of initiating conversations and initiating verbal greeting, the researchers observed him in activity rooms of the program. The program director, along with staff and peers, were dispersed throughout the building, giving him the ability to practice his skills among familiar people. A small conference room within the program was used when Paul worked on his goal of job exploration.

### Experimental Design and Data Collection

A multiple probe across goals design with multiple probes in baseline of single-subject experimental design (Horner & Baer, 1978) was used to determine the effectiveness of SDCDM delivered in a multimedia format on Paul's progress towards three goals. Initial baseline data were collected for three goals simultaneously. Then, baseline data collection continued for the goal of initiating conversation for four more sessions. During the fifth baseline sessions, baseline data collection resumed for the second tier of baseline (initiating verbal greeting) and continued until three sessions of intervention were implemented for the prior tier (initiating conversation). During the seventh baseline session for the second tier of baseline, collecting baseline data for three consecutive sessions for the third tier of baseline (job exploration) resumed.

Event and permanent product recording procedures were used to collect data on three goals (Kennedy, 2005). The rate of Paul's behaviors of initiating conversations and initiating verbal greetings with peers and staff during a 10-minute observation period was recorded using event recording procedure. Permanent recording was used to record the number of questions Paul answered during each session while working on his goal of job exploration.

### Dependent Variables

The dependent variables included the rate of initiating a conversation during a 10-minute period, the rate of initiating a verbal greeting during a 10-minute period, and the number of questions answered correctly when working on a goal of job exploration. Prior to beginning baseline data collection, Paul met with the program supervisor and the project trainers (first and third authors) to determine three goals that were important for him in his efforts to obtain employment in the community.

Initiating a conversation with peers and staff was defined any unprompted question or comment from Paul directed to a conversation partner (e.g., "Jane, how is your day going?", introducing a new idea or topic to start a conversation). Instances of responding to a conversation initiated by others, responding to an external question (e.g., a staff or peer in the lunch room asking where a certain object is located or who knows or has seen something or someone) were not considered as initiating a conversation. The number of times Paul initiated a conversation with each peer or staff member was recorded during a 10-minute observation period with a Yes=1 or No=0 score for each instance. Initiating a verbal greeting with peers and staff was defined as Paul approaching a peer or staff member, establishing eye contact and verbally greeting (e.g., "Hi", "Hello", "Good morning") with a hand shake. The correct response was recorded only when Paul initiated greeting as defined. The number of acceptable verbal greeting initiations during a 10-minute observation period was recorded with a Yes=1 or No=0 score for each instance. Initiating a verbal greeting was different from initiating a conversation. Initiating a verbal greeting required a formal greeting with a hand shake, while initiating a conversation was more social in nature and did not require Paul to start a conversation with a formal greeting. Job exploration was defined as Paul reading a sample job description online on an iPad and identifying critical information that is necessary to evaluate the fit of the job for himself. To identify critical information and evaluate the fit of the job, Paul responded to the following six questions on a worksheet on an iPad: (1) What are the general things about this job that you should know before you begin working in this job? (2) What are the specific elements about this job that you should know? (3) How can you find out about similar

Table 1
*Job Exploration Rating Scale (adapted from Benitez et al., 2005).*

| **General Category** | **Yes** | **No** |
|---|---|---|
| 1. Identified salary for this job | | |
| 2. Identified college/vocational education requirements | | |
| 3. Identified the number of hours | | |
| 4. Identified the type of hours (morning, afternoon, evening, night shift, or weekend) | | |
| 5. Identified benefits for this job | | |
| 6. Identified job responsibilities | | |
| | | |
| **Specific Category** | | |
| 7. Identified location | | |
| 8. Identified the fit of his skills to job qualifications | | |
| 9. Identified the culture of the work place, i.e., how people interact | | |
| 10. Identified physical work environment | | |
| | | |
| **Similar Jobs** | | |
| 11. Identified one way to find out about jobs that are related to that job | | |
| | | |
| **Gaining Experience** | | |
| 12. Identified one way of gaining experience (e.g., volunteering, job-shadowing, job sampling) | | |
| | | |
| **Positive Perceptions in Career Exploration/Potential of Job Obtaining** | | |
| 13. Expressed positive feelings towards the potential of obtaining these types of jobs in the community | | |
| 14. Wrote two things he did well and one thing he did not (one thing that he could improve) | | |
| | | |
| **Comments:** | | |

jobs that are related to this job? (4) If you want to get experience in this field, what is one way you can do it? (5) Write how you feel about the potential of obtaining these types of jobs in the community (6) Write two things you did well and one thing you did not (one thing that you could improve). Project trainers provided Paul with a current, active job opening (different job opening each time) from websites of different stores and community businesses (e.g., Kmart, Walmart, Target, CVS Pharmacy). Paul's progress towards his goal of job exploration was measured using the rating scale presented in Table 1. This rating scale was adapted from the rating scale used to measure career exploration of high school students with emotional and behavioral disorders using SDCDM (Benitez, Lattimore, & Wehmeyer, 2005).

### Materials

Technology (iPad 2 and Voice Thread© multimedia presentation) was used to support Paul in providing the basic understanding and use of the SDCDM, illustrating with a case example. Technology was also used to provide a medium for Paul to respond to problem-solving questions in each phase of the model and work on his goal of job exploration. Technology support was chosen based on the recommendation of Paul's program supervisor that Paul did not verbally express his opinions and responses to questions posed. However, when provided with an option to write or type his responses on a computer, Paul would express himself better than orally responding. The iPad 2 was also used when Paul read a sample job description online and answered the questions to measure his performance on the job exploration goal.

***iPad2***. The iPad 2 was used to explain the use of SDCDM with a case example and as an opportunity for Paul to work through each phase of the model and problem solve through each question. Paul accessed Voice Thread© multimedia presentations for each phase of the model: phase 1 when setting goals, phase 2 when making action plans and choosing student-directed learning strategies, and phase 3 when self-evaluating goal attainment. When responding to the problem-solving questions in each phase of the model, Paul typed his responses using the Notes application of the iPad 2.

***Voice Thread© Multimedia Presentation***. Microsoft® PowerPoint was used to create the examples of use for SDCDM phases in Voice Thread©. The Voice Thread© technology allowed the researchers to voice over the PowerPoint, taking the participant through each problem-solving question per phase, modeling the use of the SDCDM. For each phase of the SDCDM, the video included a slide that contained each of the four questions, along with a separate slide where real-life examples were presented in a scenario situation. The video would first show the question and then give prompts to consider. The next slide showed a fictional person going through each of the questions and prompts that were relevant to the scenario. Paul watched a scenario modeling the self-regulated problem-solving sequence for each phase of the SDCDM, examples of how the questions are answered, and explaining the essence of the SDCDM and its use in setting and attaining goals. An example of a fictional scenario presented in the Voice Thread© clip focused on teaching Paul to engage in a means-end problem-solving sequence. This was repeated for each of the four questions per phase. Table 2 presents SDCDM phases (Wehmeyer et al., 2003).

### The SDCDM

The purpose of SDCDM is to enable adult service providers to support adults with disabilities to self-regulate problem solving, self-direct decision making, and enhance self-determination (Wehmeyer et al., 2003). The model provides a framework for self-regulated problem-solving process and self-directed learning is the core aspect of the model. In a self-directed learning process, the teacher, practitioner, or service provider serves as a facilitator rather than direct instruction provider and supports a person with a disability in taking a meaningful and active role in setting one's career-related goals, taking part in decision-making to develop an action plan, and evaluating and modifying action plans or goals. The model does not require a facilitator to

Table 2
*SDCDM Phases*.

| Phase | Problem to Solve | Questions |
|---|---|---|
| Phase 1. Goal setting | What are my career and job goals? | What career and job do I want?<br>What do I know about it now?<br>What must change for me to get the job and career I want?<br>What can I do to make this happen? |
| Phase 2. Making a plan/taking action | What is my plan? | What actions can I take to reach my career or employment goal?<br>What could keep me from taking action?<br>What can I do to remove these barriers?<br>When will I take action? |
| Phase 3. Assessing/adjusting goal or plan | What have I achieved? | What actions have I taken?<br>What barriers have been removed?<br>What has changed to enable me to get the job and career I want?<br>Have I achieved what I want to achieve? |

have a specific expertise or training to support a person with a disability; rather, a facilitator can be anyone (parent, teacher, support staff) who will help a person with a disability in understanding the model and provide support when setting a goal, making an action plan, and adjusting a goal or plan. The level of support and assistance in using the model varies from person to person, based on individual challenges and strengths.

Each phase of the model includes four sets of problem-solving questions that can be adapted to an individual's comprehension ability and represents essential steps in the means-end problem-solving sequence: (a) identify a problem, (b) identify possible solutions, (c) identify barriers, and (d) identify consequences for each possible solution. The framework of means-end problem-solving sequence allows a person to modify his/her own behavior and self-direct actions in goal attainment. Each question within each phase includes objectives for facilitators, employment supports for adults, and examples of facilitator questions and possible participant responses to understand the objectives of the model. Objectives within each phase provide ideas for facilitators to assist adults with disabilities in engaging in a self-regulated problem-solving process. Employment supports identified within the SDCDM manual are self-directed learning strategies that individuals with disabilities use to work towards goals. These self-directed learning strategies are derived from the self-management literature. For instance, these supports include self-monitoring, self-instruction, antecedent cue regulation, self-evaluation, self-advocacy, and self-reinforcement (Wehmeyer et al., 2003).

### Procedures

At the onset of the project and prior to collecting baseline data on participant goals, Paul met with his program supervisor and project trainers (first and third authors) to determine job-related goals he wanted to achieve. Project trainers asked Paul to watch the modeling of the use of the first phase of SDCDM in a Voice Thread© multimedia presentation format on an iPad. Upon watching the multimedia presentation and while guiding Paul through phase 1 of SDCDM, project trainers instructed him on how to use the problem-solving strategy which is the essence of the model. Project trainers and Paul's program supervisor were available to answer Paul's questions about the use of SDCDM; help him identify his strengths, challenges, and supports in his current environment; and prioritize his needs in relation to obtaining employment in the community. Paul answered the following questions in the first phase of SDCDM by typing his responses on an iPad: What career and job do I want? What do I know about it now? What must change for me to get the job and career I want? What can I do to make this happen? Paul completed three worksheets on an iPad to work through the first phase of the model. After problem solving through these questions and identifying his strengths and needs, Paul chose to work on three goals: (1) initiating a conversation with peers and staff, (2) initiating verbal greeting with peers and staff, and (3) job exploration. Once three goals were set, project trainers developed dependent measures for each goal as described in the Dependent Variables section. After goals were set, Paul and his program supervisor completed goal attainment scaling (GAS) to determine a possible outcome among a five-scaled continuum, ranging from the least expected to the most expected outcome. Then, baseline data collection on three goals started with sessions occurring three days a week with one session per day.

***Baseline***. During baseline conditions, researchers recorded Paul's baseline performance related to three goals. No reinforcement or prompts for goal attainment were available during baseline sessions. For his goal of initiating conversations with peers and staff, researchers observed Paul for a 10-minute duration during lunch time once the majority of his peers and staff finished lunch. For his goal of initiating verbal greeting, researchers observed Paul for 10 minutes towards the end of the one-hour lunch break. Once lunch break was over, Paul worked on his goal of job exploration in a small conference room by reading a current job opening and answering a set of questions. The intervention condition started for each goal after a stable state of responding was achieved for three consecutive sessions.

***Intervention***. The intervention condition involved the implementation of the second phase of SDCDM. Paul worked through the second phase of the model and answered the following questions: What actions can I take to reach my career or employment goal? What could keep me from taking action? What can I do to remove these barriers? When will I take action? The major emphasis of this phase involved helping Paul identify student-directed learning strategies and teaching him how to use those strategies. The project trainers and program supervisor assisted Paul in identifying supports, challenges, and opportunities related to achieving self-selected goals. Then the project trainers developed a teaching script for the use of each self-directed learning strategy that Paul used when working on each goal. Teaching Paul to use three self-directed learning strategies included direct instruction, modeling of the strategy, role-play of the use of strategy with the trainers, and independent practice. Teaching Paul how to use self-directed learning strategies took three one-hour sessions per strategy. Once Paul showed mastery in independently using each self-directed learning strategy, the intervention data collection on the dependent measures began.

Paul's action plan for his goal of initiating conversations involved using a self-monitoring system. Paul decided to self-monitor his progress after he engaged in conversations during lunch time. A pocket-size version of the self-monitoring strategy on an index card was created and provided to Paul so he could refer to steps of conversation when working on his goal. Mastery for the goal of initiating conversations was set at initiating at least five conversations with five different peers and/or staff for two consecutive sessions.

For his goal of initiating verbal greeting with peers and staff, Paul selected self-instruction. One challenge Paul mentioned was that he would become nervous when initiating a verbal greeting and that would prevent from him initiating the greeting. A self-instruction strategy was developed and taught to Paul. Paul learned to verbalize self-instruction strategy steps and work through his challenge of getting nervous in initiating greeting. For instance, he would say, "What is the problem? I am getting nervous.", "What can I do about it? Take a deep breath, count to 5 or 10." Then, he would initiate verbal greeting. Then, he would ask himself "Did that work?" and self-reinforce. Paul used a pocket-size version of self-instruction to remind himself of the steps when working on his goal. Mastery for the goal of initiating verbal greetings was set at initiating a minimum of 10 instances of initiating greeting for two consecutive sessions.

For his goal of job exploration, Paul selected self-monitoring with a picture cue strategy. Flashcards with each step of the job exploration checklist were created and stapled together. One side of each flashcard represented a step in the task analysis of job exploration and another side represented a picture cue of that step. For instance, one side of the flashcard read, "How much would they pay me?", and the other side of the flashcard showed the image of the money. Mastery for the goal of job exploration was answering 12 out of 14 questions correctly for a minimum of two consecutive sessions.

### Maintenance

One week after finishing the intervention condition, maintenance data were collected for three sessions per goal. During this condition, Paul worked on his goals without additional assistance or feedback. Paul answered questions of the phase 3 of SDCDM to reflect on his experience of using the model and goal attainment.

### Inter-observer Agreement

Inter-observer agreement (IOA) data were collected for at least 30% of each condition across goals. IOA data were calculated using an interval agreement method by dividing the number of agreements by the number of agreements and disagreements, and then multiplying by 100% (Kennedy, 2005). Mean IOA was 100% during all conditions per goal.

### Procedural Reliability

A second trained observer collected data on the procedural reliability for 30% of the intervention condition per goal. Procedural reliability was calculated by dividing the number of occurrences by the number of occurrences and nonoccurrences, and then multiplying by 100%. The procedural reliability was 100% per goal.

### Social Validity

Upon conclusion of the intervention condition, Paul's program supervisor and behavior specialist completed an informal social validity questionnaire regarding their perceptions on the participant's goal attainment and SDCDM. The behavior specialist was blind to the goals of the study. They responded to questions related to Paul's performance on three goals before and after the intervention. Paul's responses to questions posed in phase three of SDCDM served as social validity information and provided insights into his perception about goal attainment.

### Data Analysis

To analyze data, the researchers used visual analysis and calculated the effect size. Visual analysis is the primary method of data analysis in single-case experimental designs. Using guidelines for visual analysis of single case design data (Kratochwill et al., 2013), the researchers visually examined baseline, intervention, and maintenance conditions. They examined data from each study for: (a) level, (b) trend, (c) variability, (d) immediacy of effect, (e) overlap, and (f) consistency of data patterns.

Improvement Rate Difference (IRD) is one of the nine effect sizes recommended for use with single-case design data (Parker, Vannest, & Davis, 2011). Improvement rate is calculated by identifying baseline data points equal to or above the intervention data points and then dividing the number of improved data points by total data points within the same condition. IRD score of 1.0 indicates the strong effect of the intervention on the outcome variable, 0.5 indicates chance effectiveness, and 0 indicates no effectiveness. The researchers calculated overall robust IRD for each included study using the online calculator (http://www.singlecaseresearch.org/calculators/ird; Vannest, Parker, Gonen, & Adiguzel, 2016).

## RESULTS

Visual analysis of data showed the effectiveness of SDCDM with technology support in improving goal attainment of a young adult with ASD (see Figure 1). Paul improved each of the self-selected goals during intervention and maintained skill performance at a one-week follow-up. Effect size calculations showed strong effectiveness of the intervention improving two skills and chance effectiveness in improving one skill.

***Goal 1: Initiating a Conversation.*** During baseline, Paul initiated conversations with peers and staff at a mean rate of 0.86. He initiated very short conversations with a few peers during three baseline sessions. Baseline data had some variability. Upon implementation of the intervention, Paul showed an immediate increase in the rate of conversations initiated with an increasing trend and a mean rate of 4.28. This resulted in a mean rate change of 3.42. It is important to note that the rate of initiating conversations was reported in the visual analysis of data. Thus, during some sessions he engaged in brief conversations and had time to initiate many conversations during a 10-minute observation period. While in some other sessions, he engaged in lengthy conversations that resulted in fewer instances of initiation during a 10-minute period. Observations noted that Paul engaged in lengthy conversations within a 10-minute period during the second, third, and fourth intervention sessions where his data show a slightly decreasing trend. During follow-up, Paul initiated conversations with a mean rate of 7.70 and a stable trend. Improvement rate difference (IRD) between baseline and intervention was 0.57, suggesting a chance effectiveness. IRD between baseline and maintenance was 1.0, indicating a strong effectiveness.

***Goal 2: Initiating a Verbal Greeting***. When initiating a verbal greeting with peers and staff, Paul had a low and stable baseline performance with a mean rate of 1.00. During intervention, Paul had an increasing trend in the rate of verbal greetings initiated, reaching an average rate of 9.57. This resulted in a mean rate change of 8.57. During follow-up observations, Paul initiated verbal greetings with his peers and staff with a mean rate of 17.34 counts of verbal greetings. IRD was 1.0 between baseline and intervention conditions, suggesting a strong effectiveness. The IRD between baseline and maintenance was 1.0.

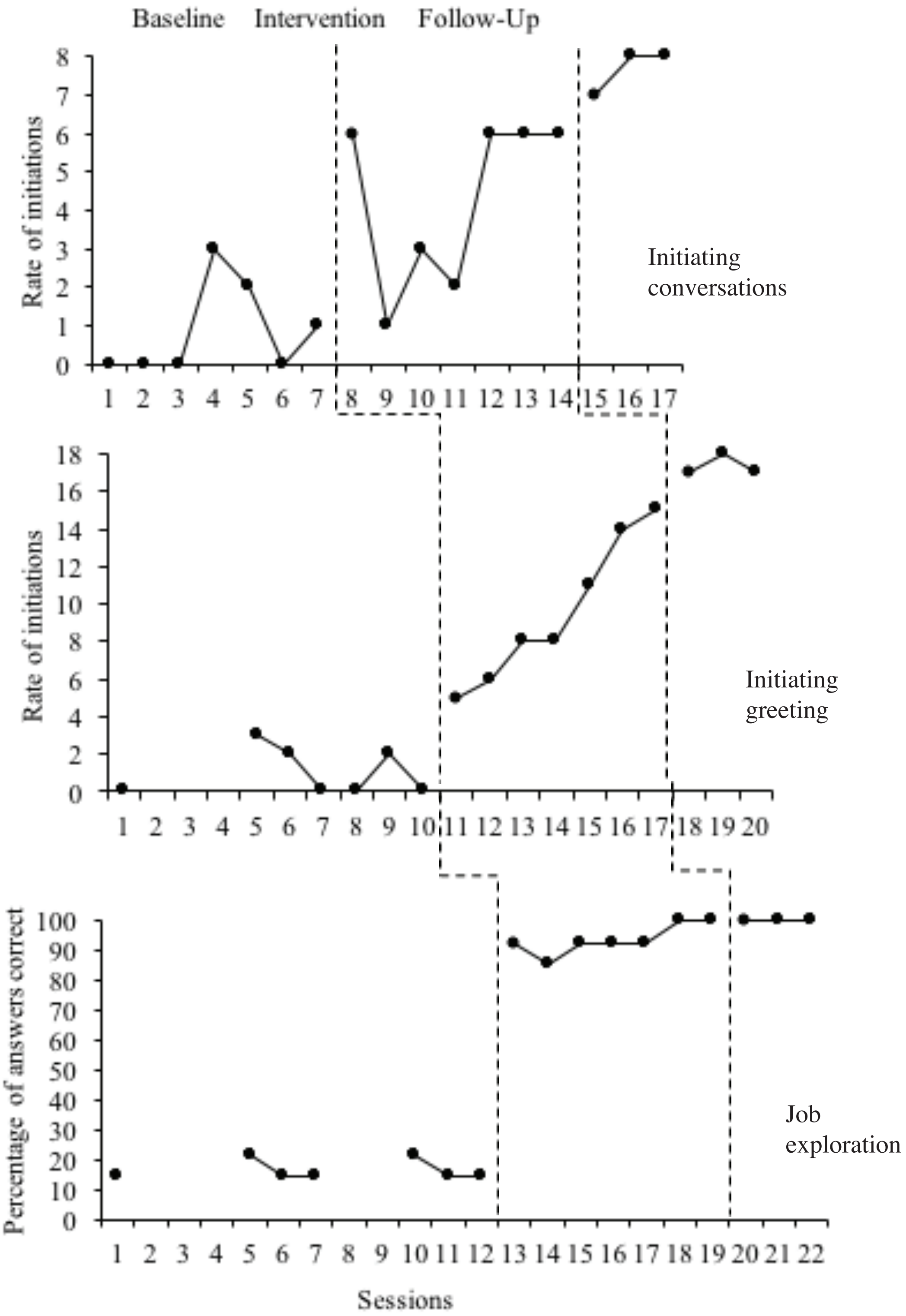
***Goal 3: Job Exploration***. When working on his goal of job exploration, Paul's baseline data had a low, stable trend with a mean percentage accuracy of 16.32. Paul showed an immediate increase in his performance during intervention with an increasing and stable trend. This resulted in a mean percentage accuracy of 93.85 during intervention with a mean change of 77.53% from baseline to intervention. During follow-up, Paul answered all questions with 100% accuracy. IRD between baseline and intervention was 1.0, indicating an effective intervention. Similarly, IRD between baseline and maintenance was 1.0.

### Social Validity

Upon conclusion of the study, Paul's program supervisor and behavior specialist answered questions regarding their perceptions about Paul's goal attainment and the use of SDCDM. Both were impressed with Paul's progress towards his goals during the study. They reported that Paul was initiating conversations with more people in the community and carrying on conversations for longer periods of time than previously. They also reported that Paul was paying attention to nonverbal features of conversation, such as using eye contact, keeping an acceptable distance between himself and his conversation partner, and staying on topic during conversation. Further, Paul became more self-aware of general expectations and requirements for having a job in the community and the skills he possessed and those he needed to gain.

Paul provided favorable comments on his progress towards his goals and use of SDCDM with self-management strategies. He noted that he learned how to "communicate more efficiently and sociably" and that his staff and friends in the program became "kinder" to him during his conversations. Paul mentioned he also learned what skills he needed to gain to get employed in the community. Regarding the use of SDCDM itself and its use via technology, Paul noted that he had a venue through which to express his thoughts and communicate his wants and needs.

Figure 1
*Paul's Rate of Conversation Initiation, Rate of Greeting Initiation, and Percentage of Job Exploration Questions Answered Correctly.*



## DISCUSSION

The purpose of this study was to examine the effects of SDCDM on progress towards self-selected goals of a young adult with ASD. The findings suggest that SDCDM was effective in improving Paul's progress towards goals and a causal relation between the intervention and progress towards goals was observed. Increases in progress towards goals were evident between baseline and intervention conditions and continued in the maintenance condition.

The findings of the present study extend and contribute to the research literature in several ways. Consistent with research on the effects of SDCDM on goal attainment of students with disabilities (Lee et al., 2015; Shogren et al., 2016), the findings suggest the effectiveness of SDCDM on improving goal attainment of young adults with ASD. The SDCDM used in the current study to teach students goal attainment builds on a history of success with SDCDM and SDLMI in teaching students with disabilities. Two of the studies focused on SDLMI include some participants who had a diagnosis of ASD (Agran, Blanchard, Wehmeyer, & Hughes, 2002; Agran, Cavin, Wehmeyer, & Palmer, 2006) and one study when examining the effects of

SDCDM (Shogren et al., 2016). This work extends the literature on teaching self-regulated problem solving to increase goal attainment of students with ASD. As an early study demonstrating the effects of SDCDM on progress towards goals of a young adult with ASD, the findings contribute to the limited literature and show promise for the use of SDCDM with young adults with ASD. Practitioners working with students and young adults with ASD can embed opportunities for engaging students in student-centered learning opportunities and teach self-regulated problem-solving skills within daily instructional activities.

Further, the core feature of SDCDM is to engage students in self-regulated problem solving to move from their current situation to a desired situation by setting goals, resolving gaps, and making decisions. Individuals with ASD experience challenges with executive functioning and frequently struggle with problem solving (Tsatsanis, 2005). Compared to peers without disabilities, students with ASD do not engage well in self-regulated problem solving and struggle with abstract or complex task demands (Alderson-Day & McGonigle-Chalmers, 2011). Consistent with the core feature of SDCDM, Paul was provided with concrete examples of working through each phase of the model and setting goals, choosing student-directed strategies, and evaluating his goal attainment. He was also provided with an opportunity to problem solve each question in three phases of the model and write his responses on a tablet computer. This allowed him to reflect on each question in writing and then discuss it with the researchers, thus opening a venue for self-expression. Students with ASD who struggle with verbal communication to express their preferences and responses, should be provided the opportunity to express their responses in multiple ways.

When working through the second phase of the model, Paul was self-aware of his challenges in his daily functioning and stated his likes and dislikes about the approaches he used in his daily instruction. One of the concerns Paul expressed many times while working through SDCDM phases, particularly during the second phase, was that he disliked being told to do certain things in a certain way and wanted to have more input into his daily activities. This allowed him to choose self-monitoring and self-instruction strategies to work towards his goals. The findings of the study provide supporting evidence that engaging students with ASD in a self-regulated problem-solving approach and enabling them to have a voice helps prepare students with ASD for success in adult life. Student-directed learning strategies have been found effective in increasing students' self-determination and access to inclusive education, academic engagement, and goal attainment in international contexts, such as South Korea (Kim & Park, 2012; Wehmeyer & Lee, 2008). Practitioners working with students with ASD in various international contexts should consider using these strategies to maximize the meaningful participation and involvement in school, work, and community settings.

This work also adds to technology research in teaching students with ASD. Paul had the tendency to give brief oral responses to any question posed to him; however, when offered a chance to write his responses, he would respond with greater detail and reflection. While working through SDCDM phases, he occasionally revisited his responses and reflected and edited as needed. Practitioners and adult service providers working with students and adults with ASD should intentionally offer adults with ASD an opportunity to engage in the task and respond in multiple ways and utilize technology to support students' engagement with the task and responses. Service providers should also utilize technology as an equalizer and to address challenges adults with ASD face in work settings. Practitioners and service providers working with young adults with ASD in international contexts should utilize technology to maximize the individual's functional independence and support in work settings. Technology used in everyday life, such as smart phones, can be repurposed to support individuals with ASD and maximize opportunities for meaningful integration into the community.

## Limitations and Directions for Future Research

As an early study examining the effects of a self-regulated problem-solving approach using SDCDM on progress towards self-selected goals of a young adult with ASD, findings show promise and limitations which warrant the need for future research. This study involved a single participant and demonstrated the three replications of the intervention's effectiveness using a multiple probe across a three-goals design. While single-case experimental methodology allows for the demonstration of a functional relation with a single participant with three replications of the effect of the intervention, best practices dictate the need for replication of effect to enhance the external validity of the findings. Thus, having a single participant in this study may be considered a limitation to the external validity of the findings. Further replications of the study using multiple baseline across subjects with additional students for replication and large sample sizes need to be conducted.

This study examined the initiations but not the quality of the conversations. However, in some intervention sessions, Paul engaged in lengthy conversations during a 10-minute observation period which, in turn, resulted in fewer initiations. Thus, future research should examine the quality of carrying out reciprocal conversations. Another limitation of the study which warrants future research is the setting where the study was conducted. Future research efforts should focus on examining the application of SDCDM with young adults with ASD who are employed in competitive employment. Additionally, applications and effects of SDCDM and technology supports in teaching students with ASD in various cultural and international contexts should be the focus of future research. Additional replications with diverse cultural groups in different geographic regions enhance the generalizability of the findings.

## REFERENCES

Agran, M., Blanchard, C., Wehmeyer, M., & Hughes, C. (2002). Increasing the problem-solving skills of students with developmental disabilities participating in general education. *Remedial and Special Education, 23*, 279–288. doi:10.1177/07419325020230050301

Agran, M., Cavin, M., Wehmeyer, M., & Palmer, S. (2006). Participation of students with moderate to severe disabilities in the general curriculum: The effects of the self-determined learning model of instruction. *Research and Practice for Persons with Severe Disabilities, 31*, 230–241. doi:10.1177/154079690603100303

Alderson-Day, B., & McGonigle-Chalmers, M. (2011). Is it a bird? Is it a plane? Category use in problem-solving in children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 41*, 555–565. doi: 10.1007/s10803-010-1077-9

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders: DSM-5 (5th ed.). Washington, DC: Author.

Benitez, D. T., Lattimore, J., & Wehmeyer, M. L. (2005). Promoting the involvement of students with emotional and behavioral disorders in career and vocational planning and decision-making: The self-determined career development model. *Behavioral Disorders, 30*, 431–447. Retrieved from http://ccbdjournals.com/

Carter, E., Lane, K., Cooney, M., Weir, K., Moss, C., & Machalicek, W. (2013). Parent assessments of self-determination importance and performance for students with autism or intellectual disability. *American Journal on Intellectual and Developmental Disabilities, 118*, 16–31. doi: 10.1352/1944-7558-118.1.16

Cimera, R., & Burgess, S. (2011). Do adults with autism benefit monetarily from working in their communities? *Journal of Vocational Rehabilitation, 34*, 173–180. doi: 10.3233/JVR-2011-0545

Dean, E. E., Burke, K. M., Shogren, K. A., & Wehmeyer, M. L. (2017). Promoting self-determination and integrated employment through the self-determined career development model. *Advances in Neurodevelopmental Disorders*. doi:10.1007/s41252-017-0011-y

Devlin, P. (2008). Enhancing the job performance of employees with disabilities using the self-determined career development model. *Education and Training in Developmental Disabilities, 43*, 502–513. Retrieved from http://daddcec.org/Publications/ETADDJournal.aspx

Fletcher-Watson, S. (2014). A targeted review of computer-assisted learning for people with autism spectrum disorder: Toward a consistent methodology. *Review of Research in Autism and Developmental Disorders, 1,* 87–101. doi:10.1007/s40489-013-0003-4

Grynszpan, O., Weiss, P. L., Perez-Diaz, F., & Gal, E. (2014). Innovative technology-based interventions for autism spectrum disorders: A meta-analysis. *Autism, 18*, 346–361. doi:10.1177/1362361313476767

Hendricks, D., & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders: Review and recommendations. *Focus on Autism and Other Developmental Disabilities, 24*, 77-88. doi:10.1177/1088357608329827

Hong, E. R., Ganz, J. B., Mason, R., Morin, K., Davis, J. L., Ninci, J., Neely, L. C., Boles, M. B., & Gilliland, W. D. (2016). The effects of video modeling in teaching functional living skills to persons with ASD: A meta-analysis of single-case studies. *Research in Developmental Disabilities, 57*, 158–169. doi:10.1016/j.ridd.2016.07.001

Horner, R. D., & Baer, D. M. (1978). Multiple-probe technique: A variation of the multiple baseline. *Journal of Applied Behavior Analysis, 11*, 189–196. doi: 10.1901/jaba.1978.11-189

Kennedy, C. H. (2005). *Single-case designs for educational research*. Boston, MA: Allyn & Bacon.

Kim, N. H., & Park, J. (2012). The effects of the family-involved SDLMI on academic engagement and goal attainment of middle school students with disabilities who exhibit problem behavior. *International Journal of Special Education, 27*, 117–127.

Knight, V., McKissick, B. R., & Saunders, A. (2013). A review of technology-based interventions to teach academic skills to students with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*, 2628–2648. doi:10.1007/s10803-013-1814-y

Kratochwill, T., Hitchcock, J., Horner, R., Levin, J., Odom, S., Rindskopf, D., & Shadish, W. (2013). Single-case intervention research design standards. *Remedial & Special Education, 34*, 26–38. doi:10.1177/0741932512452794

Lee, S., Wehmeyer, M., & Shogren, K. (2015). Effect of instruction with the self-determined learning model of instruction on students with disabilities: A meta-analysis. *Education and Training in Autism and Developmental Disabilities, 50*, 237–247. Retrieved from http://daddcec.org/Publications/ETADDJournal.aspx

Leung, R. C., & Zakzanis, K. K. (2014). Brief report: Cognitive flexibility in autism spectrum disorders: A quantitative review. *Journal of Autism and Developmental Disorders, 44*, 2628–2645. doi:10.1007/s10803-014-2136-4

Mazurek, M. O., Shattuck, P. T., Wagner, M., & Cooper, B. P. (2012). Prevalence and correlates of screen-based media use among youths with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*, 1757–1767. doi:10.1007/s10803-011-1413-8

Odom, S. L., Thompson, J. L., Hedges, S., Boyd, B. A., Dykstra, J. R., Duda, M. A., Szidon, K. L., Smith, L. E., & Bord, A. (2015). Technology-aided interventions and instruction for adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 45*, 3805–3819. doi:10.1007/s10803-014-2320-6.

Parker, R. I., Vannest, K. J., & Davis, J. L. (2011). Effect size in single-case research: A review of nine nonoverlap techniques. *Behavior Modification, 35*, 303–322. doi:10.1177/0145445511399147

Roux, A., Shattuck, P., Cooper, B., Anderson, K., Wagner, M., & Narendorf, S. (2013). Postsecondary employment experiences among young adults with an autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*, 931–939. doi: 10.1016/j.jaac.2013.05.019

Shattuck, P. T., Narendorf, S., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics, 129*, 1042–1049. doi:10.1542/peds.2011-2864

Shic, F., & Goodwin, M. (2015). Introduction to technologies in the daily lives of individuals with autism. *Journal of Autism and Developmental Disorders. 45*(12), 3773–3776.

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Rifenbark, G., & Little, T. (2015). Relationships between self-determination and postschool outcomes for youth with disabilities. *Journal of Special Education, 48*, 256–267. doi:10.1177/0022466913489733

Shogren, K. A., Gotto, S. G., Wehmeyer, M. L., Shaw, L., Seo, H., Palmer, S., Snyder, M. J., & Barton, K. N. (2016). The impact of the self-determined career development model on self-determination. *Journal of Vocational Rehabilitation, 45*, 337–350. doi:10.3233/JVR-160834

Tsatsanis, K. (2005). Neuropsychological characteristics of autism and related conditions. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and developmental disorders* (pp. 365–381). Hoboken, NJ: Wiley.

Vannest, K. J., Parker, R. I., Gonen, O., & Adiguzel, T. (2016). Single Case Research: Web-based calculators for SCR analysis. (Version 2.0) [Web-based application]. College Station, TX: Texas A&M University. Retrieved from www.singlecaseresearch.org

Walsh, E., Holloway, J., McCoy, A., & Lydon, H. (2017). Technology-aided interventions for employment skills in adults with autism spectrum disorder: A systematic review. *Journal of Autism and Developmental Disorders, 4*, 12–25. doi:10.1007/s40489-016-0093-x

Wehmeyer, M. L., Lattimore, J., Jorgensen, J. D., Palmer, S. B., Thompson, E., & Schumaker, K. M. (2003). The self-determined career development model: A pilot study. *Journal of Vocational Rehabilitation, 19*, 79–87.

Wehmeyer, M. L., Palmer, S. B., Agran, M., Mithaug, D. E., & Martin, J. (2000). Teaching students to become causal agents in their lives: The self-determining learning model of instruction. *Exceptional Children, 66*, 439–453. doi:10.1177/001440290006600401

Wehmeyer, M. L., Palmer, S., Shogren, K., Williams-Diehm, K., & Soukup, J. (2010). Establishing a causal relationship between interventions to promote self-determination and enhanced student self-determination. *Journal of Special Education, 46*, 195–210. doi:10.1177/0022466910392377

Wehmeyer, M. L., & Lee, Y. (2008). Effects of interventions to enhance the self-determination of students with disabilities in South Korea. *Journal of International Special Needs Education, 11*, 1139–1149

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# Decreasing the Off-task Behavior of Reluctant Adolescent Readers During Sustained Silent Reading Through Book Interest and Ability Matching

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## Abstract

*Teachers are often required by their administrators to implement Sustained Silent Reading (SSR) into their daily routines. Although there is research to support wide reading, there is little to support the specific practice of SSR. Recent researchers have suggested modified versions of SSR to better address the needs of struggling readers, including ensuring suitable reading selections. This study utilized a multiple baseline across students design to evaluate a modified version of SSR over four weeks with six junior high students displaying high levels of disengagement during SSR. The dependent variable included off-task behavior during SSR. The independent variable was matching books to students' interests and reading levels. Results indicated reduced levels of off-task behavior throughout the study. Across the course of the study, five of the six students' off-task behavior decreased by an average of 25% as a result of the book matching. This result confirmed a hypothesis from a previous study that matching students with books to read according to their interests and reading abilities, positively affects their time on task during SSR. This article provides practitioners with a modified version of SSR that will enhance the effectiveness of its use and suggests future research and implications for practice.*

Keywords: *adolescents, literacy, reluctant readers, struggling readers, sustained silent reading*

## INTRODUCTION

Sustained Silent Reading (SSR) is a practice used in most U.S. classrooms each school day during which, for a specified period of time, all students read books, magazines, or newspapers of their own choosing, quietly and independently. Hunt (1970) originally introduced the concept of uninterrupted sustained silent reading (USSR); in 1971, McCracken proposed that teachers implement a large group 15-minute silent reading period. He recommended that students and teachers read self-selected books, about which there are no records or reports expected, because requiring these diminishes the effectiveness of SSR. Instead, the intent of SSR is to offer reading practice, increase reading volume, and to foster an appreciation of literature and enjoyment of reading without the pressure of additional work or external evaluation. There are arguments for and against the effectiveness of SSR implementation as a practice that improves overall reading achievement for students in general (National Institute of Child Health and Human Development, 2000), but especially for those who struggle (Hairrell, Edmonds, Vaughn, & Simmons, 2010).

Early, limited research on SSR with low performing readers showed mixed results, indicating the need for further studies (Hairrell, et al., 2010; Reutzel, Fawson,

& Smith, 2008). SSR may only be appropriate for independent medium- to high-ability readers who enjoy reading (Davis, 1988; Siah & Kwok, 2010; Walker, 2000). In general, Fisher (2004) found that fewer than 40% of high school students engaged in reading during SSR. Instead, during the designated SSR period, students were observed using the time for content area assignments, completing homework for other classes or talking. Research often shows that students who are not reading are those with learning disabilities who may be too distracted to concentrate on a reading task for an extended period of time (Mikulecky & Wolf, 1977). In addition, struggling students may not have enough experience selecting appropriate text and thus choose materials too difficult or uninteresting to them, indicating the need for structured book selection (Hairrell, et al., 2010). In addition, teacher support in SSR periods is minimal. When teacher and peer attention is focused on reading, struggling readers may be reluctant to seek teacher assistance with difficult words to avoid calling attention to themselves. Nevertheless, Manning, Lewis, and Lewis (2010) reported in a review of SSR literature from 1979 to 2010 (that included 4 of 17 studies with students with reading deficits) that SSR can have a positive impact on students reading performance, including comprehension. These studies could indicate the need for finding methods to increase struggling readers' SSR participation.

Several authors have, in fact, suggested modifications to SSR to address student non-participation. These modifications include a classroom library (Pilgreen, 2000; Reutzel et al., 2010) and staff training on SSR procedures (Pilgreen, 2000). Reutzel and colleagues (2010) suggest the before, during, and after modifications of book selection guidance, conferencing, and reader's response journals for elementary age students (Reutzel, Jones, & Newman, 2010). Others have suggested a support structure that could increase struggling readers' participation (Hairrell et al., 2010). This structure includes a five-step process where students first were supported in book selection matching interest and skill level. The remaining four steps include other pre-reading, during reading, and post-reading activities (Harriell et al., 2010). In Allen, DuBois, & Heward (2006), a study of high school students contained a post-reading activity among high school students that included a five-question quiz and a game that checked for student comprehension of the content read. Student non-participation decreased from 32% pre-baseline to 3% following the quiz and game intervention. Allen et al. (2006) noted the pre-reading activity of book matching to be a confounding variable, stating a decrease in non-participation was noted following book selection (16.1% pre-baseline, to 8.6% baseline). However, based on data, it appears book matching might have functioned as an intervening variable. Of course, any modifications to the practice of SSR are counter to the original intent of SSR posed by McCracken (1971).

Before teachers of adolescents can take any steps toward modifying SSR, it is important to know that there is research to support the idea that, in general, as students mature, they read less for their own enjoyment. Scholastic (2013), for example, has conducted a biennial study of reading among 6- to 17-year-olds using a probability-based online survey. In 2012, participants who reported reading for fun five to seven times a week dropped from 48% among 6- to 8-year-olds to 28% among 12- to 14-year-olds and to 24% among 15- to 17-year-olds (Scholastic, 2013). In England, a survey of readers revealed that adolescents in that country are selecting novels to read at increasingly lower reading levels (Topping, 2017). They are more likely to read J.K. Rowling than Jane Austen. There is no definitive research as to why this trend toward less adolescent reading, and perhaps less-challenging reading, is happening, but the increased use of digital technologies by this age group across the globe, especially in the developed world, is clear.

However, Wigfield and Guthrie (1993) have argued that readers' engagement in reading can improve when they are intrinsically motivated and find personal meaning in the reading they do. Research has shown that when adolescents do read, they have definite preferences for both types of text and genres. In 1997, adolescent students indicated that horror stories were their favorite reading choice (Hale & Crowe, 2001). In another study, also conducted in the late 1990s (Worthy, Moorman, & Turner, 1999), middle school students were asked what they would read if they could choose anything they wanted; they responded that they would read scary books, comics, sports, teen magazines, and mysteries. In a more recent survey of 132 middle school students, students preferred mystery (67%) stories and adventure stories (53%), while eighth graders preferred humor (59%) and horror (49%) (Croston, 2005). Currently, according to major lists, such as those published on Amazon and *The New York Times,* there is a surge in the popularity of dystopian stories (science fiction and/or adventure), as well as realistic stories, especially when they are made into movies.

### Purpose of the Study

The purpose of this study was to contribute to research on engaging students who struggle or are reluctant to read during Sustained Silent Reading (SSR). Previous research identifies ways to modify SSR to make it more effective by assisting in book selection and implementing accountability measures (Allen et al., 2006; Brame, 2001; Bryan, Fawson, & Reutzel, 2003; Hairrell et al., 2010; Reutzel et al., 2008). This study is designed to assess the efficacy of an approach to Hairrell and colleagues' (2010) suggestion of structured book selection or book matching and to further investigate Allen et al.'s (2006) results showing book matching as an intervening variable. An additional goal was to gather data about students' reading preferences that teachers could use to guide them in building their classroom libraries or when selecting books from their libraries.

In this study, students selected books they expressed an interest in reading and that matched their reading abilities. It was conducted in one English and one science classroom in a junior high school in a middle-class area of a western state in the United States. The specific research questions addressed were:

1. What are the effects of book selection on the off-task behavior of junior-high students during SSR?
2. What are the most popular book genres for junior-high students?
3. What are the attitudes of the junior-high students about reading?

## METHODS

### Effects of Book Matching Intervention

This study was conducted over the final four weeks of a school year at a junior high school with a principal-initiated school-wide SSR program. Two different general education inclusion classrooms were studied (English and science). In the science classroom, there were 32 ninth graders: 19 females and 13 males. In the English classroom, there were 29 eighth graders: 9 females and 20 males. These two classrooms were selected because their scheduled SSR periods allowed for ease of data collection. All the teachers in the school were scheduled to implement SSR during fifth period. The English teacher implemented it at the beginning of the period and the science teacher at the end.

***Target Participants***. Each of the teachers identified three students who exhibited elevated levels of off-task behavior during SSR. Teachers were not limited to identifying students with a categorized disability under the U.S. Individuals with Disabilities Education Act (IDEA). Table 1 contains a summary of the six participating students who have been assigned pseudonyms to protect their identifies. The three participants in the science class were all ninth graders; two were female and one male. Ana, a Hispanic female, had a Scholastic Reading Inventory (SRI) Lexile© (MetaMetrics) score of 627L and attended an English as a Second Language (ESL) class. Taylor, an African American female, had a Lexile score of 1226L. Steven, a Caucasian male, had a Lexile score of 640L and received services under the IDEA category of Multiple Disabilities due to his specific learning disability and visual impairment. Even though individuals with disabilities may be labeled or identified differently across the globe, this study was conducted in the United States and therefore used the disabilities listed under IDEA, which includes the disability category of Specific Learning Disabilities.

The three participants in the English class were all eighth graders. Danielle, a Caucasian female 8th grader, had a Lexile score of 831L, received services under the IDEA category Specific Learning Disabilities and was in special education classes for math, writing, and reading. Lance, a Hispanic male whose first language was Spanish, had an uneven pattern of reading test data; his Lexile scores across four assessments were 771, 190, 0, and 242 respectively. All four tests were conducted during the same academic year. Foster, a Caucasian male, had a Lexile score of 938L and was receiving services under IDEA category Other Health Impaired due to accommodations needed because of his Attention Deficit Hyperactivity Disorder. The SRI Lexile scores were data collected from the Read 180 school's reading specialist. Four of the six students had received the Read 180 intervention at some point during junior high. Read 180 is described as a comprehensive system of curriculum, instruction, assessment, and professional development for raising the reading achievement of struggling readers in grades 4 and beyond.

***Design***. A multiple-baseline across students experimental design was used to answer the first research question about the impact of book matching on off-task behavior during the SSR period. In this design, the intervention of book matching was gradually introduced to the participants. This meant that once a participant's baseline off-task behavior was consistent and contrary to the desired direction, he/she received the matched book. The remaining target students received their books once the level of off-task behavior of the first participant decreased. Baseline data collection continued to be collected for the other participants as each individual received his/her matched book. When the behavior of the first student demonstrated a positive response to the implementation of the intervention, the next student with the most consistent baseline or data contrary to the desired direction, entered intervention. Baseline was extended for two of the students due to suspension and excessive absences. The process continued for the remaining participants. The purpose of the multiple-baseline design is to establish verification and replication of the effects of the intervention on the dependent variable (Cooper, Heron, & Heward, 2007). This multiple-baseline design allows the researcher to determine if the change in behavior is due to the intervention of book matching or other potential intervening variables. Baseline was collected during a typical SSR session (McKracken, 1971) in which the students independently read a self-selected book for 15 minutes.

***Book Matching Intervention***. A systematic, multistep process was used to ensure that the students were reading books that were of interest to them and at their reading levels. In the first step, all the students in each of the classes were asked to complete a *Student Interest* survey created for this study about their reading interests, preferences, and habits. This interest survey consisted of seven questions: (a) What is your favorite movie? And why? (b) Who is your favorite movie character? And why? (c) What is the best book you have ever read? And why? (d) Who is your favorite book character? And why? (e) Do you like to read for fun? Why or why not? (f) Do you often read materials other than books (websites, magazines, newspapers)? What are they? (g) What kinds of books do you like to read? This last question included a list of nine different genres for the students to check off if they liked them.

Once the list of genres most preferred by the students was identified, a list of books was created from information gathered by the American Library Association and by reading reviews on Amazon Books. All of the students were shown pictures of the covers of 25 different books from four genres and given a description of each book, both in writing and orally. The students were asked to identify on a *Book Show & Tell* form created for this study whether they had read the books, whether they would like to read them, and last, to rank their top four choices.

To ensure anonymity of the students targeted for off-task behavior, and to gather data for the second research question, all of the students in each class were surveyed and received a book from among their top three choices. All students were provided with a matched book to read during the designated SSR time. Those students targeted for data collection during SSR were identified by their classroom teachers as having elevated levels of off-task behavior during independent reading time. As a result, the subjects were unaware they were being observed. After the study was completed, the teachers kept all the books for their classroom SSR libraries. For the targeted students, in addition to choosing books from among their top three choices, books were also matched for reading level based on information provided by the Lexile website, the Flesch-Kincaid grade level analysis on Microsoft Word, and the school's reading specialist qualitative information about the participant's reading history. The Lexile score information and the Flesch-Kincaid information were both used because of the complex task of assessing a text's readability. The reading specialist provided information about the student's background that impacted the believability of the quantitative information. In every case, the student's interest in the book was given more weight than the readability match or the reading specialist's information. For Steven, to accommodate his visual impairment a Barnes & Noble Nook® was purchased to ensure large print for ease of reading.

In general, readability formulas are used to determine a text's difficulty. The Flesch-Kincaid Grade Level is determined by a formula that considers sentence length and word length in contemporary academic English. A Lexile text measure is based on the semantic and syntactic elements of a text. The website states that, "Many other factors affect the relationship between a reader and a book, including its content, the age and interests of the reader, and the design of the actual book. The Lexile text measure is a good starting point in the book-selection process, with these other factors then being considered" (MetaMetrics, 2014, para 4). The range for typical eighth graders is 805L to 1100L; for typical ninth graders, 855L to 1165L. Lexile information about texts can be found on the website either by searching the book itself or uploading text in the site's analyzer.

***Defining Off-task Behavior***. The dependent variable was off-task behavior during a 15-minute SSR period defined to include any of the following:

- Out-of-seat (e.g., standing up, walking around).
- Talking aloud or other vocalizations (e.g., laughing, singing).
- Making non-language noises (e.g., humming, drumming on the desk/book).
- Touching another student.
- Writing.
- Having the book closed.
- Having eyes closed or looking away from the book.

Data on all descriptors were collected on a partial interval; this means that during the 5-second interval, if at any time the student engaged in these behaviors, it was scored as off-task. For the descriptor, "eyes closed or looking away from the book," the behavior had to occur for the full five-second interval to be scored as off-task.

***Procedures to Ensure Believability of the Data***. In this study, there were three data collectors, one primary and two for inter-observer agreement. All data collectors participated in training to ensure accuracy of data collection; these sessions resulted in 95% agreement or higher. Inter-Observer Agreement (IOA) data were collected for 30% of the sessions across both baseline and intervention data collection periods. The data were calculated on an interval-by-interval basis to determine IOA; results for off-task behavior were 98.4%.

***Baseline***. After the bell rang in Mrs. Hansen's class (English), she instructed the students to get out their books and begin reading. She sat at her desk, also reading, as per typical SSR protocol. A 5-second partial interval observation form was used to record off-task behavior of the participants. Each 15-minute SSR period was divided into 10-second intervals. For each 10-second interval, the first five seconds were for observation and the second five were for recording. This procedure was followed for the full 15-minute SSR period across all target students. For each SSR period, each student was observed 30 times. A MotivAider, a small pager-like device that has a silent vibrating signal, was used to indicate the beginning and end of each 5-second interval. The MotivAider was worn on a belt or in a pocket during data collection to be inconspicuous. At the end of the 15-minute SSR period, Mrs. Hansen instructed the students to put away their books or return them to the class library, if they had borrowed one. In Mrs. Dean's class (science) SSR occurred during the final 15 minutes of class. The students were instructed to put away their materials and get out their books. The teacher sat at her desk, occasionally reading a newspaper. Meanwhile, off-task behavior of the target students was observed. The same 5-second partial interval observation as described above was used to record off-task behavior.

### Junior High Student Popular Book Genres

To answer question two regarding genres of books preferred by the junior-high students, the students completed the interest survey described earlier. In addition, they completed the *Book Show & Tell* form in which they ranked their top four choices from the 25 books shown them.

### Students' Attitudes Toward Reading and Book Matching

To answer question three regarding students' attitudes about reading, a post-study student survey was created for all the students to complete regarding the book matching process. The survey consisted of eight questions: (a) Do you know what you are supposed to do during SSR and why?, (b) Do you think it is important to read books? Why or why not?, (c) Did you like reading the book received? Why or why not?, (d) Were there some days that you did not want to read? (If yes, select from the following: (a) I chose not to read (describe what you did instead) (b) Yes, but I read anyway (c) No, I wanted to read everyday. The researchers asked these questions in one-on-one audio-taped interviews with the six target students. The rest of the students (43) in both classes were given the surveys to complete on paper.

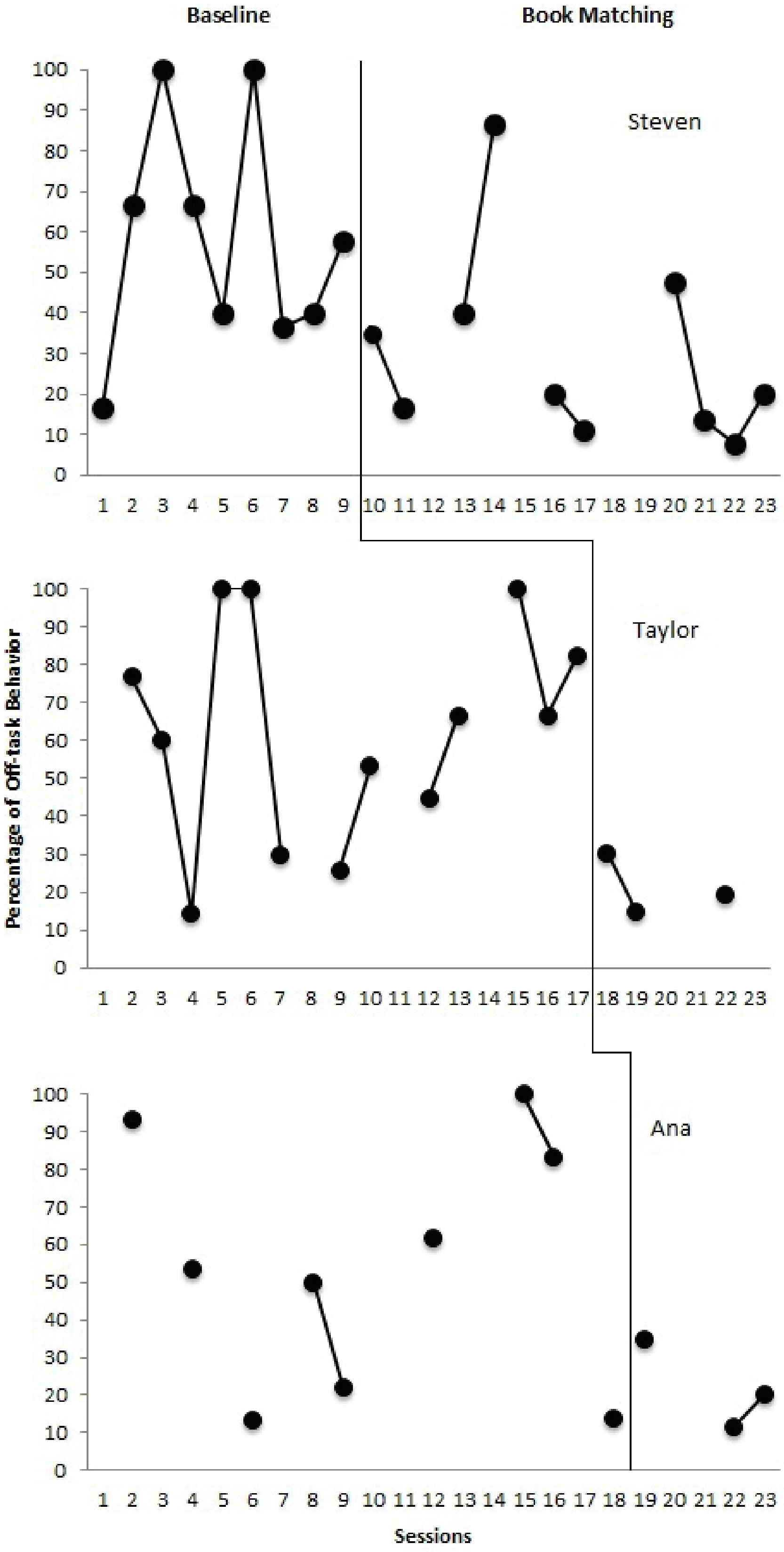
## RESULTS

### Book Matching Intervention

Each teacher identified three students with elevated levels of off-task behavior during SSR for their individual classes; observations prior to the study confirmed an elevated percentage of off-task behavior for those nominated.

Figure 1 shows participants' off-task data during baseline and intervention in the science class. During intervention, Steven, whose SRI score was 640L, was matched with *They Never Came Home* because he said the book was "really interesting." It was one of his top four choices, was a book recommended for 12- to 17-year-olds, had a 750L and a Flesch-Kincaid grade level of 2.6. According to his teacher and the reading specialist, in the past, Steven had often tried to read without appropriate support for his visual impairment.

Figure 1
*Student off-task behavior in science class during SSR. This figure illustrates the percentage of intervals of student off-task behavior during baseline and treatment.*



So, it was unclear whether his SRI score had been determined with appropriate support in place. In any case, he had expressed great interest in this book because he had read another book by the same author. During the nine days of baseline, Steven's average off-task behavior was 58% (range, 17% to 100%). In Steven's case, his elevated levels of off-task behavior may have been impacted by his inability to see the print. The teacher said he often did not have the magnifying glass that was given to him by the school. During intervention, his average off-task behavior was 36% (range, 8% to 86%).

Taylor, whose SRI score was 1226L, read *The Hunt*. She liked it because "it had action in it." It was one of her top four choices, was recommended for 12- to 17-year-olds, had a 730L, and a Flesch-Kincaid grade level of 4.9. During her fourteen days of baseline, Taylor's average off-task behavior was 61% (range, 14% to 100%). During intervention, her average off-task behavior was 38% (range, 10% to 92%). In her case, most of her off-task behavior involved talking with her neighbors. Following intervention, Taylor spent less time talking.

Ana, whose SRI score was 627L and attended an ESL class, was matched with *The Fault in Our Stars* (a realistic book about teens with cancer). It was one of her top four choices, was recommended for 14- to 17-year-olds, and had an 850L (no text selection available to test Flesch-Kincaid). She reported that she thought the book was interesting and that she "wanted to know what other people feel in situations like that." Ana missed 11 of the 23 days of the study; as a result, she began her intervention only one day after Taylor, due to the school year ending in a week. During baseline, she averaged 52% off-task behavior (range, 13% to 100%). During the three days of intervention, her average off-task behavior was 16% (range, 11% to 37%). Thus, the data show that her off-task behavior decreased, but due to her high rate of absenteeism, there are fewer data points for her.

Figure 2
*Student off-task behavior in English class during SSR. This figure illustrates the percentage of intervals of student off-task behavior during baseline and treatment.*

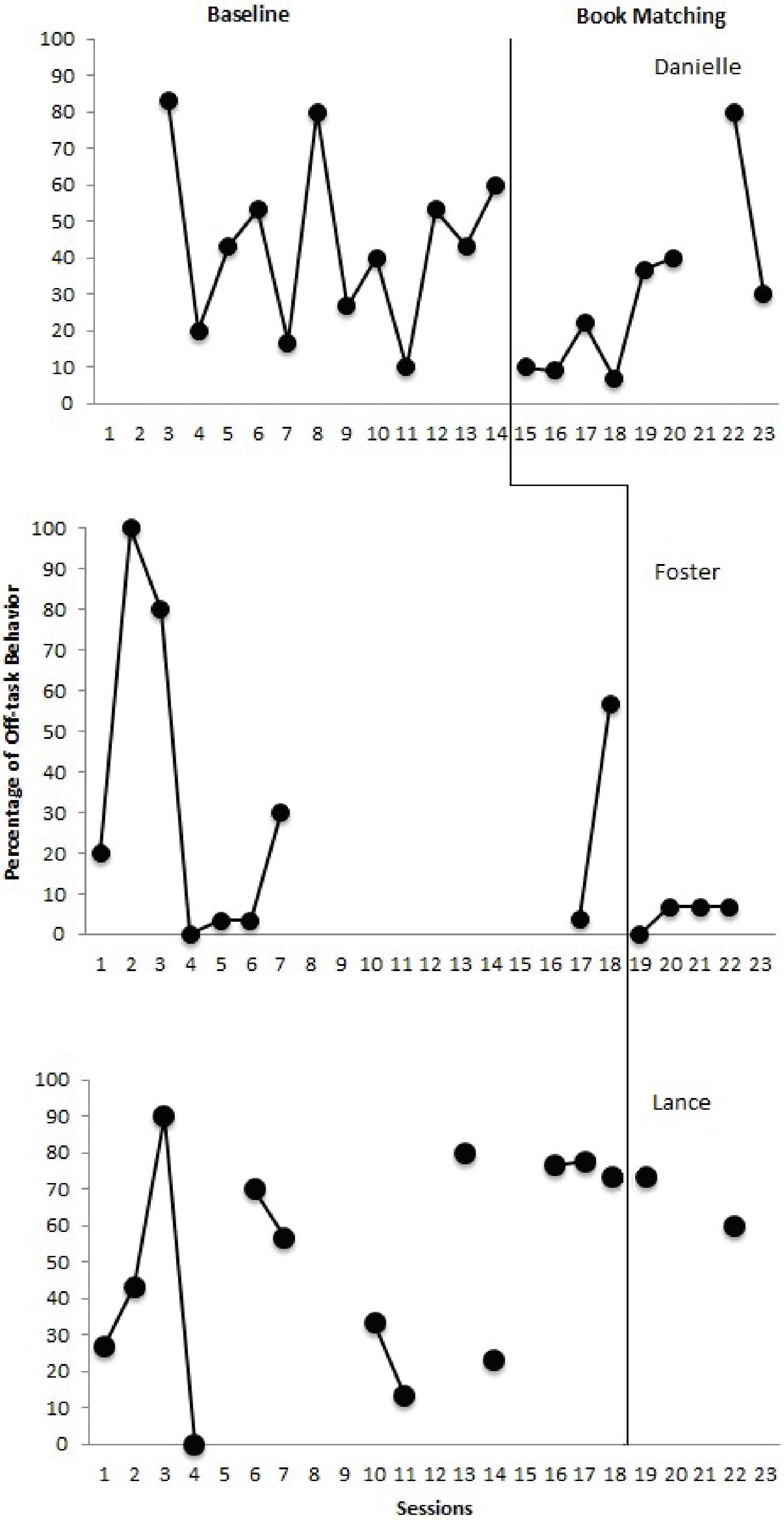


Figure 2 shows participants' off-task behavior during baseline and intervention in the English class. During intervention, Danielle, whose SRI score was 831L, read *Don't Look Behind You*. She said she liked the book because it was a mystery. It was one of her top four choices, was recommended for 12- to 17-year-olds, had a 1020L, and a Flesch-Kincaid grade level of 4.6. During her 12 days in baseline, Danielle's average of off-task behavior was 44% (range, 10% to 83%). During intervention, her average of off-task behavior decreased to 29% (range, 7% to 80%). During most of the intervention, her off-task behavior was lower than 40%. The one day in which Danielle exhibited much higher off-task behavior (80%), she spent her time playing with her hair.

Foster, whose SRI score was 938L, also read *The Hunt* (one of his top four choices.) He said he liked the book because of its "intensity." Foster's baseline off-task behavior was 33% (range, 0% to 100%). During intervention, his average off-task behavior was 5% (range, 0% to 7%). Baseline data were collected before and after the suspension and the data were very similar, 33% and 30%, respectively. During the study, Foster was suspended for two weeks.

Lance, whose highest SRI score was 730L, read *172 Hours on the Moon*. He admitted that he had not read from the book with which he was matched. It was one of his top four choices, was recommended for 13- to 18-year-olds, had a 1030L, and a Flesch-Kincaid grade level of 5.3. During baseline, Lance averaged 51% off-task (range, 0% to 90%). During the two days of intervention, Lance's average off-task was 67% (range, 60% to 73%).

## Junior High Student Popular Book Genres

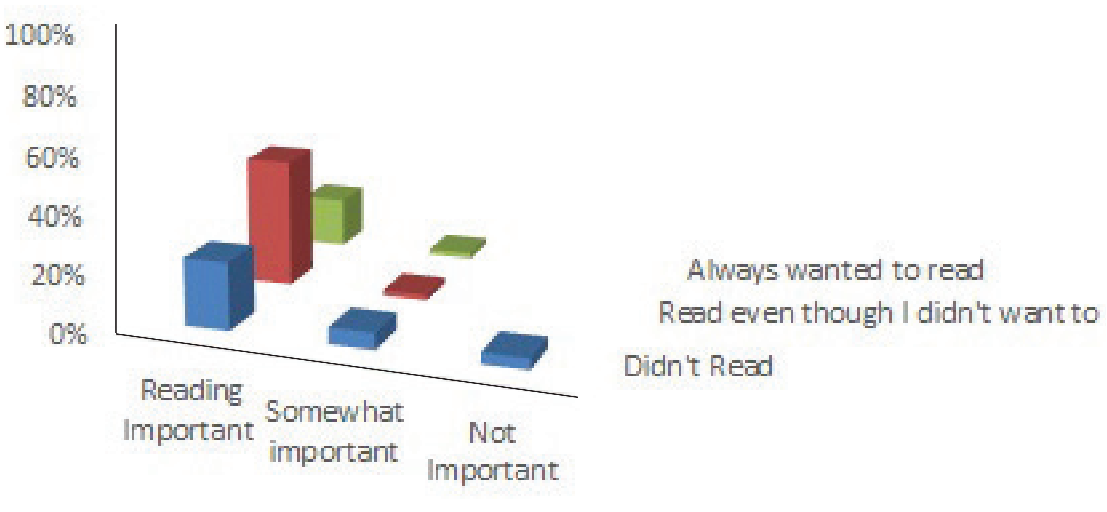
Two methods were used to assess student reading preferences. Results from the first method, *Student Interest* surveys, revealed that students' preferred genres were in this order: (1) Adventure (2) Mystery (3) Fantasy and Science Fiction (tied) (4) Romance (5) War (6) Biography, and (7) Informational. The 25 book choices were organized as mystery/adventure (nine books); romance/teen life (five books); science fiction/fantasy (five books); and biography/sport (six books). The second method came from the results gathered from the *Book Show & Tell* form; they were similar to those in the interest survey and indicated that students preferred the adventure/mystery genre, followed by fantasy/science fiction, Romance/Teen Life and finally, Biography/Sports.

### Students' Attitudes Towards Reading

Figure 3 displays student self-reported attitudes toward reading and reading behavior during SSR taken from the *Student Attitude Toward Reading* survey. There were nine of 49 students (18%) who found reading to be important or somewhat important and reported on the survey that they always wanted to read during SSR. There were 24 of 49 (49%) students who stated that reading was important or somewhat important and reported they didn't want to read, but did so anyway. Among those who didn't read, 15 of 49 students (30%) said reading was important or somewhat important. Most of the students, five of six (83%), targeted for data collection stated that they believed reading to be important or somewhat important. Nevertheless, four of the five (80%) indicated there were days they did not choose to read. However, the observational data showed that they did read more often when matched with a book. The student, Lance, who stated reading was not important, was the only targeted student whose off-task behavior actually increased with the matched book, stating that "it was boring."

Figure 3

*Student-reported attitudes towards reading and reading behaviors during SSR. This figure illustrates students' reported reading attitudes and reading behaviors.*



## DISCUSSION

Across the course of the study, five of the six students' average off-task behavior decreased as a result of the book matching. This result confirmed the hypothesis that a pre-reading strategy of matching students with books to read, according to their interests and reading abilities, positively affects their time on task during SSR. In the study by Allen and colleagues (2006) in which a post-reading activity was implemented, pre-baseline data show students' average off-task behavior as 16.1%. After the book matching, students' off-task behavior averaged 8.6%. This decrease in off-task behavior could indicate that book matching acted as an intervening variable. In this pre-reading activity study, students' average off-task behavior at baseline was 49.8%. After the book matching intervention, it was 31.2%. Data collection was not conducted during Foster's two-week suspension, resulting in missing data. The events that precipitated the suspension were not provided to the researchers, in accordance with the United States Federal Educational Right to Privacy Act.

In both the Allen et al. (2006) and this current study, book matching appeared to impact student behavior, but it did not completely solve the problem of non-participation. One explanation for this result might be that the book matches were actually not matches. The books were selected for the students based on their indicated interest in them following a preview from one of the researchers about the books selected (after reviewing their genre preferences). However, it may be that once the student actually got the book, it did not capture his or her attention or proved to be too difficult, despite all the steps taken to make the right match. This was clearly the case with Lance, as he stated he did not read the book given to him during intervention, even though it was a book in which he expressed interest. As a result, more research should be done that allows students to move quickly to another choice if a book does not appear to be the best match. It may be that after a false start or two, the student would be matched with a "just right" book and stay on task consistently.

A limitation of this study was the inability to collect maintenance data due to conducting the research at the end of the school year. Additional research that examined the long-term impact of the intervention on student behavior would strengthen the argument for taking the time to match students with reading that matches their abilities and interests. It also may have been important to collect off-task data in other classes to determine whether the level of off-task behavior was specific to the reading, or whether there were elevated levels of off-task behavior across subjects.

Another limitation of this study may have been that students were identified and selected by their classroom teachers before the intervention. Therefore, the researchers were unable to effectively provide accommodations prior to the book match intervention. This fact may have influenced baseline data for the off-task behavior of Stephen as large print was unavailable during baseline data collection.

### Junior High Book Genre Preferences

The participants in this study confirmed that the stated reading preferences of adolescent students have remained remarkably static over the last 15 years. The clear preference was for adventure and mystery books. It is also clear that, consistent with Wigfield and Guthrie's (1993) proposal that students will read if they are personally connected to their reading, almost half (44%) of the students surveyed indicated that they *liked* to read only when the book they were reading was interesting to them.

### Attitudes Toward Reading

Overall, most of the students clearly believed that reading is important. Even those who stated they did not read during SSR, 15 of 49 (30%), said reading was important or somewhat important. Moreover, five of the six (83%) targeted students (identified because of their high levels of off-task behavior) stated that they believed reading to be important or somewhat important. Thus, believing in the importance of reading was not sufficient incentive to ensure that the students would read even when given time to do so.

### Recommendations

In general, results from this study indicated that what students read can impact the degree to which they remain on task during SSR. As students were provided reading material that interested them and were able to read, they spent more time on task. Even so, the results did not show that implementing such a pre-reading strategy alone would completely eliminate student off-task behavior. It is with some caution, and with realistic expectations, that teachers who are required to implement SSR with their students may want to try to intervene in this way. Some suggestions for the classroom teacher include obtaining reading level information from the reading specialist or special educator, systematically observing student behaviors, tracking who is off-task, and then matching those students with high interest reading level books. Once the student has been given the matched book, it should quickly be fairly clear whether the intervention is working, even without a formal data collection process.

In addition, teachers could work toward building a classroom library with a greater variety of reading material at various reading levels or have students spend time with the school's reading specialist or librarian to select texts. At the very least, it would seem prudent to include more adventure and mystery books in the classroom. It is fairly easy to identify popular books by consulting lists put out by booksellers, publishers, librarians, and young adult readers themselves.

## REFERENCES

Allen, N. J., DuBois, A., & Heward, W. L. (2006, May). *The effects of a story fact recall quiz and game on off-task behavior during sustained silent reading (SSR) and the number of story facts recalled following SSR for secondary students with disabilities*. Poster presented at the 32nd Annual Convention of the Association for Behavior Analysis International, Atlanta, GA.

Brame, P. B. (2001). *Making sustained silent reading (SSR) more effective: Effects of a story fact recall game on students' off-task behavior during SSR and retention of story facts* (Unpublished doctoral dissertation). The Ohio State University, Columbus, OH.

Bryan, G., Fawson, P. C., & Reutzel, D. R. (2003). Sustained silent reading: Exploring the value of literature discussion with three non-engaged readers. *Reading Research and Instruction, 43,* 47–73. doi: 10.1080/19388070309558400

Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). *Applied behavior analysis* (2nd ed.). Columbus, OH: Merrill.

Croston, B. (2005). *An investigation of the relationship between student reading interest and teacher selected novels* (Unpublished master's thesis). Bowling Green University, Bowling Green, OH. Retrieved from https://etd.ohiolink.edu/rws_etd/document/get/bgsu1122664868/inline

Davis, Z. T. (1988). A comparison of the effects of sustained silent reading and directed reading activity on students' reading achievement. *High School Journal, 72,* 46–48.

Fisher, D. (2004). Setting the "opportunity to read" standard: Resuscitating the SSR program in an urban high school. *Journal of Adolescent and Adult Literacy, 48,* 138–150. doi: 10.1598/JAAL.48.2.5

Graham, S., & Perrin, D. (2007). *Writing next: Effective strategies to improve writing of adolescents in middle and high schools. A report to Carnegie Corporation of New York*. Washington, DC: Alliance for Excellent Education.

Hale, L. A., & Crowe, C. (2001). "I hate reading if I don't have to": Results from a longitudinal study of high school students' reading interest. *The Alan Review, 28*(3). Retrieved from http://scholar.lib.vt.edu/ejournals/ALAN/v28n3/hale.html

Hairrell, A., Edmonds, M., Vaugh, S., & Simmons, D. (2010). Independent silent reading for struggling readers: Pitfalls and potential. In E. H. Hiebert & D. R. Reutzel (Eds.), *Revisiting silent reading: New directions for teachers and researchers* (pp. 275–289). Newark, DE: International Reading Association.

Hunt, L. C. (1970). The effect of self-selection, interest, and motivation upon independent, instructional and frustrational levels. *Reading Teacher, 24,* 146–151, 158.

Kavale, K. A., & Forness, S. R. (2000). History, rhetoric, and reality: Analysis of the inclusion debate. *Remedial and Special Education, 21,* 279–296. doi: 10.1177/074193250002100505

Manning, M., Lewis, M., & Lewis, M. (2010). Sustained silent reading: An update of the research. In E. H. Hiebert & D. R. Reutzel (Eds.), *Revisiting silent reading: New directions for teachers and researchers* (pp. 112–128). Newark, DE: International Reading Association.

McCracken, R. A. (1971). Initiating sustained silent reading. *Journal of Reading, 14,* 521–524.

MetaMetrics, (2014). What is a Lexile measure? Retrieved from https://lexile.com/educators/understanding-lexile-measures/

Mikulecky, L., & Wolf, A. (1977). Effect of uninterrupted sustained silent reading and of reading games on changes in secondary students' reading attitudes. *Reading: Theory, research, and practice*. Twenty-sixth yearbook of the National Reading Conference. ED# 227440 p. 126–130.

National Institute of Child Health and Human Development. (2000). Report of the National Reading Panel. *Teaching children to read: An evidence-based assessment of the scientific research literature on reading and its implications for reading instruction* (NIH Publication No. 00-4769). Washington, DC: US Government Printing Office.

Parker, L. G. (1986). *A study of the effects of sustained silent reading on reading achievement scores of inner city middle school students* (Unpublished doctoral dissertation). University of Connecticut, Storrs.

Pilgreen, J. L. (2000). *The SSR handbook: How to organize and manage a sustained silent reading program*. Portsmouth, NH: Boynton/Cook.

Read180.scholastic.com. (n.d.). Retrieved http://www.sb.school/common/pages/DisplayFile.aspx?itemId=148652

Reutzel, D. R., Fawson, P. C., & Smith, J. A., (2008). Reconsidering silent sustained reading: An exploratory study of scaffolded silent reading. *The Journal of Educational Research, 102*(1), 37–50. doi: 10.3200/JOER.102.1.37–50

Reutzel, D. R., Jones, C. D., & Newman, T. H. (2010). Scaffolding silent reading: Improving the conditions of silent reading practices. In E. H. Hiebert & D. R. Reutzel (Eds.), *Revisiting silent reading: New directions for teachers and researchers* (pp. 129–150). Newark, DE: International Reading Association.

Scholastic. (2013). *Kids and family reading report* (4th ed.). Retrieved from http://mediaroom.scholastic.com/kfrr

Siah, P. C., & Kwok, W. L. (2010). The value of reading and the effectiveness of sustained silent reading. *The Clearing House, 83,* 168–174. doi: 10.1080/00098650903505340

Topping, K. (2017). What kids are reading: The book-reading habits of pupils in British schools. *Renaissance*. Retrieved from http://doc.renlearn.com/KMNet/R60818.pdf

Walker, B. J. (2000). *Diagnostic teaching of reading: Techniques for instruction and assessment*. (4th Ed.). Upper Saddle, NJ: Merrill Prentice Hall.

Wigfield, A., & Guthrie, J. T. (1993). *Dimensions of children's motivations for reading: An initial study*. Retrieved from http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.470.3787&rep=rep1&type=pdf

Worthy, J., Moorman, M., & Turner, M. (1999). What Johnny likes to read is hard to find in school. *Reading Research Quarterly, 34*, 12–27. doi: 10.1598/RRQ.34.1.2

Yoon, J. C. (2002). Three decades of sustained silent reading: A meta-analytic review of the effects of SSR on attitude toward reading. *Reading Improvement, 39*(4), 186–195.

# Amplifying Voices of Children with Disabilities: Perceptions of Healthcare Experiences

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## Abstract

*In this study, the authors amplify the voices of children with disabilities who have experienced different aspects of the healthcare field. This qualitative study used interviews, drawings, and medical play to discover three participants' perspectives on previous healthcare experiences. Inductive analysis was applied to investigate the child participant data with the aim to assist healthcare providers and educators in understanding the meaning of healthcare experiences for children with disabilities. The findings suggest that children with disabilities who have had experiences with general medicine (e.g., child check-ups, specialist's visits) may have primarily positive perceptions of healthcare, and can communicate this well through drawing and medical play. This study demonstrates the significance of qualitative research with children with disabilities to further understand the uniqueness of their healthcare experiences and highlights the need for collaboration between special educators and health-care professionals.*

Keywords: *children with disabilities, qualitative research, healthcare experiences, special education, medical play, Certified Child Life Specialist*

## INTRODUCTION

The United Nations Convention on the Rights of the Child supports child health as an international goal, illuminating it as a right to be provided to the "highest attainable standard of health" (p. 39) and protected by laws of nations that ratified the agreement (Todres, 2010). The World Health Organization (2015) endorses key processes in improving all aspects of child life, including maternal, newborn, child/adolescent health, across all countries. These processes involve improving programs, monitoring of programs, and related research to continue improving child health. Researchers and practitioners value the great benefits of child health, as it is well-documented that health concerns often are connected with disabilities (Centers for Disease Control and Prevention [CDC], 2017). Across the globe, children with diagnosed disabilities experience health challenges that are often manifestations of the disability itself. These disability manifestations are also called secondary conditions. For instance, a child with Down syndrome, spina bifida or multiple sclerosis may experience other physical or mental health challenges as a result of their disability. Health challenges impact the child in many contexts, including the classroom. Using the examples given above, a child with Down syndrome, spina bifida or multiple sclerosis might experience acute pain, depression, or anxiety, impacting their ability to experience maximum success in the classroom environment. This study strives to share the results of the authors' research to empower educators and medical personnel to have a developmentally-appropriate dialogue and interactions with young children with disabilities regarding their medical experiences.

Children typically find hospitalization, a nonnormative experience, to be stressful. A problem in the pediatric healthcare field is finding ways to improve the healthcare experiences of children with disabilities (Shilling, Edwards, Rogers, & Morris, 2012). Coyne (2006a) interviewed hospitalized children (ages 7–14) without disabilities and discovered they had varying fears that can be clustered into four themes: "separation from family and friends; being in an unfamiliar environment; receiving investigations and treatments; and loss of self-determination" (p. 328). As Coyne's research revealed, children without disabilities are fearful during hospitalization. Children with disabilities who require accommodations for coping in normative situations might find the nonnormative hospital to present impossible obstacles to adjustment during healthcare experiences.

The first author's experience as a Certified Child Life Specialist, an interdisciplinary healthcare team member responsible for pediatric patients' psychosocial care (American Academy of Pediatrics, 2014), reinforces that children with disabilities must be afforded opportunities to explore their perceptions of healthcare events, and be given a voice to share the meaning these experiences have in their lives. The interdisciplinary healthcare team can improve patient care outcomes for pediatric patients with disabilities by hearing directly from the children themselves (Coyne & Gallagher, 2011). Ideally, for holistic support of the child and family, a child-centered team approach would empower all stakeholders in the medical and educational systems.

Special educators are typically trained to partner with families of children with disabilities utilizing a family-centered approach. According to Bronfenbrenner's ecological theory (Turnbull, Turnbull, Erwin, & Soodak, 2006), all pieces of the environment surrounding a child impacts their growth, development, and success. Healthcare was a large part of the lives of the study participants. Bronfenbrenner's theory supports the idea that children do not compartmentalize various aspects of their lives. Their experiences outside of the school setting impact their schooling. As professionals working daily with children with disabilities, both in healthcare and education, it is necessary to understand the impact of all systems on their quality of life. The two primary systems impacting the lives of children and families—the two that bridge the microsystem and exosystem—are school and social services/healthcare. As a Certified Child Life Specialist in practice, it was the first author's experience that little communication occurred to bridge the micro and exosystems. For instance, a social worker may send information to the school, but medical personnel and special educators rarely collaborate to provide the best experiences for children and families to thrive within both systems.

## Literature Review

The American Academy of Pediatrics Committee on Bioethics (2016) stated that pediatric patients should be involved in decision-making based upon their development, have the right to know about their health, treatment choices, risks, benefits, and may choose other options. Oulton, Sell, Kerry, and Gibson (2015) conducted an ethnographic study focusing on children with learning disabilities. The researchers interviewed 135 hospital staff from England to determine effective strategies for providing individualized care. Researchers discovered that medical professionals generally found it difficult to communicate effectively with children with learning disabilities and to include them in decisions regarding their health. Most professionals spoke to the parents of the children without considering the communication ability of the child or their willingness to be involved in the decisions themselves. The study resulted in the following practice recommendations: "gaining appropriate knowledge and experience, identifying the population, focusing on the 'little things', creating a safe, familiar environment, using appropriate resources, and developing a partnership with parents" (p. 81). Special educators are equipped to provide individual, child-centered practices, and are an excellent resource for medical professionals seeking to enhance their interactions with children who have disabilities.

As a means for pediatric patients to be more involved in decisions related to their own care, Coyne (2006b) recruited eleven child participants (ages 4–15) from two different pediatric hospitals in England. The researcher gathered qualitative data via interviews, observations, and drawings finding that the children wanted to receive treatment information and be involved in their healthcare decisions, which contributed to the children feeling in control during the life-disrupting experience of hospitalization.

Coyne (2006a) used grounded theory and interviewed 11 participants (7–14 years old) from pediatric hospitals in England. By identifying their fears, Coyne explained that children need structure and safety in new environments as they are required to acclimate to the hospital's routines that can cause them to feel exasperated and helpless. Carney et al. (2003) interviewed 213 school-age children to discover their views of hospitalization. These United Kingdom researchers reported that children need information that is age-appropriate and individualized to assist them in adjusting to hospital routines in order to decrease stress. While Coyne and Carney et al.'s participants were children developing typically, one might anticipate that children with disabilities in hospitals might experience similar fears that could be exacerbated by having a disability. For example, a child with an autism spectrum disorder might need more time to learn the hospital's structure and routines. Within an inflexible hospital setting, this child with autism might feel distress. However, pediatric practitioners who understand the needs of a child with a disability can help the child cope with the healthcare environment.

Garth and Aroni (2003) interviewed four children (ages 6–12) from Australia diagnosed with Cerebral Palsy (CP) and learned the children wanted to be included in communication with the doctor, wanted to engage in answering questions asked, and be able to ask questions of the doctor. The children and mothers valued communication with the doctor. Garth, Murphy, and Reddihough (2009) conducted a larger, qualitative study in Australia looking at the role of children with CP (n = 33) in the triad relationship with parent and doctor. Adults in the partnership often hold the power and restrict the amount of child participation. The children felt they added to the partnership and it was important that they be heard and informed during their medical encounters. Based on these researchers' findings that children with disabilities desire inclusion, special educators are potential partners already equipped to assist healthcare professions in bridging the reported communication gap.

Sartain, Clarke, and Heyman (2000) interviewed seven children with various chronic illnesses (ages 8-14), their families, and professional caregivers from England to compare their thoughts about being at home vs. being in the hospital. The authors recommended that children with a chronic illness needing ongoing healthcare encounters have to be heard in order to change the services provided to them. Coyne and Gallagher (2011) conducted focus groups and interviews with school-age children and adolescents (7–18 years old, n = 55) from three different hospitals in Ireland. These researchers found that a healthcare team that communicates directly with children about choices in medical participation demonstrates respect for the child that fosters psychosocial benefit. These authors also learned that when the medical staff provided patient-centered care by incorporating the children in their healthcare decisions, the children perceived an improvement in their quality of care. These findings suggest that children are able to share their perspectives and offer healthcare staff a way to see their perceptions of illness, which provides evidence that listening to children's preferences can improve their healthcare experience.

Children with special healthcare needs often have multiple, ongoing, and invasive medical experiences that can cause physical pain and emotional anxiety. Kogan, Strickland, and Newacheck (2009) explain:

> Children with special healthcare needs (CSHCN) are defined as those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. (p. S333)

Houtrow, Okumura, Hilton, and Rehm (2011) conducted a logistic regression on data from the United States 2005-2006 National Survey of Children with Special Healthcare Needs (n = 42,322). The researchers classified children with special healthcare needs who also had a disability as a highly at-risk population due to the consequences of a serious health issue. The researchers suggested CSHCN with disabilities required healthcare-givers to concentrate on healthcare and social aspects due to a prevalence of psychosocial needs (behavioral, anxiety, depression, and social relations with peers) in this population compared to the general CSHCN group. These authors identified the CSHCN population with disabilities is underrepresented in the research literature.

Shilling, Edwards, Rogers, and Morris (2012) reviewed qualitative studies of children from birth to age 18 diagnosed with a chronic illness looking at the experiences of children with disabilities during inpatient hospitalization. The researchers found that the children's experiences were not always favorable, identifying healthcare staff communication with the children as a key component to a child's positive or negative hospital experience. McMurray and Beebee (2007) learned that hospital staff felt unsure about providing care for individuals with learning disabilities. To foster positive healthcare experiences, these authors recommended disability awareness training to increase effective communication and competent care for patients with disabilities. Special educators, experts in disability awareness, child-centered practices, and developmentally-appropriate communication would be an asset to medical practitioners.

There was limited research on children with disabilities' views and perceptions of healthcare experiences in the literature reviewed. The amount of qualitative research with this population is also limited. The purpose of this qualitative research study was to amplify perceptions of children with disabilities regarding their healthcare experiences. These perceptions inform how healthcare professionals can improve the care provided to this pediatric population. Guiding research questions included:

1. What are the children with disabilities' perceptions of healthcare experiences?
2. What meaning did these experiences have for the child?
3. How do these experiences affect the child?

This study contributed to addressing a gap in literature in an effort to promote more beneficial clinical practice for medical staff working with this population.

Table 1

*Interview Participants' Information.*

| **Participant** | **Age (years)** | **Grade** | **Diagnosis** | **Socio-economic Status** | **Family Structure** |
|---|---|---|---|---|---|
| 1 – Abe | 7 | 2nd | Autism | Upper class | Intact nuclear |
| 2 – Zeb | 10 | 5th | Unspecified physical and communication disabilities | Lower class | Single mother |
| 3 – Bob | 8 | 3rd | ADHD | Middle class | Single mother |
| *Note*: All names in this paper are pseudonyms. | | | | | |

## METHODS

### Research Design

A qualitative research design was selected for this research with children who have disabilities. Qualitative inquiry allows for participants' subjectivity, highlights participants' individual truth, and provides participants power (Grbich, 2013a). Patton (2002a) identified that qualitative data offer the ability to, "communicate someone else's experience of the world in his or her own words" (p. 47). Qualitative methodologies are well suited for partnering with children in research, since they allow for child-centered data collection methods that encourage children to share their perceptions (Clark, 2011).

### Participants

Participants with disabilities were recruited from a rural area of the southeastern United States as part of a doctoral program qualitative research study. Research approval was given by the university's Institutional Review Board. The initial recruitment goal of purposive sampling was to work with agencies that provide services to children with disabilities, but ultimately the three participants (requirement of the doctoral course) were referred from a mutual personal contact. Inclusion criteria were to be of school age (6–11 year-olds), have a diagnosed disability, and have healthcare experiences of any type (preventative or medically necessary for treatment of an illness) in any setting (inpatient, outpatient, emergency department). The three participants in this study were White males between the ages of seven and ten years old (see Table 1). Each one had a diagnosed disability (Table 1) and the majority of their medical experiences were typical healthcare experiences in doctors' office settings, which is the context for their healthcare experiences.

### Data Collection

Three forms of data collection were purposefully used to foster triangulation and ensure reliability: interviews, drawings, and medical play. The first author's previous experience as a Certified Child Life Specialist (CCLS) taught the researcher several things about working with children. First, this therapeutic work enabled the first author to build rapport with children quickly. Second, she experienced that interviews, drawings, and medical play each had a distinct role in children's expression. Third, she learned that children were often more verbally responsive when the situation was not a direct one-on-one, face-to-face discussion. They were typically most receptive to verbally answering questions and sharing experiences when they had something else to focus their attention on during an interaction. She termed this *busy hands, busy mouth*.

### Interviews

Interview was noted by Patton (2002b) to be a method that assists in getting the participant's perspective through hearing their stories. Semi-structured qualitative interviews were conducted with each participant in his home with his mother present for the interview. All interviews were approximately one hour long and occurred on a weekday afternoon after school. Each participant engaged independently with the exception of Zeb[1]. His mother remained in close proximity to interpret his verbal communication that was sometimes indecipherable to the researcher.

The interviews consisted of everyday conversations integrated with questions to begin building relationships with the children. Sartain, Clarke, and Heyman (2000) found that for children the combination of interviews and drawings was helpful for gathering data. Questions (Table 2) were continual throughout the entire interview process with overlapping drawing and medical play

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[1] All participants' names in this article are pseudonyms.

Table 2
*Sample Interview Questions.*

| |
|---|
| Have you ever been to the doctor or the hospital? |
| Can you tell me about going to the doctor? |
| What did you have to do when you went to the doctor? |
| Is anything hard for you to do at the doctor? |
| If you were the doctor, what would you do? |

portions to further highlight their communication of healthcare experiences. During drawing and medical play, questions were often solely focused on participants' specific medical experiences and the thoughts and feelings related to them.

### Drawings

The drawing activity was very beneficial during the interview process because it allowed for relationship building and the participants enjoyed the activity, a finding supported by Mitchell (2006). Spratling, Coke, and Minick (2012) found that drawing built rapport and promoted conversations with children. The children were all familiar with the process of drawing as well as the materials. Each child readily participated, which allowed for immediate freedom of expression, as they were encouraged to draw what they liked. Further into the interview, the researcher requested the children draw pictures about their healthcare experiences and each one did so without hesitation. The drawings gave another opportunity in the interview to learn more about how the children perceived experiences.

### Medical Play

Medical play, a type of play that includes "medical themes and/or the use of medical equipment" was then introduced to allow each child to explore actual medical items through play in a "role rehearsal/role reversal" situation as the doll patient's doctor (McCue, 1988, p. 158). Bolig (1990) identified non-directed medical play as helpful for children in healthcare. The non-directed approach was specifically implemented to foster the participants' freedom to share their individual medical experiences. Medical play allowed participants to demonstrate through play the experiences they had related to the medical equipment (stethoscope, blood pressure cuff, otoscope, gloves, tongue depressors, gauze, medical tape, bandages, etc.). The children's control over the play facilitated their expression of perceptions not necessarily shared via interviews or drawings. Thus, medical play revealed even more about their perceptions of previous healthcare encounters.

## RESULTS

### Analytic Strategies

***Inductive Analysis***. Inductive analysis was chosen as the analytic strategy for this research. Patton (2002a) described this analysis strategy as, "Immersion in the details and specifics of the data to discover important patterns, themes, and interrelationships; begins by exploring, then confirming; guided by analytical principles rather than rules; ends with a creative synthesis" (p. 41). Patton further elaborated that an inductive method starts with specific data and moves to more general themes with overall categories and dimensions coming from the observed phenomenon.

***Data Analysis***. After the data collection sessions, the first interaction with the data was during transcription of the audio interviews. Transcription provided reinforcement in hearing the perceptions directly through each child's voice. The next step in the analysis was reading through each transcript thoroughly and subsequently identifying codes based on the topic for each line of data.

The codes from the transcripts were typed in a list, cut out from the paper, and tangibly arranged into groupings based on code similarities (i.e. medical equipment was grouped together and people were together in another group). The code groups were assessed to determine the main topic of each of the groups, and this is where the category names originated. Codes were placed into the appropriate category and this iterative process resulted in the initial 14 categories.

The next step was to explore the 14 categories to ensure compatibility with the primary research questions:

1. What are the children's perceptions of healthcare experiences?
2. What meaning did that experience have for the child?
3. How did this experience affect the child?

This assessment shortened the category list by combining certain categories with others and deleting categories unrelated to the research questions. The result was five final categories: medical setting, medical

Table 3
*Categories and Definitions.*

| Category | Definition | Properties |
|---|---|---|
| **Medical Setting** | These are statements made regarding medical settings, which often denoted familiarity and affects perceptions. | |
| **Medical Intervention/Medical Equipment** | This category related to the interventions experienced and the equipment utilized to implement medical interventions. | Positive<br>Negative |
| **People in the Medical Setting** | This is a list of people mentioned as being present or aware of role in the medical setting. | Family members<br>Medical staff |
| **Behavior and Control** | These are various behaviors the participants exhibited, including to seek something specific or related to control. | |
| **Feelings and Emotions** | The feelings and emotions, experienced and expressed, by the participants | Positive<br>Negative |

intervention/medical equipment, people in the medical setting, behavior and control, and feelings and emotions.

Being true to an inductive analysis, the categories (shown in Table 3) derived from the participants' data were used to create definitions and properties for each category rather than relying on definitions already in existence. This is the idea Patton (2002a) defined as that of allowing data themes to come from participants without the researcher forcing the data to fit preset frameworks, which is done in deductive analysis (LeCompte & Schensul, 1999). The participants' definitions reinforce the integrity of the categories that emerged during data collection. The fit between the final five categories and the primary research questions was intact, since no new categories emerged from the codes in the transcripts. This indicated that data "saturation" (Grbich, 2013b, p. 82) was achieved with these participants. The final five categories in this research were naturally divided into two overarching components. The first component included the medical aspects (setting, equipment, interventions, people at the setting) and the second component related specifically to the child participants (behavior, control, feelings, emotions) as shown in Table 4. The findings presented here are based upon this breakdown of data into five categories, with specific categories being explored individually below.

### Medical Setting

The medical setting category was identified through statements made by the participants about medical settings they knew from previous experience. Abe[1] shared, "Not the hospital" when asked if he had ever been to the doctor or hospital. Bob stated, "I've been to the emergency room" and "I had to go to the doctor." His response to the question, "What have you had to do at the doctor before?" was "Watch TV and play", and "Watch TV. Try to go to sleep." Abe's response was "Uh, playing with toys." When asked whether going to the doctor was hard or easy, both Abe and Zeb stated "Easy." Qualitative semi-structured interviews allow flexibility for the researcher in regard to not dictating a fixed set of questions for every participant. This combined with the child-centered data collection sessions resulted in Bob not being asked this specific question. The familiar settings and child-friendly, non-medical activities the children engaged in while at the doctor may have contributed to these participants' primarily positive perceptions.

### Medical Intervention/Equipment

The category of medical intervention and medical equipment related to the participants' medical experiences. The participants identified familiarity with standard well-child medical interventions and the pieces of equipment available during the medical play session. These experiences presented a dichotomy of positive and negative, with injections being the only intervention noted as negative by all three participants.

Table 4
*Overarching Components of Categories.*

| Medical Aspects | Participant Aspects |
|---|---|
| Medical Setting<br>Medical Intervention/Equipment<br>People at Medical Setting | Behavior and Control<br>Feelings and Emotions |

Figure 1
*Bob's Drawing of "Glovs" (sic).*

Bob specifically had an affinity for gloves that exhibited his familiarity with them from previous medical experiences, "I got a bunch and took 'em home, didn't I, Mama?" He was so comfortable with this medical item that he felt safe in bringing it home. The drawing he showed the researcher was presented with this declaration, "There's a glove on the back. There's gloves at the doctor" (Figure 1). In response to the question, "What all did you have to do when you went to the doctor?" he replied, "I got some gloves." Gloves were a positive piece of equipment that contributed to his positive perception about the doctor's office.

The blood pressure cuff was a piece of medical equipment all three participants showed familiarity with during medical play. Abe said "Well, sometime I get blood pressure," and then identified it as the easiest thing about going to the doctor. When Zeb was asked about the blood pressure cuff, he identified it as being both easy and hard. He mimicked the blood pressure cuff procedure by wrapping his hand around his opposite forearm to demonstrate how the blood pressure cuff squeezes, which he identified as the hard part. Bob said "blood pressure," which he explained, "Yeah, you just squeeze it." During medical play with the doll patient and the blood pressure cuff, his medical description was, "He's all blood pressured." The fact that he coined his own term for the medical intervention showed his comfort level with the experience. This was probably due to the role reversal of control in medical play. He shared a comment that confirmed his role reversal, "I'm his doctor."

The participants knew of the thermometer, and "the ears thing," commonly known as the otoscope, that "He checks my eyes, and so um, like my mouth" and "Checking their ears, checking eyes." Bob's response to seeing the stethoscope and being asked, "What's it do?" by the researcher was, "Listen to your heartbeat." Abe knew the role of the doctor as "checks my heartbeat" related to the stethoscope as he shared, "Um, you use for your heartbeat," when he saw it during medical play. The participants' ability to verbally label and describe the uses for these items during medical play reflected their knowledge and positive perceptions of previous medical experiences through uninhibited engagement with the equipment.

The only invasive medical intervention mentioned during this interview and medical play session was, "Well, sometimes get shots and flu shots," and "flu shots." Zeb made a hand sign in response to the question, "So can you tell me about going to the doctor?" His mother translated the sign, saying, "Shots; he don't like them." It was autumn, the time of year children often receive the influenza immunization, and it was a recent experience for Zeb and possibly all three participants.

The initial topic of injections was raised with Bob, asking the question, "Is anything hard for you to do when you go to the doctor?" His sibling assisted the researcher in translation of the question and instructed him to tell the researcher what Bob was "scared of." When asked, "Is there anything you would tell doctors and nurses about how to make going to the doctor better for kids?," his reply was, "Not having shots." The question was posed, "So if you were in charge of the hospital, Bob, what would you do to make it a nice place for kids?" He was consistent in his response: "Be nice to them if they get a flu shot. They wouldn't get it." This participant's experiences with injections were so negative, he deemed them scary. His mother corroborated, stating, "He's terrified of needles."

Bob described injections as, "They poke me. It feels like a pinch," and did not offer any type of coping method for the medical experience. Abe shared that, "Sometimes it hurts a little," when he gets an injection and verbalized his coping mechanism as, "I close my eyes." When asked, "What should he do with this one?" in reference to a needleless syringe, he shared this coping plan for his doll patient: "Close his eyes while he had shots." All three participants identified injections as a negative medical experience in their lives and only one participant identified how to help himself. The researcher found this reflects most children's experience

Figure 2
*Abe's Drawing of His Doctor's Office Visit with Doctor, Himself, and Mother.*

with needle interventions as the fear often overwhelms their ability to cognitively identify coping methods, which must be learned in order for the children to find them effective (Hart & Rollins, 2011).

### People at Medical Setting

People in the medical setting were identified as people being present or those the participants were aware of who had a role in the medical setting. Family members were most predominant within this category.

The researcher asked Abe, "Can you draw a picture of the last time you went to the doctor and the doctor's office that you were in or the doctor or the nurse?" He responded by drawing very intently. Abe said his picture was of, "My doctor, my mom at the table, and two chairs" (Figure 2). He then identified the doctor as the one sitting at the table with the computer and his mother as the one with the big smile. The context for Abe in this drawing was a general check-up with a specialist in a children's hospital. He gave no indication in his transcript responses that he associated any negative meaning with the experience or that the experience was perceived as anything but typical for him. The researcher interpreted this as a typical, normative experience in his life.

This discussion of people began when Bob was asked to draw a visit to the hospital or doctor's office. When asked to share who was in his picture, he began by stating, "Mom and me," then progressed to sharing, "And one more person… that stayed a while: It's my sissie." He elaborated, "She's my mom's sister." Then he named the individuals in his drawing in their order of appearance, "That's me, that's sissie, that's my mom" (Figure 3).

Bob's interest in the Child Life specialty initiated some questions and comments that displayed his knowledge of medical staff. He asked the researcher, "Are you a paramedic?" Then he stated, "I thought you said you were a doctor." These statements revealed his familiarity with these healthcare team members and no perceptions either negative or positive were expressed.

### Behavior and Control

The category of behavior and control only came up with Bob, possibly due to his diagnosis of attention-deficit/hyperactivity disorder. His exhibition of numerous behavior and control exertions, and the researcher's knowledge of the importance of control to children in healthcare, provided the rationale for keeping this category in the analysis. Children having medical experiences often feel they have no control and look for both information and opportunities to take control in order to cope (Goldberger, Mohl, & Thompson, 2009). The various behaviors the participant exhibited were predominantly in the codes of information-seeking and control taken.

Information-seeking appeared in several questions asked by Bob, "What's this for?" and "What's this mean? I need help. How do you do this?" referring to the thermometer. The question, "What do you want me to do it on?" was looking for direction on where was an appropriate place to utilize the stethoscope.

Examples of control being exerted or taken by this participant were the most often noted behavior. These were often declarative in nature: "Ok, I'll pick out all of my favorites. No looking," and "There, read that." Those instances directly related to medical play included, "No, not my patient", "Let's check his ears", "Now we need to put his together", "More medicine", and "Can I take Mom's pressure, blood pressure?" Exerting control related to his perceptions of healthcare experiences demonstrated his understanding that control of the medical items allowed the one in possession to be in charge of the situation and often in charge of those involved, too.

Medical play was instrumental in Bob's ability to take control. One other notable code was seeking validation, "Look at my patient, Mama," which was demonstrated by Bob despite having all of the control in medical play. This need for validation revealed his vulnerability and need for his mother's support, which would also contribute to positive healthcare experiences. This

Figure 3
*Bob's Drawing of His ER Visit with Mother and Sissie.*

interaction reveals that a combination of adult support and the child's ability to have shared control within the healthcare experience eases health challenge stressors.

### Feelings and Emotions

Bob expressed and described feelings and emotions during the interview. His discussion of people who were with him at the hospital included this description: "We're all sad." He changed his mind about one aspect of this drawing: "Why did I draw me a smiley face? I meant to draw a sad face." He repeated this exact quote when reflectively asked, "You meant to draw a sad face?" His ability to change and redraw the facial expression to represent the true feeling he experienced is a reflection of the therapeutic-ness of drawing the experiences during interview (Figure 3). The participant's description when asked about needles being scary was, "They poke me. It feels like a pinch."

In the middle of medical play he shared his feelings about the session, "It's fun." Near the end of the medical play session when asked if there was anything his patient did not like today he responded, "He liked all of it." This projection of feelings onto the doll indicated the participant's comfort level with medical play due to primarily positive previous experiences.

Abe showed his drawing to the researcher, who stated, "You look happy, too. Everybody's got smiling faces on because you said the hospital makes you happy, huh?" He seemed to have drawn a realistic representation of his medical experience with some positive affect attached to the drawing (Figure 2). Through medical play, Abe shared, "He feels happy," in reference to his doll patient's thoughts about the medical play procedures. When asked, "What do doctors do when they take good care of kids?" he replied, "Make them happy." Abe consistently reported his perceptions of medical experiences as positive through interview, drawing, and medical play, which was a strong example of the quality of triangulation of methods in this research.

## DISCUSSION

### Interpretation of Findings

The objective of this study was to discover the perceptions of children with diagnosed disabilities regarding their healthcare experiences. The participants in this study experienced primarily preventative well-child and typical sick-child doctor's visits. They occasionally visited a specialist (e.g., neurologist) for their disability, but those encounters were usually noninvasive. Thus, within the context of these experiences, their perceptions were predominantly positive. The meaning they attributed to these experiences was normative (non-threatening) and these non-stressful encounters with medical staff resulted in a positive affect (feeling).

One participant had a nonnormative mental health crisis visit to the emergency room that impacted him and his family negatively, which was communicated with negative perception, meaning, and affect from the interview and drawing he produced (Figure 3). This instance was considered an atypical medical experience for this specific participant and would have been so if experienced by the other two participants as well.

The only common negative perception was related to injections or "shots" as the participants named them. All three participants expressed a negative connotation regarding the experience of injections and exhibited negative affect when discussing these experiences. This procedure is often done within the scope of a standard well-child or sick-child visit so all three were very familiar with the injection experience and assigned negative meaning to it.

### Quality of Research

The use of three data collection methods provided triangulation of the data (Lapan, 2004). The combination of medical play with interviews and drawings was significant to producing well-triangulated quality results. Interviews relied on verbal communication that some children may find challenging when speaking with an adult or even due to their disability. Drawings allowed children to express what they understood and perceived about their world and provided a medium for the expression of feelings that may be difficult to share verbally. Consistency of participants' responses within the findings substantiated the effectiveness of triangulation of these methods within this research.

The sample of three participants was small and thus limited the extent to which the findings from this study can be generalized to a broader population.

### Contribution to Literature

Children with disabilities may not automatically have negative perceptions, meanings, or affect related to typical healthcare experiences. There are various challenges children with disabilities face within the healthcare system, as noted by many authors in the review of literature; however, this research revealed that not all children with disabilities have difficulty coping with routine healthcare visits. A quantitative study focused on CSHCN with disabilities found that this group of children had the same needs when in healthcare situations as typical children (Houtrow, Okumura, Hilton, & Rehm, 2011). This research reiterated that children be individually assessed for their need for psychosocial intervention within medical situations. Discovering that these participants coped with typical healthcare appointments like their peers without disabilities demonstrates that children with disabilities may not require specialized services for their success with healthcare interventions. Findings from this study need to be interpreted with caution due to a small sample size.

### Future Implications

***Clinical Practice***. Clinical practice considerations include awareness that children with disabilities may not need more support for typical healthcare encounters than their peers who do not have a disability. This highlights the need for each child to be assessed and treated as an individual, regardless of a diagnosed disability or lack thereof. This knowledge may alleviate healthcare providers' anticipation of challenges during medical encounters, which would lead to more comfortable interactions, making it a more positive experience for everyone.

An additional issue for clinical practice was working with the children to fully understand their point of view by hearing their perceptions. Healthcare providers from every discipline would benefit by incorporating play and drawing into their assessment time with all children. Age appropriate play and drawing allow child patients the opportunity to become comfortable in the medical setting and provide non-verbal expressive opportunities to communicate perceptions of their experience.

Another component to contemplate for future research on including children with disabilities is the severity of health-related diagnoses. The impact of the diagnosis on children's perception, meaning, and affect is likely to become more negative with lengthier and more invasive healthcare experiences, which would potentially create more stress for the children, their parents, and healthcare professionals.

***Medical Play.*** One implication for future research is the value of a Certified Child Life Specialist (CCLS) utilizing medical play as a data-gathering method. Medical play is typically an intervention used in clinical practice by a CCLS, but in this research, it was utilized as a data collection tool. In this new role, medical play provided participants the ability to convey in another distinct modality their knowledge, experience, and emotions related to medical equipment and interventions. It offers participants control via role reversal, allowing them to demonstrate perceptions, meaning, and true affect. From this CCLS researcher's experience, medical play is a highly instrumental data collection tool that should be used when doing research with children regarding their healthcare experiences.

***Education Connections.*** While this study focuses on the medical field, fears (outside of school) affect how children are able to learn and interact in a school setting (Roberts, Wurtele, Boone, Ginther, & Elkins, 1981). As special education professionals, it is necessary to understand how children with disabilities perceive their healthcare experiences. When writing individualized plans and working through behavior concerns in the classroom, educators may utilize findings from this study and others related to children with disabilities and healthcare experiences. Awareness of the child's healthcare experiences impacts child interactions within the educational setting and may be the missing piece to successful transdisciplinary partnerships. Medical play would be especially effective with children with disabilities who are nonverbal and cannot share health concerns in a traditional mode. Historically, both the medical and education fields have functioned within a multidisciplinary team. Medical play and its associated communication methods would aid professionals in both fields in moving toward transdisciplinary team functionality, resulting in greater benefit to the family system.

***International Relevance***. Child health is an international concern with many issues associated with disability. As practitioners in the international community, working toward effective service delivery, developmentally and disability appropriate strategies (assessment, intervention, and research) are essential throughout the world. As an international community, it is crucial to reach out to one another, sharing strategies that improve child health and resulting education for all children and families. This article provides a qualitative research framework with clinical practice implications to influence child-centered care in both educational and medical settings. The voices of children should be paramount to both areas of practice, regardless of their geographic home.

## Conclusion

This research amplified the voices of children with disabilities by asking about their perceptions of healthcare experiences, the meaning assigned, and the effect on the life of the child. Child responses given through semi-structured interview, medical play, and drawings of healthcare experiences revealed that these participants, despite a disability diagnosis, had typical healthcare encounters, with "shots" being the unanimous negative experience. While typical healthcare encounters may seem insignificant, the healthcare experiences of all children are unique, and when necessary, should be shared with educators as they impact the educational experience. Each of the participants shared a desire to be heard by medical professionals who, in turn, may value children advocating for their own health. Ecological systems theory consists of interaction between systems, in this case micro- and exosystems, substantiating that what happens in the medical setting overflows into the educational system. A dialogue between systems, and a privileged voice of the child, are crucial for maximum development.

Research with children who have diagnosed disabilities has much potential to affect their healthcare and educational experiences. Interdisciplinary healthcare team members making a conscious effort to individually assess each patient's needs may discover that children with disabilities in typical medical experiences are just like their peers without disabilities. Educators who better understand health issues that may be a manifestation of a child's disability may discover that children with disabilities are more eager to learn when the educator better understands their individual needs. This realization may allow healthcare providers and educators to be more comfortable and effective when providing care, creating a positive experience for all involved. This journey of qualitative research in healthcare amplified the voices of children with disabilities and verifies the many contributions of qualitative research in various fields of study.

> "The travels we take down the 'infinite path' can only be facilitated by a type of research that gets to the bottom of things, that dwells on complexity, and that brings us very close to the phenomena we seek to illuminate." (Peshkin, 1993, p. 28)

## REFERENCES

American Academy of Pediatrics. (2016). Informed consent in decision-making in pediatric practice. *Pediatrics, 138*(2), 1484–1490.

American Academy of Pediatrics. (2014). Child life services. *Pediatrics, 133*(5), e1471–e1478.

Bolig, R. (1990). Play in health care settings: A challenge for the 1990's. *Children's Healthcare, 19*, 229–233.

Carney, T., Murphy, S., McClure, J., Bishop, E., Kerr, C., Parker, J., Scott, F., Shields, C., & Wilson, L. (2003). Children's views of hospitalization: An exploratory study of data collection. *Journal of Child Healthcare, 7*, 27–40.

Centers for Disease Control and Prevention. (2017, August). Disability overview: Impairments, activity limitations, and participation restrictions. Retrieved from Centers for Disease Control and Prevention website http://www.cdc.org

Clark, C. (2011). *In a younger voice: Doing child centered qualitative research*. New York, NY: Oxford University Press.

Coyne, I. (2006a). Children's experiences of hospitalization. *Journal of Child Healthcare, 10*, 326–336.

Coyne, I. (2006b). Consultation with children in hospital: Children, parents', and nurses' perspectives. *Journal of Clinical Nursing, 15,* 61–71.

Coyne, I., & Gallagher, P. (2011). Participation in communication and decision-making: Children and young people's experiences in a hospital setting. *Journal of Clinical Nursing, 20,* 2334–2343.

Garth, B., & Aroni, R. (2003). ‘I value what you have to say’. Seeking the perspective of children with a disability, not just their parents. *Disability and Society, 18*(5), 561–576.

Garth, B., Murphy, G. C., & Reddihough, D. S. (2009). Perceptions of participation: Child patients with a disability in the doctor-parent-child partnership. *Patient Education and Counseling, 74,* 45–52.

Goldberger, J., Mohl, A. L., & Thompson, R. (2009). Psychological preparation. In R. Thompson (Ed.), *The handbook of child life: A guide for pediatric psychosocial care* (pp. 160–198). Springfield, IL: Charles C. Thomas.

Grbich, C. (2013a). Introduction. *Qualitative data analysis: An introduction* (2nd ed.) (pp. 3–14). Thousand Oaks, CA: Sage.

Grbich, C. (2013b). Grounded theory. *Qualitative data analysis: An introduction* (2nd ed.) (pp.79–91). Thousand Oaks, CA: Sage.

Hart, R., & Rollins, J. (2011). Tension release. *Therapeutic activities for children and teens coping with health issues* (pp. 133–148). Hoboken, NJ: Wiley.

Houtrow, A., Okumura, M., Hilton, J., & Rehm, R. (2011). Profiling health and health-related services for children with special healthcare needs with and without disabilities. *Academic Pediatrics, 11*(6), 508–516.

Kogan, M., Strickland, B., & Newacheck, P. (2009). Building systems of care: Findings from the national survey of children with special healthcare needs. *Pediatrics, 124* (Supplement), S333–S336.

Lapan, S. (2004). Evaluation studies. In K. deMarrais & S. Lapan (Eds.), *Foundations for research: Methods of inquiry in education and the social sciences* (pp. 235–248). Mahwah, NJ: Erlbaum.

LeCompte, M., & Schensul, J. (1999). Analysis from the top down. *Analyzing and interpreting ethnographic data* (pp. 45–66). Walnut Creek, CA: Altamira Press.

McCue, K. (1988). Medical play: An expanded perspective. *Children’s Healthcare, 16*(3), 157–161.

McMurray, A., & Beebee, J. (2007). Learning disability awareness. *Learning Disability Practice, 10*(3), 10–14.

Mitchell, L. (2006). Child-centered? Thinking critically about children’s drawings as a visual research method. *Visual Anthropology Review, 22*(1), 60–73.

Oulton, K., Sell, D. S., Kerry, S., & Gibson, F. (2015). Individualizing hospital care for children and young people with learning disabilities: It’s the little things that make the difference. *Journal of Pediatric Nursing, 30*, 78¬–86.

Patton, M. (2002a). Strategic themes in qualitative inquiry. *Qualitative research and evaluation methods* (pp. 37–74). Thousand Oaks, CA: Sage.

Patton, M. (2002b). Qualitative interviewing. *Qualitative research and evaluation methods* (pp. 339–427). Thousand Oaks, CA: Sage.

Peshkin, A. (1993). The goodness of qualitative research. *Educational Researcher, 22*(2), 23-29.

Roberts, M., Wurtele, S., Boone, R., Ginther, L., & Elkins, P. (1981). Reduction of medical fears by use of modeling: Preventive application in a general population of children. *Journal of Pediatric Psychology, 6*(3), 293–300.

Sartain, S., Clarke, C., & Heyman, R. (2000). Hearing the voices of children with chronic illness. *Journal of Advanced Nursing, 32*(4), 913–921.

Shilling, V., Edwards, V., Rogers, M., & Morris, C. (2012). The experience of disabled children as inpatients: A structured review and synthesis of qualitative studies reporting the views of children, parents, and professionals. *Child: Care, Health and Development, 38*(6), 778–788.

Spratling, R., Coke, S., & Minick, P. (2012). Qualitative data collection with children. *Applied Nursing Research, 25*, 47–53.

Todres, J. (2010). Children’s health in the United States: Assessing the potential impact of the Convention on the Rights of the Child. *Child Welfare, 89*(5), 37–56.

Turnbull, A., Turnbull, R., Erwin, E., & Soodak, L. (2006). *Families, professionals, and exceptionality: Positive outcomes through partnerships and trust*. Upper Saddle River, NJ: Pearson.

World Health Organization. (2015, September). *Maternal, newborn, child and adolescent health: Planning, monitoring and research*. Retrieved from World Health Organization website http://www.who.int/maternal_child_adolescent/planning/en/

# Planning Quality Services for Students with Significant Support Needs

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## Abstract

*Using a comprehensive set of quality indicators grounded in evidence-based practices, evaluation, planning, and improvement of services for students with the most significant support needs can be completed. This nine-step process is described with examples for implementation.*

Keywords*: Severe disabilities, quality indicators, service provision*

Sara was a third-year special education teacher at a middle school. She had nine students with Significant Support Needs (SSN) on her caseload, and she had six paraeducators assisting her throughout the day. Sara believed her students should be in general education classes, when possible, to access the general education curriculum; her principal supported her in this decision. However, she was concerned about how the curriculum was being modified for all of her students in general education classes. She also was unsure if the students' IEP goals were being consistently reinforced and if communication systems were being used. Over the past two years, Sara developed services in the least restrictive environment, and most students spent a majority of their day in the general education classroom. Sara contacted and met with the teachers who had her students in general education classes. Some of the teachers were comfortable modifying curriculum to meet student needs, but others were unsure and left curriculum modification up to the paraeducators. The paraeducators worked with Sara, who modified as much as possible, but the general education teachers often added new tasks without giving Sara the content to modify. A couple of teachers stated that they preferred the paraeducators to modify the curriculum "on-the-fly" (these general educators generally didn't plan more than one or two days in advance). As Sara spoke with and observed teachers, she found some were more skilled than others in making modifications and that students' IEP goals were inconsistently practiced across content areas. Student engagement in the classes also fluctuated in the content areas. When questioned, most teachers indicated they were willing to learn how to make modifications more effectively and wanted to improve student outcomes. Sara knew she wanted to help the general education teachers and her paraeducators understand the best way to work with the students. She also wanted to make sure the instruction her students received was based on evidence-based practices, and she wanted to improve their outcomes. She began searching for her next step.

## INTRODUCTION

"Sara" provides an example of the process of evaluating and improving services for students with significant support needs (i.e., students with severe disabilities). This example is a compilation of a variety of experiences the authors' encountered during the implementation process and does not represent one teacher or school. This process was developed to address the struggle of effective program evaluation and improvement for students with significant support needs (SSN), especially at the secondary level (Downing, 2005).

One issue is focusing research in this area, given the relatively low number of students with SSN; these students make up less than 1% of the U. S. public school population. Typically, these students have a significant cognitive disability, sometimes paired with communication, sensory, and/or physical disabilities. These students require substantial modifications and supports to access standards-aligned education (Browder & Spooner, 2006). Providing education for students with SSN presents substantial challenges to both general and special educators.

One persistent problem for students with SSN is that, despite the Individuals with Disabilities Education Act (IDEA, 2004) mandate for the least restrictive environment, and despite the publication of evidence-based practices for students with SSN, these students and their families often struggle to access standards-based education (Browder & Spooner, 2006; Kennedy & Horn, 2004). Additionally, students receiving special education services continue to lag behind typical peers in academic achievement, often due to lower expectations (Aron & Loprest, 2012).

The following sections describe a process for improving educational services for students with SSN using a rubric of *Quality Indicators for Assessing Individualized Services for Students with Significant Support Needs* to evaluate services, and then to implement changes based on that evaluation. This process involves a continuous reflection and action sequence whereby the individuals are striving to ensure services are evidence-based. Rubrics are documented in the research as effective tools for assessment (Bal & Trainor, 2015; Chard, Ketterlin-Geller, Baker, Doabler, & Apichatabutra, 2009). Additionally, Blumberg (2013) suggests that critical self-assessment should integrate information from a variety of sources. The assessment process described in this article is intended to assist educators in developing their knowledge and skills about the implementation of services for students with SSN and, in turn, improve the educational outcomes of these students. Specific steps provide a guide for educators to use the rubric to improve special education services.

Resource

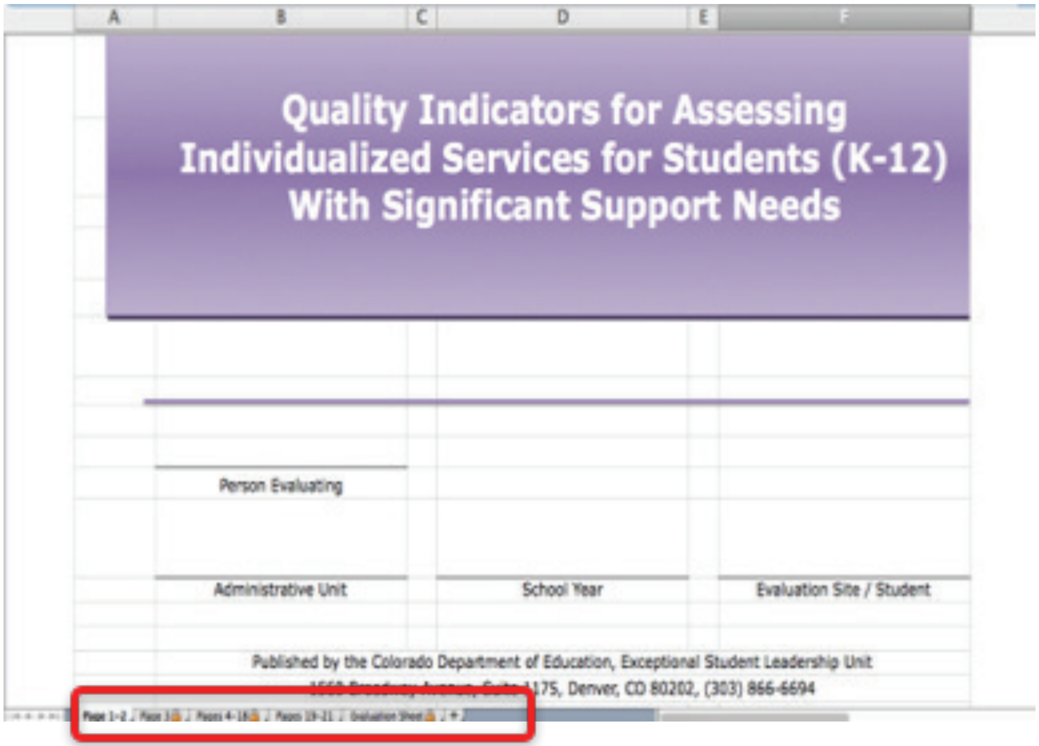
The *Quality Indicators for Assessing Individualized Services for Students with Significant Support Needs and the Summary Score Sheet* can be found on the Colorado Department of Education's website at https://www.cde.state.co.us/cdesped/ssn_qi

### Using the *Quality Indicators for Assessing Individualized Services for Students with Significant Support Needs* to Improve Services

In an attempt to improve services and, therefore, outcomes for students with significant support needs, the U.S. state of Colorado developed the rubric of *Quality Indicators for Assessing Individualized Services for Students (k-12) with Significant Support Needs* (QIs)

Figure 1

*The QI Excel document cover page with bottom tabs for the different sections.* (Source: Colorado Department of Education, 2010.)



Quality Indicators for Assessing Individualized Services for Students (K-12) With Significant Support Needs

Person Evaluating

Administrative Unit

School Year

Evaluation Site / Student

Published by the Colorado Department of Education, Exceptional Student Leadership Unit

175, Denver, CO 80202, (303) 866-6694

(Colorado Department of Education, 2010). “Quality indicators are statements of specific practices that have been documented through research and/or school-based experiences to promote the creation of inclusive learning communities where all students can be successful” (New Jersey Council on Developmental Disabilities and the New Jersey Coalition for Inclusive Education, 2010). The items in the Quality Indicators for Assessing Individualized Services for Students (k-12) with Significant Support Needs (Colorado Department of Education, 2010) were identified through an extensive review of research literature and are designed to evaluate a given service’s degree of implementation of those research-based services for students with significant support needs (Browder, Spooner, Ahlgrim-Delzell, Harris, & Wakeman, 2008; DiPaola, Tschannen-Moran, & Walther-Thomas, 2004; Friend & Cook, 2012; Roach & Elliott, 2006; Stecker, Lembke, & Foegen, 2008; Snell & Brown, 2011; Wehmeyer, 2004).

The intent of the *Quality Indicators for Assessing Individualized Services for Students (k-12) with Significant Support Needs* (QI) (Colorado Department of Education, 2010) is to provide guidance to educators and educational teams to evaluate, develop, and implement goals leading to an improvement in services for students with SSN. The QI tool was developed as an Excel document, enabling the evaluator to complete the evaluation using a tablet or computer. The scores are then automatically tallied and summarized at the end of the document. The document is separated into different sections on tabs at the bottom of the document. Tab 1 is the cover and directions, Tab 2 is a description of how each section of the tool is divided, Tab 3 contains the assessment tool, Tab 4 is the action plan form, and Tab 5 contains the evaluation sheet with the summary of the scores (see Figure 1). These sections will be discussed in detail.

The QI process has been developed into a nine-step practice for improving services for students with SSN (see Figure 2). The process of developing the content of the QI document included identifying the services for students with SSN with a strong evidence-base in the research. Asking experts in the field to review the content and identify any missing, redundant, or unnecessary items was completed to refine and validate the QIs. This was followed by five years of field-testing, data collection, and analysis. Analyzing five years of data revealed the QIs as being both valid and reliable, as well as sustainable across time (Brewer & Carroll, 2014).

Figure 2
*Steps to Improving Services for Students with SSN.*

1. Build your team
2. Assess the service delivery using the QIs
3. Compile the data
4. Review the data
5. Develop the Action Plan
6. Implement the Action Plan
7. Revisit the Action Plan and review progress
8. Reassess using the QIs at the end of the year
9. Develop a new Action Plan for the upcoming year

When developing the QIs, 10 different domains were identified. These domains were considered to be the broad categories of service delivery, consisting of general themes across a student’s day. The 10 domains are Inclusive Culture, Collaboration, Communication, Instruction, Paraeducators, Progress Monitoring, Positive Behavior Support, Self-Determination, Transition, and Health and Safety. The next task was to further subdivide the domains into indicators; indicators are specific areas to target within the domain. For example, the Communication domain was subdivided into two indicators: *expressive* and *receptive* language. Each indicator was then further partitioned into discrete measureable components. These components are the observable measures for which to look when determining if the services are being addressed. Figure 3 provides an example of the domain, indicator, and component for Communication (domain), Expressive Language (indicator), and the associated components.

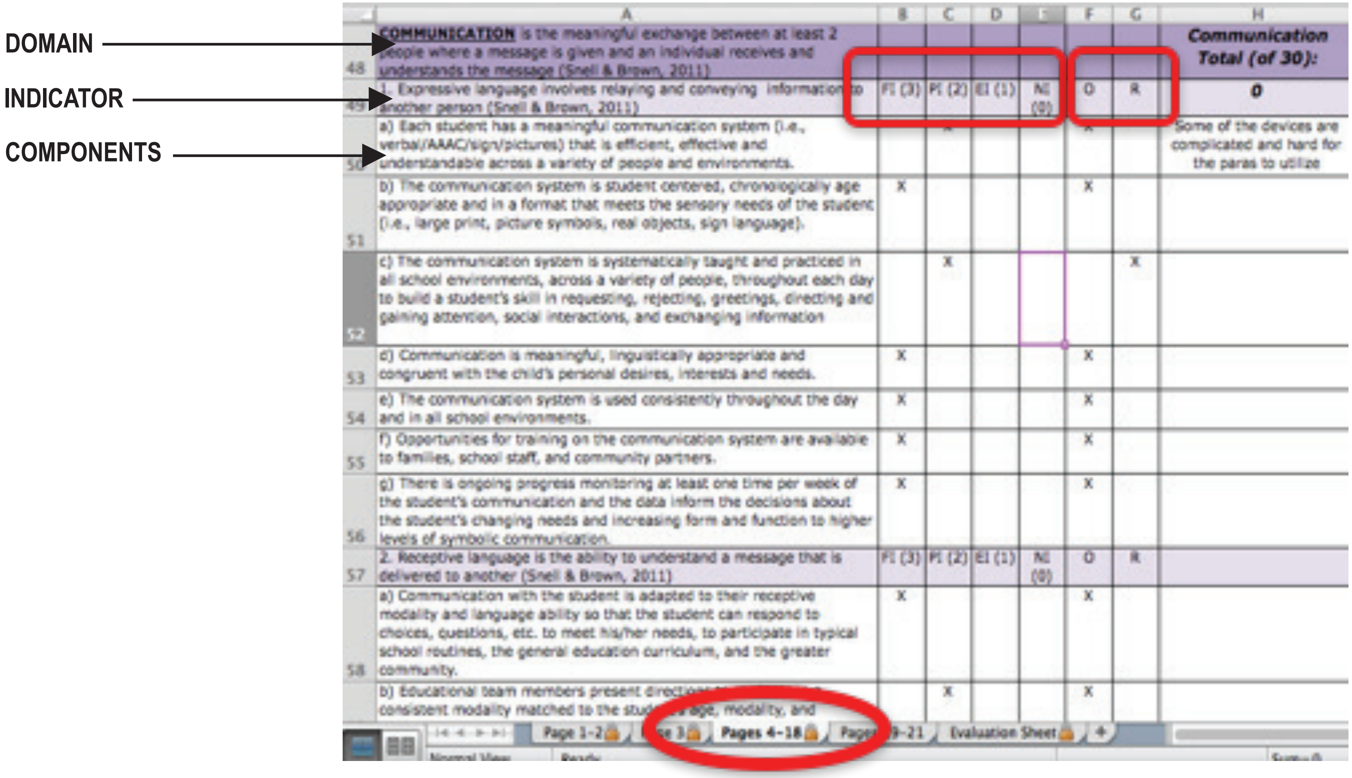
The components are rated based on the evaluator’s knowledge of the services provided to students with SSN. The services are scored as fully implemented (3 points), partially implemented (2 points), emerging implementation (1 point), or not implemented (0 points) by the evaluator. Additionally, evaluators indicate if they scored the components based on personal observation (O) or if the scoring was based on information reported by others (R). Space is provided to describe the evidence-base for the score (e.g., data sheets documenting training or implementation of IEP goals) as well as space for additional comments the evaluator feels helps to explain the scoring. Totaled scores are then totaled and presented in graphic form on the Evaluation Sheet (see Figure 4).

As a word of caution, the quality indicators are not intended to replace policy or regulation, but they can be used as a guide to help improve the evidence-based services for those educating students with SSN. The goal

Figure 3

*Sample of a scored QI rubric. Domains are located on pages 4-18 and can be found on a tab at the bottom of the document; Column A contains the descriptions of the Domains, Indicators, and Components; Columns B-E contain the scores for the components; Columns F & G contain the documentation for the data source.*

(Source: Colorado Department of Education, 2010.)



| | A | B | C | D | E | F | G | H |
|---|---|---|---|---|---|---|---|---|
| 48 | **COMMUNICATION** is the meaningful exchange between at least 2 people where a message is given and an individual receives and understands the message (Snell & Brown, 2011) | | | | | | | ***Communication Total (of 30):*** |
| 49 | 1. Expressive language involves relaying and conveying information to another person (Snell & Brown, 2011) | FI (3) | PI (2) | EI (1) | NI (0) | O | R | ***0*** |
| 50 | a) Each student has a meaningful communication system (i.e., verbal/AAAC/sign/pictures) that is efficient, effective and understandable across a variety of people and environments. | | X | | | X | | Some of the devices are complicated and hard for the paras to utilize |
| 51 | b) The communication system is student centered, chronologically age appropriate and in a format that meets the sensory needs of the student (i.e., large print, picture symbols, real objects, sign language). | X | | | | X | | |
| 52 | c) The communication system is systematically taught and practiced in all school environments, across a variety of people, throughout each day to build a student's skill in requesting, rejecting, greetings, directing and gaining attention, social interactions, and exchanging information | | X | | | | X | |
| 53 | d) Communication is meaningful, linguistically appropriate and congruent with the child's personal desires, interests and needs. | X | | | | X | | |
| 54 | e) The communication system is used consistently throughout the day and in all school environments. | X | | | | X | | |
| 55 | f) Opportunities for training on the communication system are available to families, school staff, and community partners. | X | | | | X | | |
| 56 | g) There is ongoing progress monitoring at least one time per week of the student's communication and the data inform the decisions about the student's changing needs and increasing form and function to higher levels of symbolic communication. | X | | | | X | | |
| 57 | 2. Receptive language is the ability to understand a message that is delivered to another (Snell & Brown, 2011) | FI (3) | PI (2) | EI (1) | NI (0) | O | R | |
| 58 | a) Communication with the student is adapted to their receptive modality and language ability so that the student can respond to choices, questions, etc. to meet his/her needs, to participate in typical school routines, the general education curriculum, and the greater community. | X | | | | X | | |
| | b) Educational team members present direction[illegible] consistent modality matched to the stud[illegible] age, modality, and | | X | | | X | | |

is to use the QIs in their entirety to improve services and ensure all students experience a quality education through the implementation of research-based academic and functional systems (Colorado Department of Education, 2010).

### The Process: Steps to Improving Services for Students with SSN

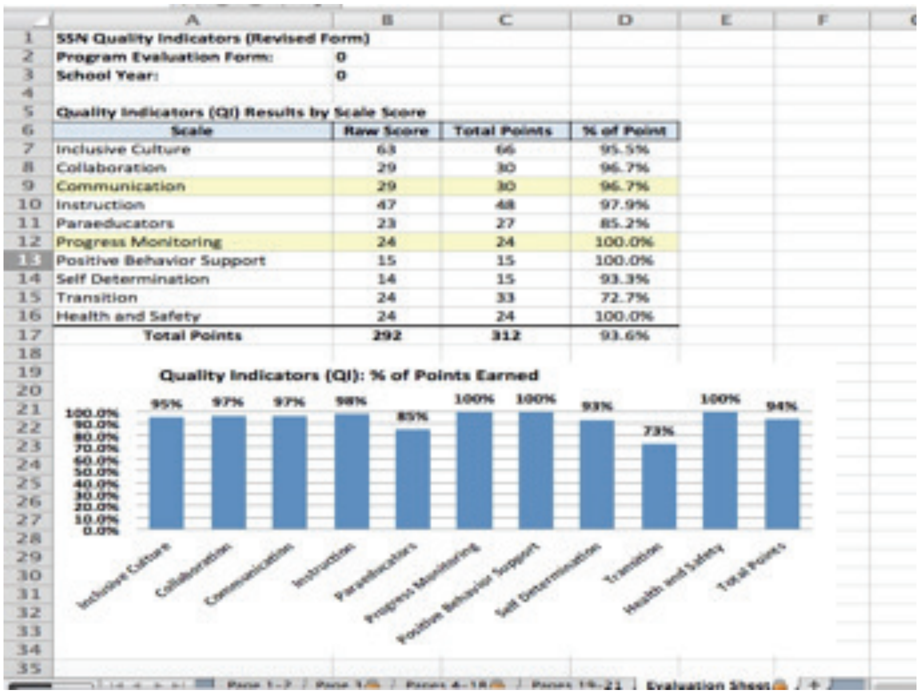
The implementation of QIs in a number of districts throughout Colorado has allowed the authors of this paper to gather feedback and fine-tune the process by attempting to make the evaluation, scoring, and planning process an easy and meaningful one. An important aspect of the QI process is that it is not a one-time event, but rather, a recursive process. That is, the QI process is used to improve and strengthen services for students with SSN and with each passing year, the services improve by targeting priority areas and developing a realistic action plan.

Educational teams should make sure the QI process is meaningful, but not overwhelming. The process can help teams understand what they do well and self-identify what areas need additional focus. Completing the process gives a team a way to structure formative assessment and ongoing planning for the next academic year, keeping the team engaged in continuous improvement. The steps for this process, listed in Figure 2, are described in detail below.

### Step 1—Build Your Team

To begin, discuss the process with the school team and/or an administrator to determine the commitment to the process. Having a cohesive team ready to take a critical look at the services to students with SSN, and one in which everyone is committed to change, is important to the success of the process and provides a good start to the improvement process. The process requires individuals to look at what they are doing well and, as a team, design a plan for improving the services in areas of identified need.

Figure 4
*A sample completed QI evaluation page with final scores.*
(Source: Colorado Department of Education, 2010.)



SSN Quality Indicators (Revised Form)
Program Evaluation Form: 0
School Year: 0

Quality Indicators (QI) Results by Scale Score

| Scale | Raw Score | Total Points | % of Point |
|---|---|---|---|
| Inclusive Culture | 63 | 66 | 95.5% |
| Collaboration | 29 | 30 | 96.7% |
| Communication | 29 | 30 | 96.7% |
| Instruction | 47 | 48 | 97.9% |
| Paraeducators | 23 | 27 | 85.2% |
| Progress Monitoring | 24 | 24 | 100.0% |
| Positive Behavior Support | 15 | 15 | 100.0% |
| Self Determination | 14 | 15 | 93.3% |
| Transition | 24 | 33 | 72.7% |
| Health and Safety | 24 | 24 | 100.0% |
| Total Points | 292 | 312 | 93.6% |

If a team process is not possible and an individual teacher desires to evaluate their services in order to improve his/her program, this process can still be completed. While a team process is preferable, the goal is to improve services for students with SSN, and it may need to begin with one individual taking the lead and starting the process. It is suggested that, if an individual teacher evaluates the services in his/her program without the benefit of a team, the results be reviewed with an administrator or mentor, and the remainder of the steps followed.

The team members should be selected from administrators, special education teachers, related service providers, speech/language pathologists, paraeducators, and others involved with the services to students with SSN in a given program. A team of at least three individuals generally provides sufficient data to provide an overall review of the services.

Once the team is identified, determine who will lead the process; this may be the special education teacher or any team member identified by the team as a leader. Tasks for the lead person(s) include setting a timetable for QI completion, compiling and averaging QI rubric scores on the Excel spreadsheet, analyzing comments, setting meeting times, and creating agendas. The lead person ensures the process is linked to the QI data.

It can also be helpful if the services are evaluated by one or two individuals who are not part of the team (e.g., district employees). This outside perspective can be valuable. A district-level person may also suggest additional resources when developing an action plan and support action items that require district approval.

### Step 2—Assess the Service Delivery Using the QIs

To ensure a comprehensive review of services, individual members independently evaluate the services using the QIs. This provides multiple perspectives and a more comprehensive review of the services. It helps if itinerants who work with multiple schools and/or teachers, such as teachers of the visually impaired, occupational therapists, physical therapists, and school psychologists, complete the QIs, as they can offer a unique perspective. Their interactions with students provides them the opportunity to understand the services, yet they can be somewhat separated from the intensive service delivery within the school.

A team may also have paraprofessionals complete the QIs to understand their outside perspective of service delivery to students with SSN. This provides additional information and can help educators understand service provision from the paraeducator's point-of-view. After completing the QI evaluation process, each evaluator can review their own scores on the final page of the document. The Evaluation Sheet lists the data in table form as well as in graphic display (Figure 4).

### Step 3—Compile the Data

Once all QIs have been completed individually, select a lead person to collate and enter the individual data for each domain area onto the evaluation sheet. Figure 5, the evaluation sheet, is a separate Excel document designed to display a summary of each individual's score and an average of those scores. Compiled numeric data for the quality indicators results in scores for each domain area. There are separate columns for external evaluators' scores (if used by the team) to help the team understand their outside perspective. The presentation of all individual average scores and the average final score provides information for a more robust discussion.

Sara met with her mentor, Patricia, and expressed her desire to improve services for her students with SSN and to ensure services were based on current research. Patricia met with the school principal, who supported the improvement process, and a team meeting was scheduled. The team members invited to the meeting included the special educator, speech pathologist, school psychologist, school principal, occupational therapist, and Patricia, the coordinator. It was decided not to include paraeducators in the initial process. Patricia explained the purpose of the meeting to the team and told them she had learned about the *Quality Indicators for Assessing Individualized Services (k-12) for Students with Significant Support Needs* and that the team could use it as an evaluation and improvement tool. Patricia explained the evaluation process to the team, and they decided they would take two weeks to independently complete the QIs. Even though she was considered the external evaluator, everyone would send Patricia his/her results to compile.

Next, Sara began her evaluation using the QIs. When she began the evaluation of the Communication domain, she started reviewing her students' expressive language skills. She observed them using their expressive language skills in general and special education classrooms, the cafeteria, and in the community (see Figure 3). She knew their expressive language systems were meaningful, but she also knew that not everyone understood their systems; therefore, they were not always effective and efficient. She also knew that while she was trained on the communication devices for her students who used them, others were not. She observed the students in several situations and was able to score the QIs as "observed" for some components. But Sara still needed to interview a couple general education teachers and paraeducators to gather data about who was trained and if communication was being practiced across environments.

Finally, compile any comments into a supporting document, taking care to honor all responses. For example, if participants comment that they do not understand the concept or terminology of an indicator, note and address this as you develop your action plan. This will be discussed in subsequent steps.

### Step 4—Review the Data

To ensure transparency, all data and comments are presented to the team, including external evaluators, if applicable. The team then reviews the summary data, celebrates where they scored well, and reviews items with lower scores. The team discusses the data, rank-ordering the 10 domain scores and then prioritizing the QIs based on those scores to shape future plans. Prioritizing does not need to follow the rank based on the evaluation scores. Although some items might score as a high-need area, a team may choose not to address that area for a variety of reasons. For example, if the scores for transitioning to another school results as a high-need area, a team may not have control over the process, and might defer that goal to another time.

Targeting improvement areas requires thought and discussion as the team sets goals. The team must assure their plan is realistic and not over-burden themselves with too many objectives. Once the team selects two or three improvement areas, they move on to the action plan.

### Step 5—Develop the Action Plan

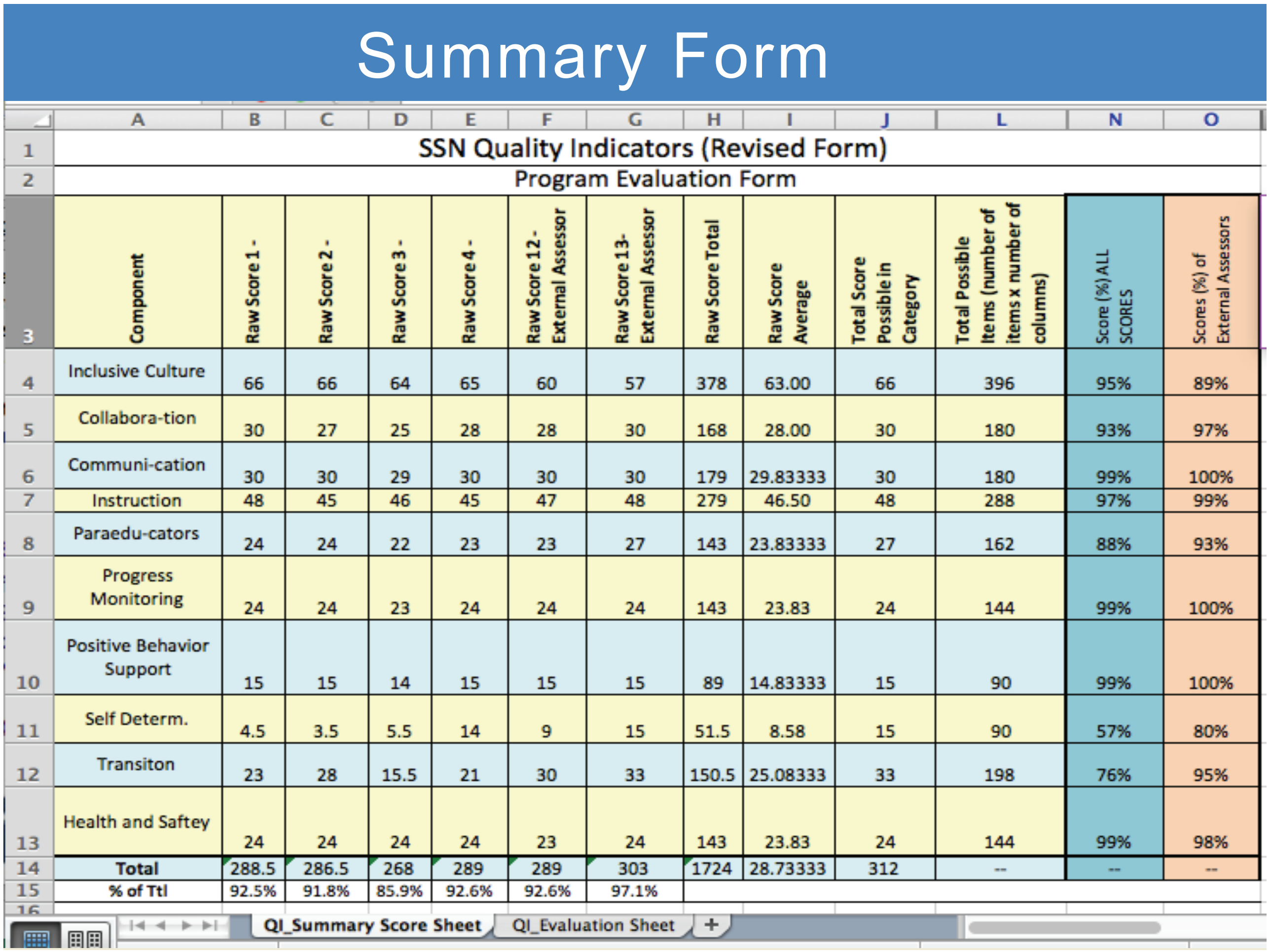
To develop an action plan, access the fourth tab on the QIs. Select two or three objectives to address during the school year. Describe the objectives based on targeted achievements, adding steps for implementation. Once objectives have been developed, determine the necessary personnel, information, and resources; set deadlines, and schedule the team's next progress meeting. Table 1 is an example of one team's action plan for one year, focusing on the Paraeducator and Instruction domains.

### Step 6—Implement the Action Plan

Implementing the action plan is essential. Further, gathering resources and coordinating with other personnel to ensure all timelines are completed is critical to ensure success. For example, if the team has decided that a specific training is needed, identifying an individual to secure appropriate resources and to schedule training is essential. Often, personnel can be found in a district or a local university for low or no cost to assist with that training. Another example might be to implement data systems needed for progress monitoring of students' IEP goals. Taking the time to determine and develop a data tracking system can dramatically increase accountability. Identifying an individual to meet with an administrator to gain support may be a critical first step. A team may identify an action plan item not working as planned or that cannot be implemented as

Figure 5

*Summary Score Sheet showing the raw and average scores from each evaluation. Columns 1-4 are the team member's scores, and Columns 12 and 13 show external evaluators' scores. The second column to the right represents the average of all scores. The right column represents only the average of the external evaluators' scores.* (Source: Colorado Department of Education, 2010.)



Summary Form

SSN Quality Indicators (Revised Form)

Program Evaluation Form

| | A | B | C | D | E | F | G | H | I | J | L | N | O |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 3 | Component | Raw Score 1 - | Raw Score 2 - | Raw Score 3 - | Raw Score 4 - | Raw Score 12 - External Assessor | Raw Score 13- External Assessor | Raw Score Total | Raw Score Average | Total Score Possible in Category | Total Possible Items (number of items x number of columns) | Score (%) ALL SCORES | Scores (%) of External Assessors |
| 4 | Inclusive Culture | 66 | 66 | 64 | 65 | 60 | 57 | 378 | 63.00 | 66 | 396 | 95% | 89% |
| 5 | Collabora-tion | 30 | 27 | 25 | 28 | 28 | 30 | 168 | 28.00 | 30 | 180 | 93% | 97% |
| 6 | Communi-cation | 30 | 30 | 29 | 30 | 30 | 30 | 179 | 29.83333 | 30 | 180 | 99% | 100% |
| 7 | Instruction | 48 | 45 | 46 | 45 | 47 | 48 | 279 | 46.50 | 48 | 288 | 97% | 99% |
| 8 | Paraedu-cators | 24 | 24 | 22 | 23 | 23 | 27 | 143 | 23.83333 | 27 | 162 | 88% | 93% |
| 9 | Progress Monitoring | 24 | 24 | 23 | 24 | 24 | 24 | 143 | 23.83 | 24 | 144 | 99% | 100% |
| 10 | Positive Behavior Support | 15 | 15 | 14 | 15 | 15 | 15 | 89 | 14.83333 | 15 | 90 | 99% | 100% |
| 11 | Self Determ. | 4.5 | 3.5 | 5.5 | 14 | 9 | 15 | 51.5 | 8.58 | 15 | 90 | 57% | 80% |
| 12 | Transiton | 23 | 28 | 15.5 | 21 | 30 | 33 | 150.5 | 25.08333 | 33 | 198 | 76% | 95% |
| 13 | Health and Saftey | 24 | 24 | 24 | 24 | 23 | 24 | 143 | 23.83 | 24 | 144 | 99% | 98% |
| 14 | Total | 288.5 | 286.5 | 268 | 289 | 289 | 303 | 1724 | 28.73333 | 312 | -- | -- | -- |
| 15 | % of Ttl | 92.5% | 91.8% | 85.9% | 92.6% | 92.6% | 97.1% | | | | | | |

designed. The team may remedy this situation by, for example, establishing another course of action, getting help from outside sources, or postponing that item.

### Step 7—Revisit the Action Plan and Review Progress

Use data to periodically review the action plan to ensure the team is progressing toward its goals. Depending on the team and the goals/objectives, this review may be an informal meeting after school for 15-30 minutes or a formal team meeting thoroughly discussing progress. During action plan review, the team determines whether it needs additional resources, adjustments, or training. If the goals have been met, new goals can be developed to keep the focus on continued improvement.

### Step 8—Reassess Using the QIs at the End of the Year

At the end of the academic year, the team again completes the QIs to determine growth during the year. The team leader develops a timeline for completion and again collects everyone's data. A summary evaluation form is then used to compare the data from the first evaluation and the yearend evaluation. Compiling and reviewing scores with the team helps to celebrate progress. In subsequent years, when the team becomes familiar with the process, the QIs need to be completed at yearend and data will be used to develop an action plan for the upcoming year.

Table 1
*An Example of an Action Plan Based on Evaluation Data.*

| **Quality Indicator** | **Objectives Not Observed** | **Objectives Selected** | **New Objective and How Implemented** | **Persons Responsible/ Initiation Date** |
|---|---|---|---|---|
| Priority #1: Paraeducators | Team reported need to provide instruction to paraeducators in:<br>1.f.i. Instructional methodologies and data collection<br>1.f.ii. Prompting and prompt fading strategies<br>1.f.iii. Assistive technology | 1.f.ii. Prompting and prompt fading strategies<br>1.f.ii. Assistive technology (AT) | 1.f.ii. Professional development for paraeducators on specific prompting and prompt fading strategies<br>1.f.iii. Professional development for paraeducators on AT devices used by two students | Patricia will provide prompting and prompt fading strategies PD during inservice time for paraeducators and coaching for two weeks following.<br>Start date: Oct. 2<br>Follow-up check-in: Nov. 10, Jan. 10, April 15.<br>SLP, Assistive Tech, and PT will provide training on AT devices.<br>Start date: Sept.<br>Weekly follow-up for three weeks, again before finals, and at beginning of spring semester |
| Priority #2: Instruction | Team reported need for gen. ed. Training in how to modify instruction.<br>2.d. Principles of Universal Design<br>2.e. Modifications are in place and implemented by all staff. | 2.d. Universal Design for Learning (UDL) strategies | 2.d. Professional development for general education teachers on principles of UDL with specific examples of how to meet needs of SE students, second language students, and others who struggle with learning. | Patricia will provide PD during staff late start meeting on curriculum modification.<br>Start date: Oct. 22<br>Sara will follow up with individual teachers Oct. 23 through Nov. 21.<br>Sara will check in with all gen. ed. teachers in Spring. |

### Step 9—Develop a New Action Plan for the Upcoming Year

After reviewing the yearend data, a new action plan is developed for the next academic year. Starting the year with a plan in place helps the team fluidly continue the improvement process. Keeping the team focused on evidence-based practices, and providing a vehicle for continued evaluation and improvement of services for students with SSN, then becomes a part of the culture. As team membership changes, frequent reviews and ongoing evaluations help orient new members to the expectation of providing evidence-based services to students with SSN.

## CONCLUSION

Many special educators struggle with day-to-day tasks and have little time to devote to improvement of service delivery for students with SSN. Using the *Quality Indicators for Assessing Individualized Services for Students (k-12) with Significant Support Needs* process assists special education teams recognize their strengths in providing quality services to students with SSN and also structure needed improvements. This process, which initially may seem time-consuming, provides a structure to improve services to students with SSN and makes it worth the effort.

When Patricia received the evaluation scores from the other team members, she compiled the scores, and the team met to review the data. The team commented that the process of completing the QIs made them more aware of evidence-based services. They were pleased to see they were not only implementing some of the services (e.g., health and safety, inclusive culture), but also identifying services that needed to be addressed. The team rank-ordered their results and found Paraeducators and Instruction to be the two domains with the lowest average scores. As team members reviewed data and discussed results, they identified additional domains that needed changes; however, since they wanted to make sure they were successful, they limited goals for the first year to the two domains, Paraeducators and Instruction. Using these results, the team discussed the specific indicators and components under the two domains identified as their priority domains. Next, they developed the Action Plan to guide improvement. They delineated how they would address each domain to improve their services (Table 1) during the academic year. Their Action Plan goals would allow them to track progress and maintain momentum throughout the year. Each person agreed to the plan, and each had action items for which they were responsible. A "team check-in" was scheduled for one month later.

## REFERENCES

Aron, L., & Loprest, P. (2012). Disability and the education system. *Future of Children, 22*(1), 97-122. Retrieved from http://files.eric.ed.gov/fulltext/EJ968439.pdf

Brewer, R. D., & Carroll, D. (2014, November). *What could be more fun? Quality indicators and data*. Paper presented at the 2014 Teacher Education Division of the Council for Exceptional Children, Indianapolis, IN.

Bal, A., & Trainor, A. A. (2015). Culturally responsive experimental intervention studies: The development of a rubric for paradigm expansion. *Review of Educational Research*. doi:10.3102/0034654315585004

Blumburg, P. (2013). *Assessing and improving your teaching: Strategies and rubrics for faculty growth and student learning*. San Francisco, CA: Jossey-Bass.

Browder, D. M., & Spooner, F. (Eds.). (2006). *Teaching language arts, math and science to students with significant cognitive disabilities*. Baltimore, MD: Brookes.

Browder, D. M., Spooner, F., Ahlgrim-Delzell, L., Harris, A. A., & Wakeman, S. (2008). A meta-analysis on teaching mathematics to students with significant cognitive disabilities. *Exceptional Children, 74*, 407-432. Retrieved from http://journals.sagepub.com/doi/abs/10.1177/001440290807400401?journalCode=ecxc

Chard, D. J., Ketterlin-Geller, L. R., Baker, S. K., Doabler, C., & Apichatabutra, C. (2009). Repeated reading interventions for students with learning disabilities: Status of the evidence. *Exceptional Children, 75*, 263-281. doi:10.1177/001440290907500301

Colorado Department of Education. (2010). *Quality indicators for assessing individualized services for students (k-12) with significant support needs*. Denver, CO: Author.

DiPaola, M., Tschannen-Moran, M., & Walther-Thomas, C. (2004). School principals and special education: Creating the context for academic success. *Focus on Exceptional Children, 37*(1), 1-10. Retrieved from http://www.academia.edu/20968156/School_Principals_and_Special_Education_Creating_the_Context_for_Academic_Success

Downing, J. (2005). Inclusive education for high school students with severe intellectual disabilities: Supporting communication. *Augmentative & Alternative Communication, 21*, 132-148.

Friend, M., & Cook, L. (2012). *Interactions: Collaboration skills for school professionals* (7th ed.). Boston, MA: Pearson.

Individuals with Disabilities Education Act of 2004, 20 U.S.C. §1400 et seq. (2004).

Kennedy, C., & Horn, E., (Eds.). (2004). *Inclusion of students with severe disabilities*. Boston, MA: Allyn & Bacon.

New Jersey Council on Developmental Disabilities and the New Jersey Coalition for Inclusive Education. (2010). *Quality indicators for effective inclusive education guidebook*. East Brunswick, NJ: Author.

One month after implementing the action plan, the team held a 20-minute progress review. During the review, Patricia shared that she scheduled training for the general education staff on modifications. Sara stated she was working with her paraprofessionals to schedule training with the assistive technology specialist, speech and language pathologist, and occupational therapist. The plan continued to go well during the year. However, during a check-in meeting in February, team members noticed that the dates on the action plan were not specific for the spring semester. This was a concern as they had relied on the dates to stay "on track." They rectified this by revising the plan and adding more times for check-in with each other to monitor implementation of the goals.

Near the end of the academic year (in May), Sara and her team completed the QIs for the second time. This time, they wanted to determine the level of change within their program across the year. All team members completed the QIs and then met for a final time.

Reviewing the results from the beginning-of-the-year QIs with the end-of-the-year QI results, the team realized what started as a school with good service delivery for students with SSN was now a school with enhanced service delivery. They had set and met most of their goals. Their paraprofessionals were now more highly trained, and more curriculum was being modified and implemented within the general education classrooms. They also believed that student learning outcomes had improved. The team decided to continue the QI process to maintain momentum.

Reviewing the data again with goals in mind, the team decided to continue working with general educators on modifying curriculum and continue paraeducator training during the upcoming year. They also added a new goal in the communication domain: Ensure all students were increasing their receptive and expressive language skills. With a new Action Plan developed, the team would be ready to begin the new academic year in the fall. At the conclusion of the meeting, Sara commented she believed using the QIs helped the team see what they were doing well, helped them and others recognize their hard work, and provided them with a concrete plan to start the next school year.

Roach, A. T., & Elliott, S. N. (2006). The influence of access to general education curriculum on alternate assessment performance of students with significant cognitive disabilities. *Educational Evaluation and Policy Analysis, 28*, 181-194. Retrieved from http://www.jstor.org/stable/3699531

Snell, M. E., & Brown, F. (Eds.). (2011). *Instruction of students with severe disabilities* (7th ed.). Upper Saddle River, NJ: Pearson.

Stecker, P. M., Lembke, E. S., & Foegen, A. (2008). Using progress monitoring data to improve instructional decision making. *Preventing School Failure: Alternative Education for Children and Youth, 52*(2), 48-58.

Wehmeyer, M. L. (2004). Beyond self-determination: Causal agency theory. *Journal of Developmental and Physical Disabilities, 16*(4), 337-359. doi: 10.1007/s10882-004-0691-x

# JIASE SUBMISSION GUIDELINES

**The Journal of the International Association of Special Education (JIASE)**
Articles that have not been previously published and are not under review by any other publication and meet the International Association of Special Education (IASE) mission statement aims are invited for review. Both research articles and articles for practitioners (PRAXIS) will be given equal consideration.

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The International Association of Special Education (IASE) 16th Biennial Conference will be held in collaboration with Sebastian Kolowa Memorial University (SEKOMU) in Magamba, Tanzania, East Africa, from July 13–17, 2019. Our theme is: **Empowering Persons with Disabilities: Developing Resilience and Inclusive Sustainable Development**.

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If you have any further questions regarding the conference, please contact our IASE Liaison, Susan Pursch: iasesecretary@gmail.com

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