



Theses and Dissertations

2020-05-18

What are Stakeholders' Perceptions of Rural School District Needs to Effectively Educate Students with Autism Spectrum Disorder

Kari Lyn Pugh
Brigham Young University

Follow this and additional works at: <https://scholarsarchive.byu.edu/etd>



Part of the [Counseling Psychology Commons](#)

BYU ScholarsArchive Citation

Pugh, Kari Lyn, "What are Stakeholders' Perceptions of Rural School District Needs to Effectively Educate Students with Autism Spectrum Disorder" (2020). *Theses and Dissertations*. 8393.
<https://scholarsarchive.byu.edu/etd/8393>

This Thesis is brought to you for free and open access by BYU ScholarsArchive. It has been accepted for inclusion in Theses and Dissertations by an authorized administrator of BYU ScholarsArchive. For more information, please contact scholarsarchive@byu.edu, ellen_amatangelo@byu.edu.

Stakeholders' Perceptions of a Rural School District's Needs to Effectively
Educate Students with Autism Spectrum Disorder

Kari Lyn Pugh

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of
Educational Specialist

Terisa Gabrielsen, Chair
Ryan O. Kellems
Mikle South

Department of Counseling Psychology and Special Education
Brigham Young University

Copyright © 2020 Kari Lyn Pugh

All Rights Reserved

ABSTRACT

Stakeholders' Perceptions of a Rural School District's Needs to Effectively Educate Students with Autism Spectrum Disorder

Kari Lyn Pugh

Department of Counseling Psychology and Special Education, BYU
Educational Specialist

The prevalence of autism spectrum disorder (ASD) has continued to rise each year. This fact has significance in the area of education. The rise in prevalence of autism means an increase of students with autism in schools. Educators have the need to be prepared to provide an appropriate education for these students but may not have training or resources to be effective. Rural communities may have even more concerns about education for students with ASD due to geographic isolation and the lack of available educators in their area trained to support the specific needs of these students. To determine the best use of available resources and identify critical needs, a study of stakeholder perceptions of the needs of students with ASD was conducted in one rural Utah school district of approximately 3,000 students.

Key stakeholders were provided an opportunity to respond to an online needs assessment questionnaire regarding the educational interventions and services available in the rural school district, as well as rate the effectiveness of the above-mentioned services. Key stakeholders included parents and caregivers of children with ASD, the rural school district's educators, community care providers, and individuals 12 years and older who have been classified as having an ASD in the rural school district. Further, upon completion of the online needs assessment, the participants were invited, if they wished to elaborate further, to meet by phone or in person in an interview format with the researcher to discuss their perceptions in more detail than was possible in the online needs assessment questionnaire. Sixty-eight individuals completed the questionnaire.

Mixed methods were used to analyze the data. Quantitative data were first analyzed using descriptive statistics to characterize patterns in responses between groups. The qualitative data from open-ended questions in the survey and the in-person interviews were analyzed using consensual qualitative research methods.

Results showed that all stakeholders believe that better communication from the school district and more training are needed for educators and related professionals. These results have implications for the school district as they plan their use of available resources to better meet the needs of students with ASD. Pursuit of targeted training options for educators may be one of the most effective use of available resources to meet these needs.

Keywords: education, autism spectrum disorder, rural, evidence based practices

ACKNOWLEDGMENTS

First of all, I would like to thank my family for supporting me through this process.

Thanks to my sweet husband and head cheerleader, Kurtis, for making all those dinners and washing all those dishes. Thanks also to my children, Ann, Jake, and Josh for reminding me that I can do hard things.

I would also like to thank my chairperson Terisa Gabrielsen, and committee members Ryan Kellems and Mickle South for all of their support throughout the process.

TABLE OF CONTENTS

TITLE PAGE	i
ABSTRACT.....	ii
ACKNOWLEDGMENTS	iii
TABLE OF CONTENTS.....	iv
LIST OF TABLES	vii
LIST OF FIGURES	viii
DESCRIPTION OF THESIS STRUCTURE.....	ix
Introduction.....	1
Statement of the Problem.....	3
Statement of Purpose	4
Research Questions	4
Method	5
Participants.....	5
Settings.....	6
Online survey	6
In-person interview.....	7
Measures	7
Procedure	8
Administration one	9
Administration two.....	9
Research Design.....	10
Data Analysis.....	10

Results.....	11
Educators’ Perceptions of Educational Needs for Students with ASD.....	15
Parent/Caregivers’ Perceptions of Educational Needs for Students with ASD.....	18
Community Health Care Perceptions of Educational Needs for Students with ASD.....	24
Individuals with ASD Perceptions’ of Educational Needs for Students with ASD	27
Discussion.....	29
Limitations	32
Implications for Future Research.....	33
Implications for Practitioners.....	33
Conclusion	34
References.....	36
APPENDIX A: Review of the Literature.....	39
ASD and Need for Services	39
Educational Concerns for Students with ASD.....	41
Educational Laws.....	43
Individuals with Disabilities Education Act (IDEA)	43
Endrew F. v. Douglas County School District	46
Other pertinent case law	47
Necessity of educational interventions.....	48
Parents' Educational Concerns.....	49
Stakeholder Concerns	51
Educator concerns	51
Community care providers’ concerns.....	53

Educational Needs of Students with Autism Spectrum Disorder	54
Autism Interventions.....	55
Early screening	55
Use of data.....	56
Evidence-based practices	57
Student to teacher ratios	58
Individualized Education Program (IEP)	59
Summary and Critique	60
Statement of the Problem.....	61
References	62
APPENDIX B: Instrument.....	66
APPENDIX C: Consent Form	79
APPENDIX D: Interview Script.....	81

LIST OF TABLES

Table 1	<i>Demographic Characteristics of Respondents</i>	12
Table 2	<i>Ranked as Top Educational Priority</i>	13
Table 3	<i>Educators' Perceptions of Autism Specific Interventions</i>	17
Table 4	<i>How Well Informed Stakeholders Feel Regarding Autism Services Provided</i>	19
Table 5	<i>Parent/Caregiver Perceptions of Autism Specific Interventions</i>	22
Table 6	<i>Health Care Providers' Perceptions of Autism Specific Interventions</i>	26
Table 7	<i>Individuals with ASD Perceptions of Education Services</i>	28

LIST OF FIGURES

<i>Figure 1</i>	Perceived effectiveness of ASD interventions.....	14
<i>Figure 2</i>	Perceived effectiveness of ASD interventions by participants indicating awareness of interventions in the school district.....	14
<i>Figure 3</i>	Educators' perceptions of importance of educational interventions by grade range.....	16
<i>Figure 4</i>	Educators' perceived effectiveness of interventions by grade range.....	16
<i>Figure 5</i>	Educators' perceptions of effectiveness of autism specific interventions.....	17
<i>Figure 6</i>	Educators' perceptions of effectiveness of autism specific interventions by participants indicating awareness of interventions in the school district.....	18
<i>Figure 7</i>	Parent/caregiver perceptions of importance of educational services by grade range.....	20
<i>Figure 8</i>	Parent/caregiver perceptions of effectiveness of interventions by grade range.....	22
<i>Figure 9</i>	Parent/caregiver perceptions of effectiveness of autism specific interventions.....	23
<i>Figure 10</i>	Parent/caregiver perceptions of effectiveness of autism specific interventions by participants indicating awareness of interventions in the school district.....	23
<i>Figure 11</i>	Community health care providers' perceptions of importance of education services by grade range.....	25
<i>Figure 12</i>	Community health care providers' perceptions of effectiveness of interventions by grade range.....	25
<i>Figure 13</i>	Community health care providers' perceptions of autism specific interventions.....	26
<i>Figure 14</i>	Community health care providers' perceptions of effectiveness of autism specific interventions by participants indicating awareness of interventions in the school district.....	27

DESCRIPTION OF THESIS STRUCTURE

This thesis, *Stakeholders' Perceptions of a Rural School District's Needs to Effectively Educate Students with Autism Spectrum Disorder*, is written in a hybrid format. The hybrid format brings together traditional thesis requirements with journal publication formats.

The preliminary pages of the thesis reflect requirements for submission to the university. The thesis report is presented as a journal article and conforms to length and style requirements for submitting research reports to education journals, as well as a report to be shared with the local school district and community.

The extended literature review is included in Appendix A. This thesis format contains two reference lists. The first reference list contains references included in the journal-ready article. The second list includes all citations used in the Appendix entitled "Review of the Literature," Appendix B includes the Instrument used to identify stakeholders' needs, Appendix C includes the Consent Form, and Appendix D includes the Interview Script.

Introduction

The prevalence of autism spectrum disorder (ASD) is increasing significantly, to the point where individuals with autism are found in every community; including rural communities. According to the Centers for Disease Control and Prevention (CDC), the current prevalence of individuals with ASD is one in 59, which is roughly double the prevalence in 2004 (Baio et al., 2018). The availability of educational services may not be keeping pace with this increase, particularly for students with autism who live in rural communities. Along with the increased presence of these students in the classroom are the educators, paraprofessionals, and caregivers who may feel unprepared to adequately provide the necessary educational interventions and support. This is further compounded by the fact that ASD is a complex disorder that may impact a variety of facets of the child's life (e.g., social, academic, behavioral; Kogan et al., 2018). Research findings in an autism study completed in urban areas by Iadarola et al. (2015) found educational needs for students with autism were not being met reliably. Resources may be more available in an urban area, but needs are still not being met because of other barriers to accessing services. ASD related resources may be much more difficult to access in rural communities. Training emerged as an important theme for meeting autism education needs in the urban study. In particular, paraprofessionals felt unprepared and unsupported in their role with the students on the spectrum. Findings also indicated a need for administrators to improve school-wide support of all students and improve the culture of their building to be more inclusive of all students (Iadarola et al., 2015).

The Autism and Developmental Disabilities Monitoring (ADDM) Network also found that the prevalence of ASD is steadily increasing over time, suggesting that these trends may continue in the future (Baio et al., 2018). The substantial increase in the prevalence rates of ASD

indicates a corresponding and enduring increase in the necessity for high-quality supports and interventions for persons with ASD dispersed throughout the United States. To best serve these students, educators must determine educational best practices and be trained in those practices (evidence-based interventions) while taking into consideration that each student on the autism spectrum may have individual needs, strengths, and weaknesses. One size may not fit all, in terms of educational programming (Shyman, 2012).

Early identification and intervention are generally held to be of utmost importance to improve outcomes for children with ASD (Centers for Disease Control and Prevention, 2018). That being said, not only do these individuals need to begin early with educational interventions, but the interventions chosen should be effective. One study of ASD undertaken by Barrow (2017) interviewed families of young children with autism, in an effort to determine what interventions were needed by these families. A common theme identified in this study indicated a need for effective early intervention services (Barrow, 2017). Earlier diagnosis of ASD was also identified as a necessary precursor to early intervention. Autism identification and diagnosis has been shown to be possible and stable in children as young as two years old (Guthrie, Swineford, Nottke, & Wetherby, 2013), but treatment rarely begins before a child's third or fourth birthday (Barrow, 2017). This finding is consistent with the CDC/ADDM data which shows the median age of diagnosis to be 52 months, with only 42% receiving a comprehensive evaluation prior to their third birthday (Baio et al., 2018). This apparent gap in intervention services of one and a half to two and a half or more years constitutes a great deal of lost educational time for a young child with ASD. This lost time is likely to be compounded by rural isolation and difficulties accessing services, including diagnostic services.

In an effort to better support students with ASD and their families in rural communities, educators would be best served if they consider the input of the perceptions of families and individuals with ASD as stakeholders. Taking a family-centered, interdisciplinary approach to improvement of services is likely to result in improvements in services provided and satisfaction with those services (Christon & Myers, 2015).

Statement of the Problem

There is some perception throughout the rural community in this study that a child with ASD may have to leave his or her rural home in order to receive effective educational interventions (T. Black, personal communication, October 10, 2018). Although it is not known how or when this perception began, it illustrates an apparent disconnect between the educational services provided in the area and the various stakeholders involved. For a family and/or multiple families to have to relocate to receive adequate educational interventions for their child is in direct opposition to the spirit and intent of the Individuals with Disabilities Education Improvement Act (IDEA, 2004). Efforts should be made for a family to receive a free and appropriate education in the community in which they reside. Also, perceptions of the adequacy of interventions for students with ASD may be influenced by the lack of knowledge of evidence-based practices and if this is the case, stakeholders with different relationships to individuals with ASD can be made aware of discrepancies that may exist to promote action to remedy any gaps identified.

Before plans can be made to improve access to services and overcome whatever barriers are in place, more information from stakeholders (parents, educators, and community practitioners) is necessary to guide decision-making and allocation of resources.

Statement of Purpose

The purpose of this study was to examine stakeholders' perceptions of what a rural school district needs to do to effectively educate students with autism spectrum disorder. We conducted a needs assessment of the perceptions regarding educational interventions for students with ASD in a rural school district in the western United States. The opportunity to research this problem was intended to open the door for parents and educators to comment on necessary improvements in educational services, as well as to provide opportunities for families and educators to be better informed as to evidence-based interventions which may be currently in place for their children, or could be put in place for their children.

Research Questions

This study addressed the following research questions:

1. What do educators of students with autism spectrum disorder perceive to be of importance and effective in terms of educational services and supports for the students?
2. What do families of students with autism spectrum disorder perceive to be of importance and effective in terms of educational services and supports for the students?
3. What do community care providers of students with autism spectrum disorder perceive to be of importance and effective in terms of educational services and supports for the students?
4. What do students with autism spectrum disorder perceive to be of importance and effective in terms of educational services and supports for the student?

Method

Participants were invited to participate by responding to a needs assessment questionnaire. Also, participants were informed that they were able to end their participation in the research at any time, without consequence. The research was approved by the Institutional Review Board (IRB) at Brigham Young University. Procedures and settings for research will be described in more detail in this section.

Participants

Participants in this study were selected according to their current or past residency in the rural county and their interest in or experience with ASD. As of July 1, 2017, the population estimate of the county was 15,356 residents (U.S. Census Bureau, 2017). According to the Centers for Disease Control and Prevention, the prevalence of autism is one in 59 people (2018), suggesting at least the possibility of approximately 260 individuals with ASD (of all ages) living within the county. The number of students from kindergarten through high school in the rural school district with an educational classification of ASD during the 2018-19 school year was 14, though the local special education department believes there are far more students with ASD who have not reported a medical diagnosis, may not have a diagnosis, or whose parents have not sought special education services for their child through an Autism educational classification. Also, early intervention students and many kindergarten students may have an educational classification of Developmental Delay rather than ASD through age seven. Many other students may have ASD but are potentially undiagnosed or not qualified for services under the ASD classification, instead, they may be classified for services under the category of Specific Learning Disability (K. Perkins, personal communication, October 17, 2018). We anticipated identifying up to 100 educators and the 14 families and their students with Autism

classifications, as well as 20 community care providers. It was unknown how many respondents would be recruited by social media, website, and flyers. Ultimately, we had 68 individuals complete the online survey (two individuals with ASD, 34 educators, 20 parent/caregivers, six individuals that identified themselves as parent and educator, and six health care providers).

Male and female participants aged 12 years and older were included (the young age was to accommodate students with ASD as stakeholders). Participants included males, females, primarily American Indians and Caucasians, individuals with ASD, parents/caregivers, educators, and community care providers with relationships with individuals with ASD. All respondents needed to be residents of the designated county (the county comprises the school district) or have resided within the county in the past five years.

Participants were invited through a variety of methods, including the following flyers posted throughout the county, social media advertisements (i.e., local community Facebook groups), the rural school district webpage, and a flyer mailed with an email sent on two occasions to the homes of the rural school district families enrolled in special education services who have an educational classification of ASD. It is challenging to determine the exact number of participants that were reached during the advertisement of the needs assessment, due to the variety of methods involved. However, we are aware that the homes of fourteen parents with students with ASD were reached by email and/or mailers.

Settings

Online survey. Participants were invited to complete an anonymous online needs assessment questionnaire through Qualtrics (Provo, Utah). The link to the questionnaire was provided on all electronic announcements. The paper flyer indicated the URL for the school district website to find the link.

In-person interview. At the conclusion of the online questionnaire, participants were also invited to participate in an in-person, teleconference or telephone interview (see details below) if they wished to give us more information.

Measures

A unique needs assessment was developed, including nine questions regarding demographic information about the respondent. The remainder of the online survey includes questions regarding the educational needs of students with ASD. The questionnaire included nineteen questions, including multiple choice, rankings, and open-ended responses about services received, importance of a variety of services, and perceptions of effectiveness of services received. The needs assessment included questions regarding the perceived importance and effectiveness of services at varying age levels (e.g., Early Intervention, school age, transition services, etc.). The questionnaire also included questions regarding the perceived importance and effectiveness of ASD specific interventions currently being used by the rural school district (e.g. Discrete Trial Training (DTT), Applied Behavior Analysis (ABA), Get Ready (i.e., learning how to pay attention in class from the Superheroes Social Skills curriculum, Jenson et al., 2011), Speech Language Therapy (SLT), Tactile Defensiveness (i.e., improving sensory sensitivities), Social Skills, and Video Modeling. The questionnaire was evaluated by Microsoft Word Flesch-Kincaid Reading Ease algorithm to determine ease of reading for participants to ensure that participants with at least a 5th grade reading level or above would be able to access the questionnaire and respond effectively.

During the development of the needs assessment questionnaire, nine individuals previewed the needs assessment and made suggestions regarding the wording and the questions included in the assessment. Needs assessment previewers included two parents and/or caregivers

of students with ASD, one classroom special education educator, one general education teacher, one school social worker, the special education director for the rural school district, one of the principal researchers on the study, and two thesis committee members. Suggestions for improvement were taken into consideration and the questionnaire was revised in an effort to make it more user friendly.

At the conclusion of the needs assessment questionnaire, respondents were redirected to a separate Qualtrics webpage detailing an opportunity to discuss responses in person with the researchers if they wished, thus protecting the confidentiality of their responses. There was no obligation to meet further. However, they were invited to leave their name and phone number for follow-up discussions about their responses. If they chose to complete the follow up interview with researchers, they needed to complete an informed consent form. Those following through with the consent form and interview were given the opportunity to discuss their answers to the needs assessment questions in more detail, as well as respond to additional questions and volunteer information. The responses were recorded by the researchers by means of notetaking and audio or video recordings. Interviews took place in the school-based office of the researcher or in the participant's home via teleconference. Transcripts were created of each interview for analysis.

Procedure

A web-based needs assessment questionnaire on Qualtrics, beginning with an invitation to complete the form and the purpose of the study, was utilized as the main data collection method. Implied consent was assumed by completion of the anonymous online assessment following a consent disclosure statement. The online format of the needs assessment questionnaire protected the anonymity of the respondents, as no identifying information was

asked. To the best of our knowledge there will be no way to identify respondents by their answers.

The rural school district special education director sent flyers to the homes of families with students with ASD as their educational classification. Flyers were posted in local businesses, schools, and other high traffic areas within the county. Information was also posted on social media (i.e., local community Facebook groups) and emailed to educators and families by the special education director. Researchers made a personal visit to community health care provider locations in an effort to include them in the research. The rural school district website also provided a link to the needs assessment. The web address to access the needs assessment questionnaire was posted on the flyers, as well as an electronic link on electronic flyers.

For participants who may not have had access to the Internet or those who preferred a hard copy of the questionnaire, a phone number was provided on all flyers posted in the community. Paper needs assessment questionnaires could be mailed to those who contacted the researcher (by phone) with their mailing addresses. A self-addressed stamped envelope for respondents to return anonymous responses back to the researchers was included. Two of the sixty-eight completing participants used the mail option for their needs assessment responses.

Administration one. Participants were directed to the online Qualtrics survey or they were emailed or mailed a paper copy of the needs assessment questionnaire. Results from Qualtrics would be unidentifiable, thereby protecting the confidentiality of the respondents. Data were collected on the Qualtrics website for download and analysis.

Administration two. Participants choosing to participate in a follow-up interview were able to choose to meet by phone, in person at their home, or in the office of the researcher. Two participants completed administration two. These participants were given a consent form to read

and sign prior to the interview. Upon their consent to participate, they were given the opportunity to give more details about their perceptions of education for students with ASD in the designated county in Utah. This interview was guided by a selection of interview questions related to the original questionnaire. It was also an opportunity for participants to explain their responses in more depth if they wished.

Research Design

The research design for this study uses mixed methods to include both qualitative and quantitative data. The main data collection (the questionnaire) included some open-ended responses as well as Likert-type scales and rankings. The interview included open-ended responses only. Independent variables included the various stakeholders in the study (such as, parents/caregivers, educators, community care providers, and individuals with ASD). The stakeholders' perceptions of educational interventions and effectiveness served as the dependent variables in this study.

Data Analysis

Perception of each stakeholder group were evaluated using a quantitative analysis, using descriptive statistical methods to characterize responses between the respondent groups. Similar analysis was also conducted on the group as a whole. Because the groups were very uneven in size, no attempts at statistical analysis of differences between groups was deemed to be meaningful.

Open-ended questions and responses recorded in the interviews were coded and analyzed by trained undergraduate research assistants. Analysis of open-ended questions included determining prevailing themes across responses and reporting direct quotes that represent the significance of statements. These responses were analyzed using consensual qualitative research

methods (CQR: Hill, Thompson, & Williams, 1997). Two independent undergraduate researchers reviewed all qualitative data (i.e., open-ended responses and interviews). Both undergraduate researchers had prior experience with autism and one has a sibling with autism. Neither had ever been employed by the school district, nor did they have any contact with the school district. Domains were easily established by the content of the open-ended questions. Core ideas were generated by consensus of both researchers. Cross-analysis was then performed and audited by a third researcher with extensive autism clinical experience. The auditor had been employed by a school district for one year, but not the school district of interest. The first author was not directly involved in analysis of these data, as she is an employee of the school district and may not be as free of bias as unrelated researchers may be.

Results

Upon completion of the unique ASD questionnaire for the rural school district, there were 91 participants that began the needs assessment. Of those 91 participants, 68 (75%) completed at least 50% of the questionnaire which gave us enough to gain useful data from their responses. The stakeholders completing the questionnaire included two individuals with ASD (3% of total respondents), 34 educators (50%), six individuals who were both educators and parent/caregivers (9%), 20 parent/caregivers (29%), and six health care providers (9%). The majority of participants were Caucasians (75%) and females (67%). Most participants had a graduate degree (44%) or a bachelor's degree (35%; See Table 1).

According to each stakeholder groups' perception of the educational interventions at each age level, all groups ranked Early Intervention as the number one priority on a Likert scale with 7- most important priority to 1- least important (see Table 2) for educational services and interventions for children with ASD. Perceived effectiveness of ASD specific interventions was

Table 1

Demographic Characteristics of Respondents

	Individual with ASD n= 2	Educator n= 34	Educator & Parent n= 6	Parent/ Caregiver n= 20	Health Care Provider n= 6	Total n= 68
Gender <i>n</i> (% of subgroup)						
Male	--	10 (29)	3 (50)	5 (25)	2 (33)	20 (29)
Female	2 (100)	23 (68)	2 (33)	15 (75)	4 (66)	46 (67)
Other/No Response	--	1 (3)	1 (17)	--	--	2 (3)
Race, <i>n</i> (% of subgroup)						
Caucasian	2 (100)	29 (85)	4 (66)	12 (60)	4 (66)	51 (75)
African American	--	--	1 (16)	--	--	1 (1)
American Indian	--	3 (9)	--	8 (40)	1 (16)	12 (17)
Other/No Response	--	2 (6)	1 (16)	--	1 (16)	4 (6)
Insurance, <i>n</i> (% of subgroup)						
Private Insurance	2 (100)	30 (88)	6 (100)	11 (55)	6 (100)	55 (81)
Medicaid/CHIP	--	1 (3)	--	3 (15)	--	4 (6)
Indian Health	--	1 (3)	--	--	--	1 (1)
No Insurance	--	--	--	6 (30)	--	6 (9)
No Response	--	2 (6)	--	--	--	2 (3)
Education Level, <i>n</i> (% of subgroup)						
Some High School	1 (50)	--	--	--	--	1 (1)
High School Grad	--	--	--	1 (5)	--	1 (1)
Some College	--	--	--	4 (20)	--	4 (6)
Associate's	--	3 (9)	--	4 (20)	1 (16)	8 (11)
Bachelor's	1 (50)	14 (41)	2 (33)	6 (30)	1 (16)	24 (35)
Graduate	--	17 (50)	4 (66)	5 (25)	4 (66)	30 (44)
Years involved w/ ASD, <i>n</i> (% of subgroup)						
Less than 5 years	--	10 (29)	--	2 (10)	2 (33)	14 (20)
6-10 years	--	8 (23)	--	6 (30)	3 (50)	17 (25)
11-15 years	--	6 (18)	1 (17)	2 (10)	--	9 (13)
16-20 years	1 (50)	6 (18)	3 (50)	3 (14)	--	13 (19)
21+ years	1 (50)	4 (12)	2 (33)	7 (35)	1 (17)	15 (22)

Note. Percentages in columns are based on respondent subgroup by column.

also compared across stakeholder groups, with educators generally rating each intervention as effective in comparison with the parent/caregiver group generally rating the interventions as less effective (see Figure 1). However, it is interesting to note the stark difference between Figure 1 and 2 (see Figure 2). In Figure 2, only stakeholders that had indicated a familiarity with the district's ASD specific interventions are included. In Figure 2, parent and health care providers' ratings generally increase while educators' ratings decrease.

Table 2

Ranked as Top Educational Priority

	Individual with ASD n= 2	Educator n= 34	Educator & Parent n= 6	Parent/ Caregiver n= 20	Health Care Provider n= 6	Total n= 68
Age Range n (% of subgroup)						
Early Intervention	1 (50)	23 (67)	2 (33)	8 (40)	5 (83)	39 (57)
Preschool Services	--	5 (15)	--	4 (20)	--	9 (13)
K-3 rd	--	--	1 (17)	1 (5)	--	2 (3)
4 th -6 th	--	--	--	1 (5)	--	1 (1)
7 th -8 th	--	--	--	--	--	--
High School	--	--	--	--	--	--
Transition Services	--	--	1 (17)	2 (10)	--	3 (4)
No response	1 (50)	6 (17)	2 (33)	4 (20)	1 (17)	14 (20)

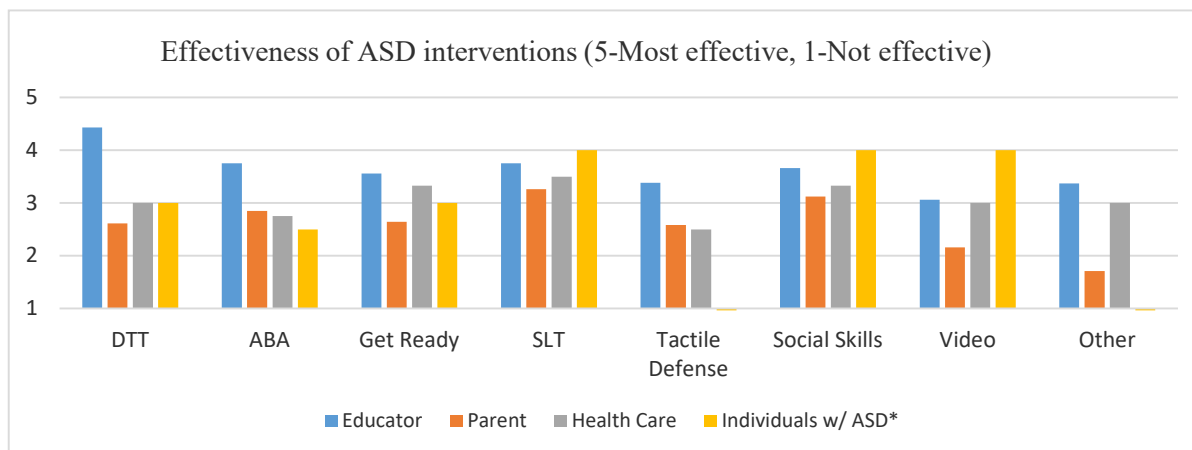


Figure 1. Perceived effectiveness of ASD interventions, n=68. DTT=Discrete Trial Training, ABA=Applied Behavior Analysis, SLT=Speech/Language Therapy, Tactile Defense also called Improving Sensory Sensitivities. Ratings are perceptions of any stakeholders that chose to answer the questions. Only 2 individuals with ASD participated in the needs assessment/questionnaire, with a majority of questions only answered by one of the individuals.

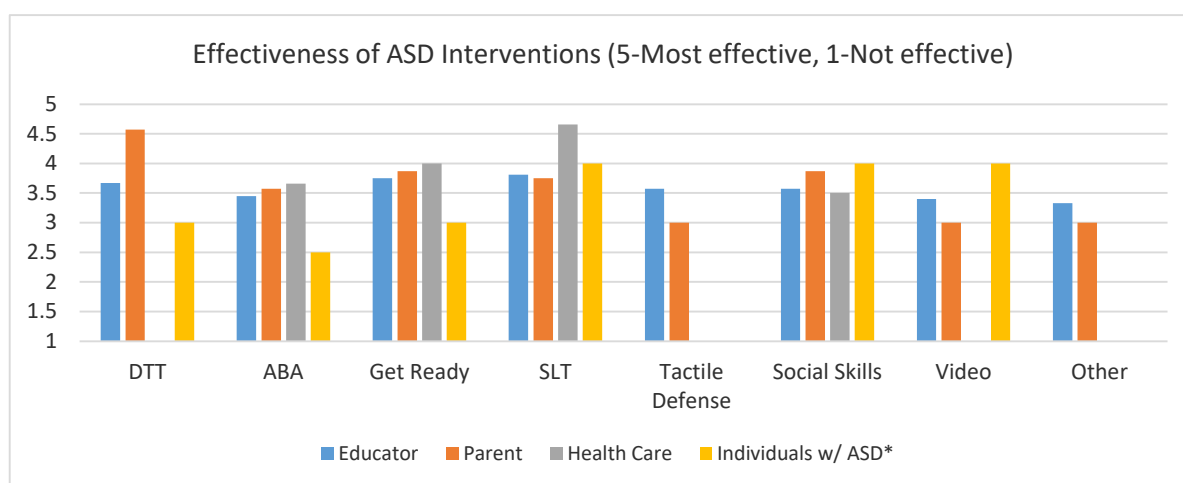


Figure 2. Perceived effectiveness of ASD interventions by participants indicating awareness of interventions in the school district. Rating perceptions include only those stakeholders that indicated an awareness of the District's ASD specific interventions.

Educators' Perceptions of Educational Needs for Students with ASD

Educators were asked to rank their perceptions of the importance and effectiveness of educational services at varying ages, as well as, how effective they perceived the services to be for students with ASD (see Figures 3 and 4). Further, they were asked to identify interventions they were familiar with and the perceived effectiveness of those interventions.

Educators were given an opportunity to share their knowledge and perceptions regarding specific interventions; such as Discrete Trial Training (DTT), Applied Behavior Analysis (ABA), Get Ready (i.e., learning how to pay attention in class from the Superheroes Social Skills curriculum, Jenson et al., 2011), Speech Language Therapy (SLT), Tactile Defensiveness (i.e., improving sensory sensitivities), Social Skills, and Video Modeling. Educators seemed to have some knowledge of each of the interventions, but were most familiar with ABA (70%), SLT (70%), and Social Skills training (68%; see Table 3). In regard to the perceived effectiveness of these interventions, when including all educator participants, ABA and SLT both had mean scores of 3.75 (with 5 being most effective) and Social Skills training mean score was 3.66. Discrete Trial Training was perceived as the most effective with a mean of 4.43 (see Figure 5). However, when we consider the data from only the perspective of the educators who indicated a familiarity with the district's interventions, we notice some variation in the responses. Educators that indicate a familiarity show lower perceptions of effectiveness, with a mean of 3.45 (ABA), 3.81 (SLT), 3.57 (Social Skills), and 3.67 (DTT; see Figure 6). SLT was the only intervention that was seen to be equally effective between the educators' group at large and those with experience/awareness of interventions.

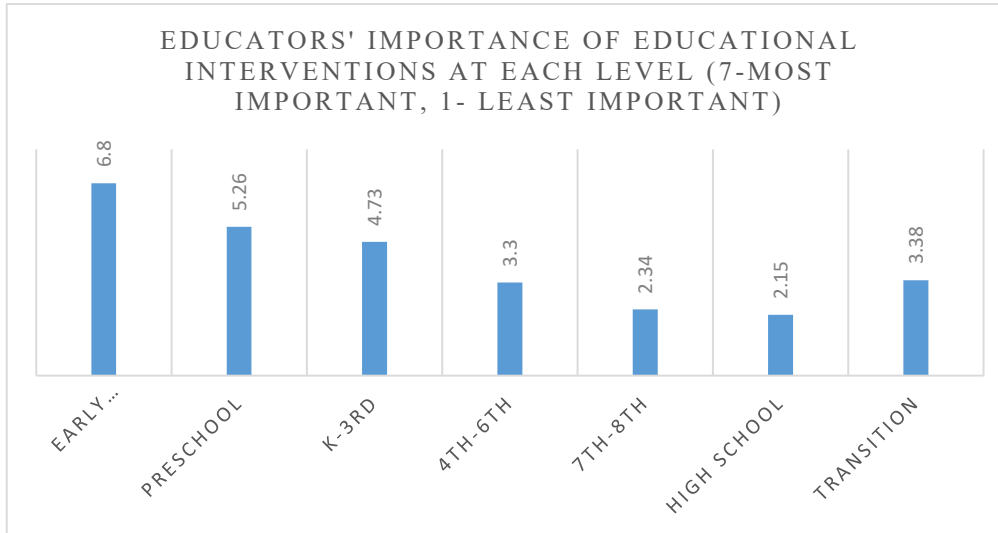


Figure 3. Educators' perceptions of importance of educational interventions by grade range, n=34.

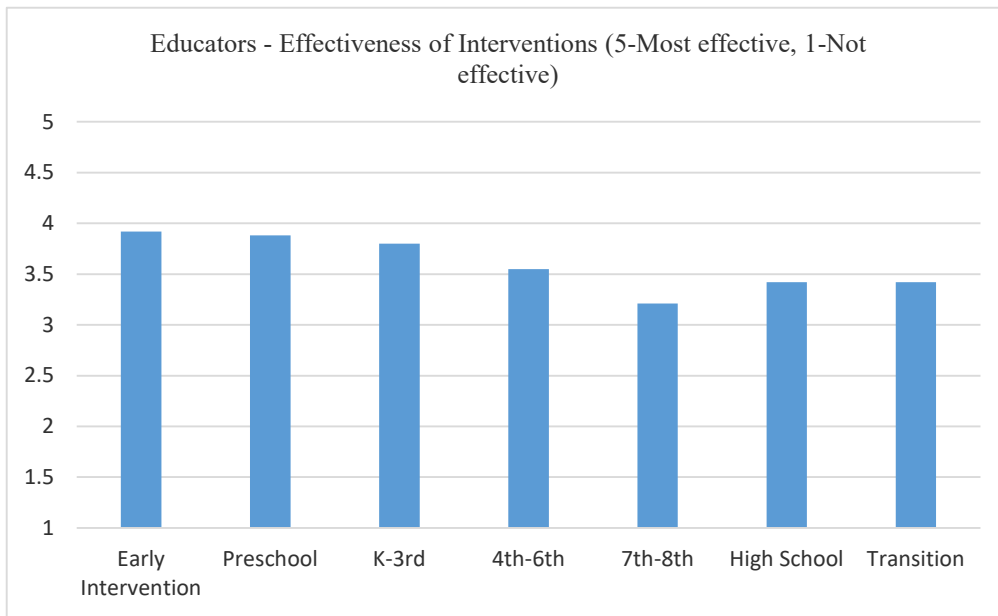


Figure 4. Educators' perceived effectiveness of interventions by grade range, n=34.

Table 3

Educators' Perceptions of Autism Specific Interventions, n (%)

Discrete Trial Training	Applied Behavior Analysis	Speech Language Therapy	Social Skills	Get Ready	Tactile Defense	Other	Video Modeling
11 (32)	24 (70)	24 (70)	23 (68)	15 (44)	10 (29)	4 (12)	6 (18)

Note. Interventions used/seen used (respondents allowed to indicate multiple interventions), 34 respondents.

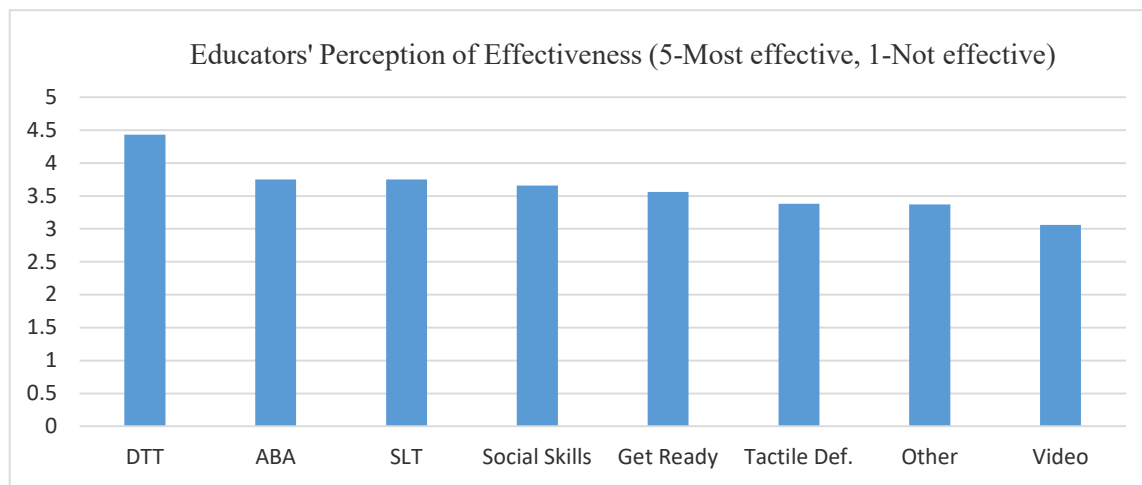


Figure 5. Educators' perceptions of effectiveness of autism specific interventions, n=34. Rating perceptions include any educators who chose to respond to this question.

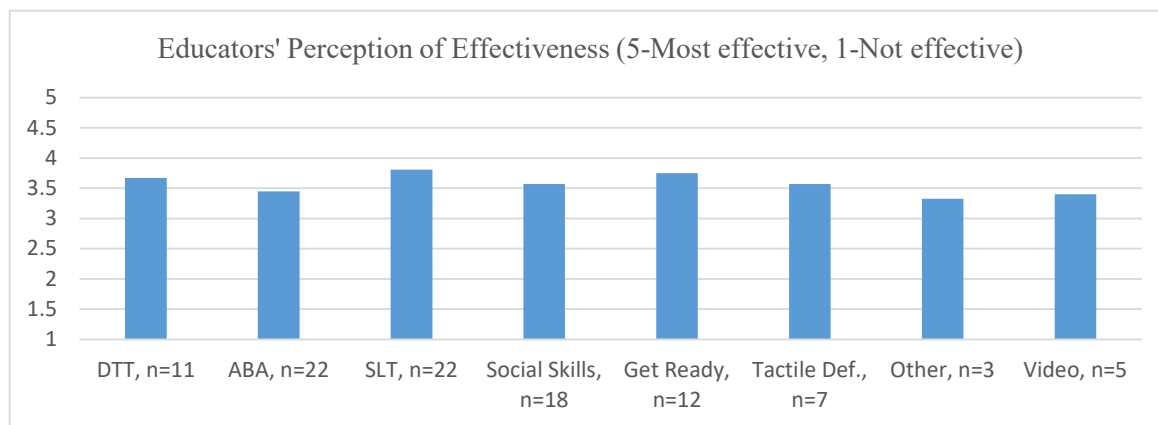


Figure 6. Educators' perceptions of effectiveness of autism specific interventions by participants indicating awareness of interventions in the school district. Rating perceptions include only those educators who indicated an awareness of the District's ASD specific interventions.

Finally, educators were asked to rate how well informed they feel parents are regarding the services provided for students with ASD. On a scale of 5-Very well informed to 1-No information, only 3% of educators felt that parents were very well informed (6% well informed, 23% neutral, 47% not well informed, and 9% no information). Overall, in terms of how well-informed parents of students with ASD seem to be, the educators had a mean score of 2.40 (SD 0.89; see Table 4). Educators provided several possible reasons there are roadblocks to communication with families, including inadequate outreach and advertising by the school district; lack of parent involvement and awareness in the process; and lack of resources and services for ASD provided.

Parent/Caregivers' Perceptions of Educational Needs for Students with ASD

Parents and caregivers of individuals with ASD were asked to share their perceptions of importance and effectiveness of interventions for their children. The majority of the parents and caregivers (combined with the educators who were also caregivers) perceived EI to be the most

Table 4

How Well Informed Stakeholders Feel Regarding Autism Services Provided, n=68

<i>n</i> (%)	Individual with ASD	Educator	Parent/Caregiver	Health Care Provider
5- Very well	-	1 (3)	1 (5)	-
4- Well	-	2 (6)	-	-
3- Neutral	1 (50)	8 (23)	4 (22)	2 (33)
2- Not well	-	16 (47)	8 (44)	2 (33)
1- No info	-	3 (9)	5 (28)	2 (33)
No response	1 (50)	4 (12)	-	-
M (SD)	3.00*	2.40 (0.88)	2.11 (0.99)	2.00 (0.82)

Note. Only two respondents with ASD.

important level of intervention ($M=5.65$) with 7 being “most important” and 1 being “least important” (see Figure 7). In regards to the perceived effectiveness of EI for parents and caregivers, the mean score was 2.57 or “less effective” (see Figure 8).

Transition, K-3, and Preschool services, respectively, were the next highest ranked educational interventions of importance for parents/caregivers (K-3 services $M=4.45$, Transition services $M=4.40$, Preschool services $M=4.10$; see Figure 7). Of these top four rated services for students with ASD, parents/caregivers felt that K-3 services were the most effective with a mean of 2.90, followed by Preschool services with a mean of 2.84, EI with a mean of 2.57, and finally Transition services with a mean of 2.40 (see Figure 8).

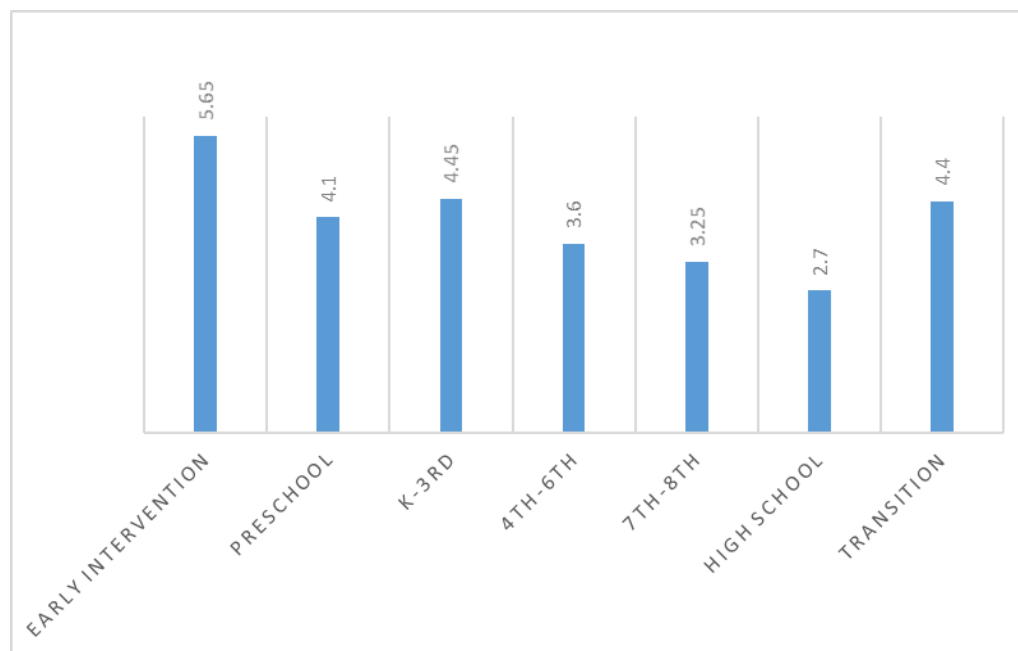


Figure 7. Parent/caregiver perceptions of importance of education services by grade range, n=26. 7 being “Most Important” to 1 being “Least Important.”

In terms of educational interventions, parent/caregivers had a limited awareness of the interventions available and/or provided for their student with ASD. One parent made the comment regarding the lack of communication from the district, another parent said, “just knowing what resources, what to ask for, what we can be made more aware of as far as services and accommodations. I think would be really helpful.”

Parent/caregivers were the most familiar with ABA, SLT, and Social Skills training (53% ABA, 46% SLT, and 38% Social Skills; see Table 5). As far as perceived effectiveness of the interventions, all parents that responded were the most satisfied with SLT (M=3.26). ABA is currently viewed as a highly effective intervention for students with ASD (Rosenblatt & Carbone, 2019, p. 74), with that being said, it is interesting to note the perceptions of effectiveness by parent/caregivers (M=2.85; see Figure 9). It is interesting to compare Figure 9 and Figure 10, including the selected parent/caregivers that indicated a familiarity with the district’s ASD specific interventions. In Figure 10, all ratings of effectiveness perceptions were

higher. These stakeholders perceived the effectiveness of SLT to have a mean of 3.75, ABA (M=3.57), and DTT (M=4.57; see Figure 10). It would appear that those parents that have an increased familiarity with the ASD specific interventions, also view those interventions more positively.

Another positive note, in a phone interview with a parent, the parent shared areas that were working well and were appreciated, including speech therapy. Other positive parent comments included, “I appreciate their efforts in helping ASD students,” They have been very patient and are trying hard to make and keep accommodations,” and “The one on one with the school counselor [psychologist is working well].”

Beyond a lack of awareness of ASD specific interventions provided by the school district, the parents and caregivers felt that all educators involved with their children needed more training and preparation in working with students with ASD. One parent described their concerns by saying, “I just have a hard time because teachers aren’t prepared on how to work with my child. It’s pretty much the middle of the year before things are put in place.”

When asked how well-informed parents feel regarding the services for their students with ASD, most parents feel that they are not very well informed. On a scale of 5-Very well informed to 1-No information, parents mean score was 2.11 with a standard deviation of 0.99 (see Table 4). Parents expressed an interest in being better informed regarding the services available for their student and more support and responsiveness from the district.

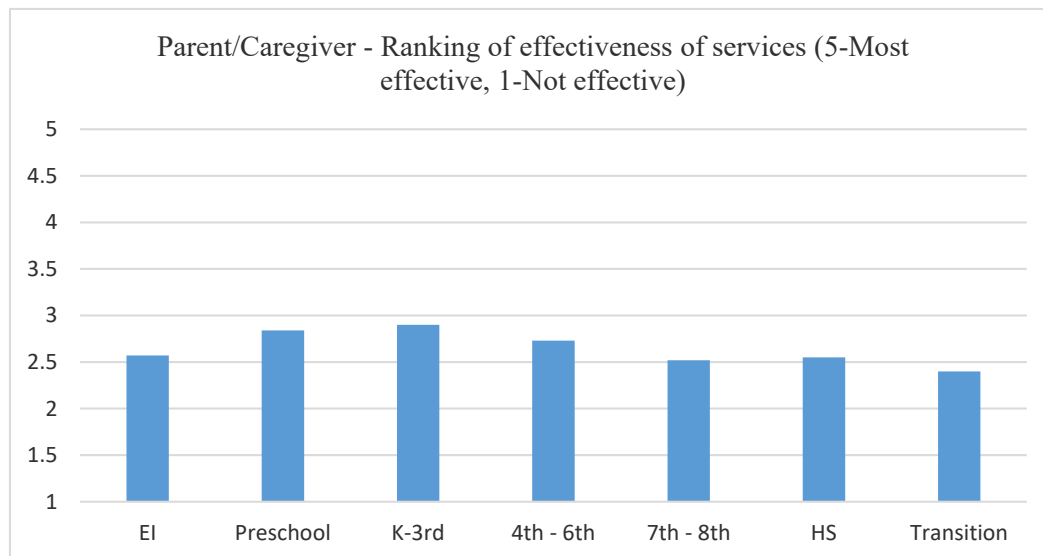


Figure 8. Parent/caregiver perceptions of effectiveness of interventions by grade range, n=26. Participants identified as both “Parent” and “Educator” are included in parent/caregiver data and counseling services by their child’s school psychologist/school counselor.

Table 5

Parent/Caregiver Perceptions of Autism Specific Interventions, n (%)

Speech Language Therapy	Social Skills	Applied Behavior Analysis	Get Ready	Discrete Trial Training	Improving Sensory Sensitivities	Video Modeling	Other
12 (46)	10 (38)	14 (53)	8 (30)	8 (31)	7 (26)	3 (11)	4 (15)

Note. Interventions used/seen used (respondents allowed to indicate multiple interventions), 26 respondents

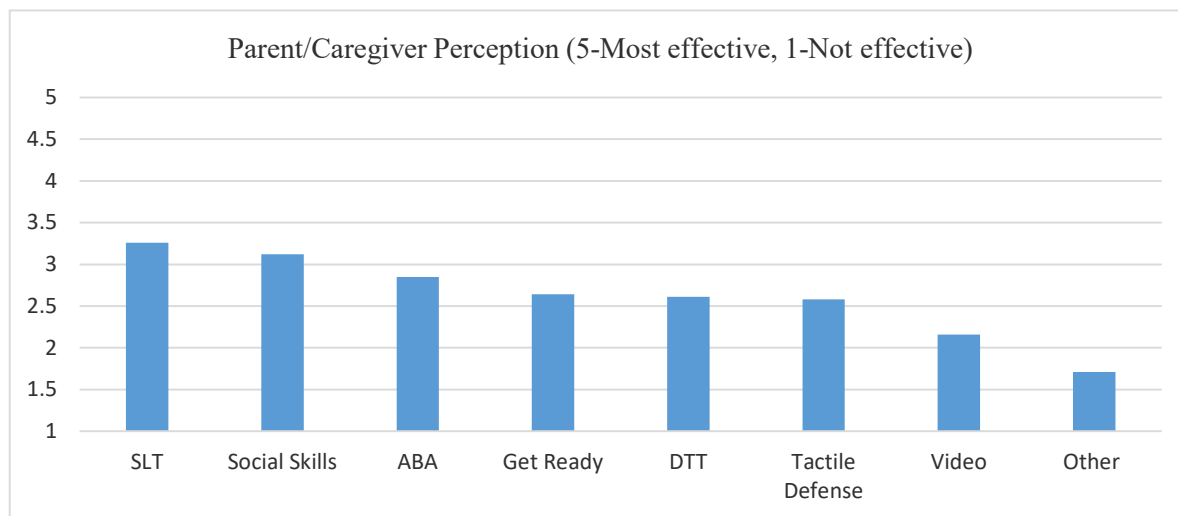


Figure 9. Parent/caregiver perceptions of effectiveness of autism specific interventions. Rating perceptions include any parents/caregivers that chose to respond to this question.

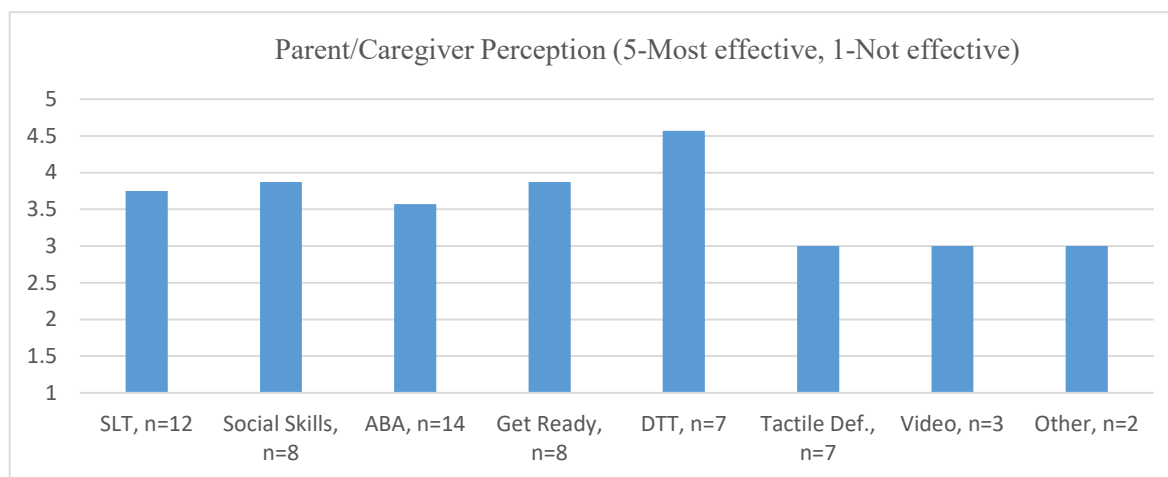


Figure 10. Parent/caregiver perceptions of effectiveness of autism specific interventions by participants indicating awareness of interventions in the school district. Rating perceptions include only those parents/caregivers that indicated an awareness of the District's ASD specific interventions.

Parents also shared some positive thoughts in their qualitative responses. Parents expressed appreciation for varying special education staff and the efforts made by these staff in behalf of their children. One parent commented, “[the] SPED dept tries to keep up by offering

more services like speech/occupation[al] therapy. I appreciate their efforts in helping ASD students with the social skills too.”

Community Health Care Perceptions of Educational Needs for Students with ASD

Health care providers in the county were asked to share their perceptions of the importance and effectiveness of interventions for students with ASD. The majority (83%) agreed with the other stakeholder groups that EI should be the top educational priority for students with ASD (see Table 2). When ranking the importance of educational interventions (7-top priority, 1-least important priority), health care providers top four areas were EI and Preschool services with a mean of 6.00, Kindergarten with a mean of 4.66, and Transition services with a mean of 3.33 (see Figure 11). In terms of effectiveness of these top four areas, with 5 being most effective and 1 being not effective, EI had a mean score of 3.00, Preschool M=2.66, K-3 M=2.83, and Transition M=2.5 (see Figure 12).

Community health care providers were most familiar with ABA (50%), SLT (50%), improving sensory sensitivities (i.e., Tactile Defensiveness; 33%), and Social Skills training (33%; see Table 6). Speech Language Therapy was perceived to be the most effective of these familiar interventions with a mean score of 3.50. Social skills training was viewed by health care (see Figure 13). Of those health care providers that indicated a familiarity with the district’s ASD specific interventions, their perceptions of effectiveness increased. They perceived SLT to be very effective, with a mean of 4.66, Get Ready (M=4.0), and Social Skills (M=3.5; see Figure 14). Once again, it would appear that when the stakeholders are more aware of the interventions, they view them more positively.

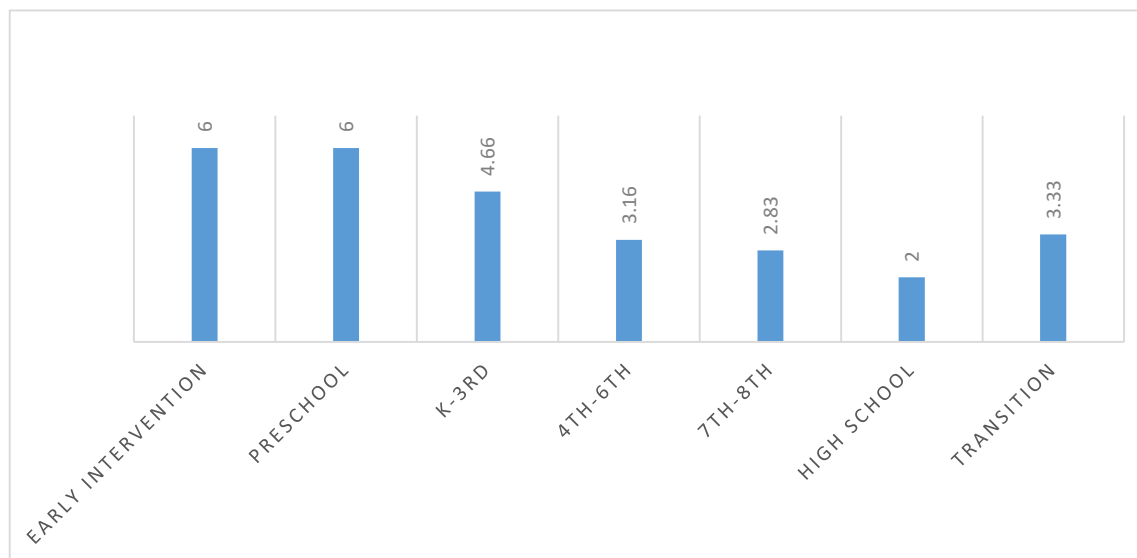


Figure 11. Community health care providers' perceptions of importance of education services by grade range n=6. 7 being "Most Important" to 1 being "Least Important."

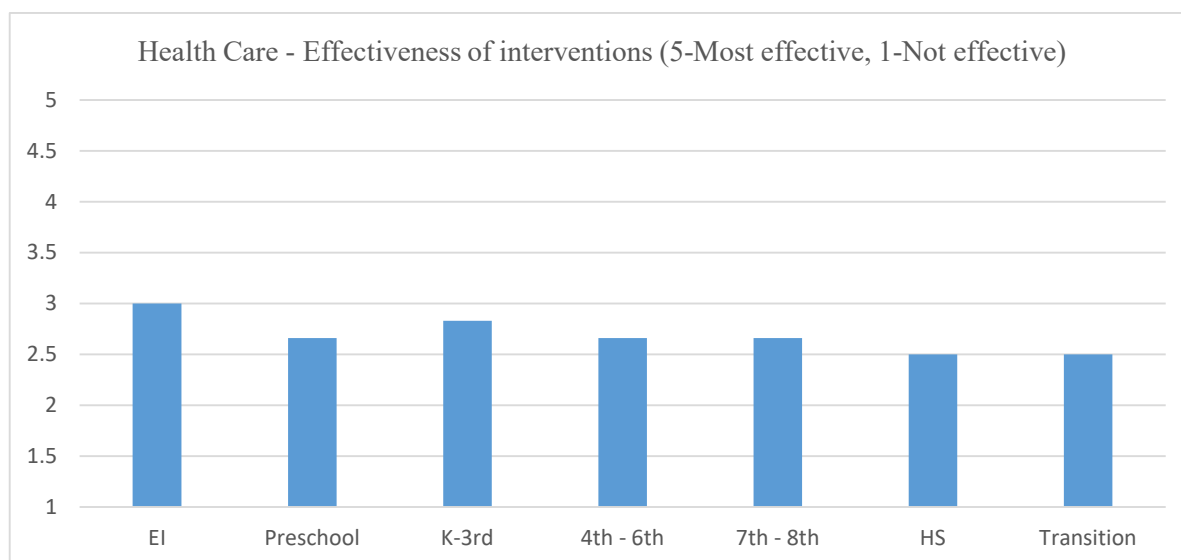


Figure 12. Community health care providers' perceptions of effectiveness of interventions by grade range, n=6

Table 6

Health Care Providers' Perceptions of Autism Specific Interventions, n(%)

Speech Language Therapy	Get Ready	Social Skills	Discrete Trial Training	Video Modeling	Other	Applied Behavior Analysis	Improving Sensory Sensitivities
3 (50)	1 (17)	2 (33)	--	--	2 (33)	3 (50)	2 (33)

Note. Interventions used/seen used, n=6.

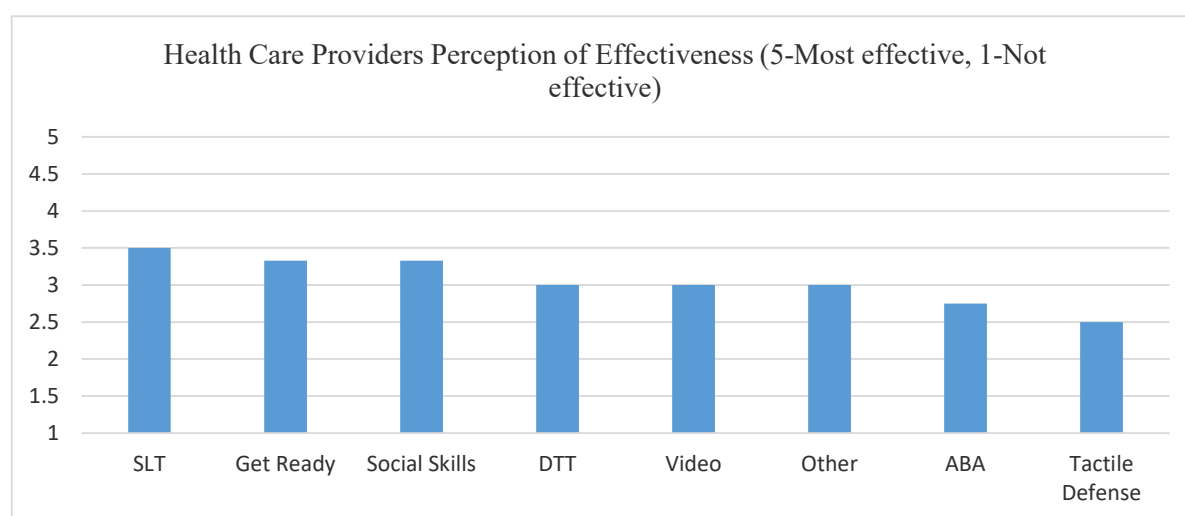


Figure 13. Community health care providers' perceptions of autism specific interventions, n=6. Rating perceptions include any health care providers that chose to respond to this question.

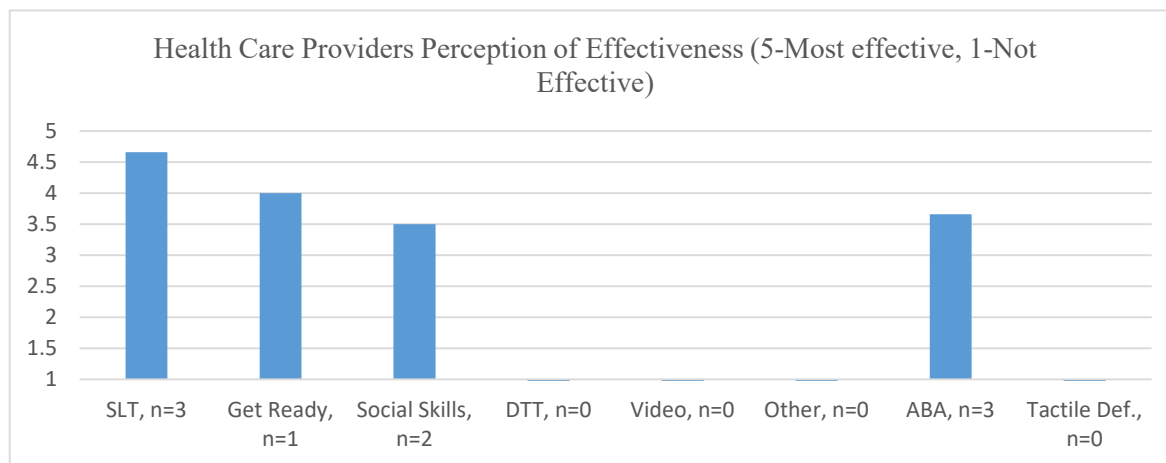


Figure 14. Community health care providers’ perceptions of effectiveness of autism specific interventions by participants indicating awareness of interventions in the school district. Rating perceptions include only those health care providers that indicated an awareness of the District’s ASD specific interventions.

Health care providers gave the impression that they felt parents did/do not receive information from the school district regarding autism services provided. With 5 being very well informed and 1 being no information, this stakeholder group had a mean score of 2.00 or “not well informed” (SD=0.82; see Table 4). One community health care provider encouraged the district to let “the communities [k]now more about what services are offered,” still others identified concerns about the lack of awareness and the need for helping the communities become more familiar with the services provided.

Individuals with ASD Perceptions’ of Educational Needs for Students with ASD

Individuals on the autism spectrum were also asked to share their perceptions of the importance and effectiveness of educational interventions provided. One of the individuals responded to the question regarding top educational priority ranking EI as the top priority (see Table 2).

In regard to specific educational interventions, between these individuals one or the other was familiar with ABA, Get Ready, SLT, Social Skills training, and Video Modeling (see Table

7). In regard to the perceived effectiveness of these interventions 50% felt ABA was effective and 50% not effective; 100% were neutral in regard to Get Ready; 50% felt SLT was effective and 50% not applicable; and 50% felt Social Skills training was effective and 50% not applicable (see Table 7).

Lastly, only one of the individuals with ASD responded to the question, “How well informed did/do parents feel regarding autism services provided?” On a Likert scale of 5-very well informed to 1-no information, this individual rated a 3-neutral (see Table 4).

Table 7

Individuals with ASD Perceptions of Education Services

Seen/Used <i>n</i> (%)	Discrete Trial Training	Applied Behavior Analysis	Get Ready	Speech Language Therapy	Improving Sensory Sensitivities	Social Skills	Video Modeling	Other
	-	1 (50)	1 (50)	1 (50)	-	1 (50)	1 (50)	-
Intervention effectiveness, <i>rating score</i> (%)	Discrete Trial Training	Applied Behavior Analysis	Get Ready	Speech Language Therapy	Improving Sensory Sensitivities	Social Skills	Video Modeling	Other
	3 (50)	4 (50) 1 (50)	3(100)	4 (50)	-	4 (50)	4 (50)	-

Qualitative analysis of open response questions and interviews added some additional areas of educational services that are going well and areas for improvement. Some positive comments across stakeholder groups included appreciation for one-on-one instruction, social skills training, and behavioral interventions. One parent commented, “I believe the majority of employees [in the school district] are doing the best they know how and/or have time to do.”

Areas of concern addressed in interview and open-ended questions included statements such as, there are “not enough resources,” “paraprofessionals are hired to work with students, but no training is provided. Paras are doing their best with the little support and help they have,” and “the student needs to be in a class at their level of cognition, even if that is kindergarten. I’m not saying putting high school students in a kindergarten class but throwing a student who functions at a kindergarten level into a high school class doesn’t work.”

Discussion

The study examined the perceptions of educational interventions for students with ASD from various stakeholders including individuals with ASD, educators, parents and/or caregivers, and community health care providers. A needs assessment regarding the importance of educational interventions, as well as their perceived effectiveness was given to the participants in an effort to determine what is working and what could use improvement in a rural school district. Sentiments across stakeholders agreed on some suggested areas of improvement. One was better communication of interventions and services with parents and caregivers. Previous research by Barrow (2017), confirmed that parents with disabilities feel they lack good information regarding services for their child. These parents also felt the necessity to learn to navigate the system for themselves (Barrow, 2017). The participants of this study reported similar experiences. From parents to health care providers, there was a strong sentiment about lack of awareness of services available to these students. Lack of communication between special education professionals and parents and caregivers was also a strong theme.

Another need was for more and/or better training for educators and paraprofessionals throughout the district. Parent comments regarding the need for more training for professionals include statements like, “get training...,” “I just have a hard time because teachers aren’t

prepared on how to work with my child...,” “in Reservation schools, lack of training [for] educators about ASD,” and so on.

Another area of concern amongst stakeholders was a need for improved social skills support for students/children with ASD. Whereas ASD is a developmental disability defined by diagnostic criteria in the Diagnostic and Statistical Manual of Mental Health Disorders, Fifth Edition (DSM-5) that include deficits in social communication and social interaction with accompanying restricted, repetitive patterns of behavior, interests, or activities that persist throughout life (American Psychiatric Association [APA], 2013), we see by definition that these individuals will most likely need support and skills training in this area. Stakeholders also share a concern for the lack of trained professionals (teachers, paraprofessionals, and other trained professionals) to serve these children.

Quantitative data received from the participants of this research suggest concerns regarding a lack of effectiveness of ASD programs. McKenney (2017) suggests the need for a school and IEP team to put into place a plan using care, data, and evidence-based practices. When these vital components are put into place, the educational program should have more likelihood of appropriately meeting the needs of the child with ASD. The information and data regarding the effectiveness of the program should be evaluated regularly and shared with the interested parties concerning the student (McKenney, 2017). Further, the IEP team would be wise to be cognizant of the fact that one intervention may not fit all students (Shyman, 2012).

Special education theory and practice are built on the premise that *individualized* intervention is necessary for students with disabilities (Education for All Handicapped Children Act, 1975). Qualitative responses from stakeholders shared this same sentiment. One educator stated that “education [was] not tailored to needs,” another parent commented the need to “start

with a better one [to] one educator for each kid with autism,” and a health care provider stated concerns that the students were not receiving specialized services, rather the school personnel had a goal to “just supervise them for the day.”

Another important area for consideration, though not formally evaluated in this study, is early diagnosis. In an effort to improve services for children with ASD, earlier diagnosis is an area of utmost importance. When asked what changes should be made to better serve students with ASD, one educator commented that earlier diagnosis would be beneficial. Murphy and Ruble (2012) stated that, “clear evidence now exists for the link between early diagnosis, access to early interventions services, and positive development outcomes” (Murphy & Ruble, 2012, p. 3; see also Blane & Borden, 2008; Rogers & Vismara, 2008). A federal mandate and systems are in place to improve outcomes for children with disabilities by beginning service and interventions earlier with Part C of the Individuals with Disabilities Education Improvement Act (IDEA, 2004). Before this time, “IDEA addressed the special education needs of children between three and twenty-one with no provisions for infants and toddlers” (Barrow, 2017, p. 66). Provision for a system, however, does not guarantee the quality of that system, nor does it necessarily provide the resources necessary to deliver services. In the current climate of qualified provider shortages, rural areas can explore better access to diagnostic services through partnerships, care networks, and telehealth opportunities.

Across the stakeholder groups there were many similarities, as well as differences. Each group demonstrated a concern for a lack of information received by parents with regard to autism services provided. Also, each group had some degree of knowledge of such services as ABA, SLT, and social skills training. However, their perceptions of effectiveness varied to an extent. Individuals with ASD, and hypothetically those with firsthand knowledge of these interventions,

felt they were effective. Educators, parent/caregivers, and health care providers were fairly split on their opinions of these interventions. However, among these three stakeholder groups, educators appeared the most favorable in their perceptions of effectiveness of services. This was only true, however of the group in general. When we analyzed only those who indicated they were aware of services in the district, educators had less favorable perceptions of the effectiveness of all services, with the exception of speech and language services, which was constant. In the larger group of educators, some also commented on the patience and caring of the special education teachers in the district, one stated, “We have wonderful special education teacher[s] who do amazing things with autistic kids!” That being said qualitative data still suggests a need for autism specific training expressed by both parents and educators. Parent perceptions of effectiveness of interventions were higher in the subgroup who stated they were aware of each type of intervention.

Limitations

This study is limited in its scope because it is confined to the residents of a single rural school district. Another limitation of the study was the sampling procedures (selection bias as participants self-selected into the study). The responding participants had higher education levels in comparison to county and state demographics. Also, the participants’ racial makeup was primarily Caucasian (75%), whereas the county demographics are more balanced between Caucasian (47.3%) and American Indian (49.2%) residents (U.S. Census Bureau, 2017). Therefore, the generalization of the findings may be limited. The intention is to use the results to improve training and implementation of evidence-based services for students with ASD in the school district. It is unknown how well these results will generalize to other rural school districts, but the results may nevertheless prove informative for others.

Implications for Future Research

The findings of this study offer insight into the perceptions of ASD stakeholders. These results not only include educators, parent/caregivers, and community health care providers, but individuals with ASD as well. The logical next step for this research would be to implement changes and research the satisfaction with the changes made across the same stakeholder groups. Data regarding effectiveness of interventions and other services (e.g., assessment of ASD and co-morbid conditions) may also be collected and analyzed to institute an ongoing quality improvement process for services to benefit students with ASD.

Implications for Practitioners

Upon completion of research the following recommendations are submitted for improvements suggested by stakeholders. Improved communication by school district with stakeholders regarding the services and interventions provided to students with ASD in the rural school district. The perceived need for improved awareness and communication may be easily addressed by educators through strategic and purposeful planning. Perhaps regular communication could occur via district newsletter, webpage, family and/or community mailers/emails, etc.

Many concerns or perceived weaknesses in programming for students with ASD might be alleviated simply through better understanding of the interventions in use and data showing the effectiveness of such interventions. Community health care providers' perceptions of ASD specific services and resources may also be enriched through strategic advertising and communication from the local school district. The health care system may be where some parents receive first confirmation of an ASD diagnosis for their child. Strengthened partnerships

between health care and educational systems can streamline primary access to community services available for ASD.

A second recommendation for the school district consists of increased educator training. Educators, as well as students with ASD would be benefitted greatly by receiving high quality training specific to these students' needs. A third recommendation is to improve follow up communication with parents about progress being made by their child. Since a lack of knowledge and awareness was a topic of concern for parents, improved feelings of collaboration may occur by simply implementing better and more regular communication of information to parents regarding their student's improvements. A last recommendation is to look into improving investment in early intervention and transition services, resources, and awareness. Early intervention and transition services were perceived as being of high importance but were also perceived as being ineffective services. Perhaps as educators are receiving ASD specific and related services, there could be included trainings on innovative ways to increase and/or improve the interventions provided.

The process of conducting this needs assessment was expected to benefit practitioners in the planning and execution of educational services according to the standard of 'free and appropriate public education (FAPE)' for students with ASD in this rural school district, as well as other students (McKenney, 2017). The findings may also benefit other rural school districts either in conducting their own needs assessment or by the utilization of our results as a guide for improving their own services.

Conclusion

A common theme among participants' qualitative and quantitative responses was the need for improved awareness, communication, and training for ASD services and interventions.

Further, early intervention was viewed as the top educational priority by each participating demographic. However, EI was not viewed as very effective by all participants with the exception of the educators. If in fact EI is an effective intervention as viewed by the educator participants, enhanced data and evidence may need to be shared with other stakeholders to help improve perceptions of effectiveness. On the other hand, if data were collected and found to suggest that EI is not as effective as perceived, efforts to increase effectiveness ought to be implemented. Transition services were also viewed as a necessary priority in educating students with ASD. That being said, the effectiveness of transition services was perceived as being “less effective” by parents/caregivers and health care providers. Training and communication improvements can also be targeted within these age ranges as a focused effort.

Throughout the concerns and perceived weaknesses expressed by stakeholders, a common theme seems to hold true--the lack of awareness and communication. Perhaps the implementation of an advisory committee would serve to improve communications and foster strong relationships among stakeholders (e.g., a committee including educators, parents/caregivers, health care providers, other community members, etc.). Many, if not all, parents desire to be an active, collaborative, and informed participant in their child’s life and education (Auert, Trembath, Arciuli, & Thomas, 2012). With regard to the parent of a child with a disability, they may especially feel a desire to receive knowledge and understanding as they navigate the road with their child. Educators also feel a lack of awareness and/or training with regards to providing services and educating these students. This lack of training is perceived as a frustrating area of weakness but may be easily resolved through appropriate training and ongoing support from those with the appropriate knowledge base (Corkum et al., 2014).

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author
- Auert, E., Trembath, D., Arciuli, J., & Thomas, D. (2012). Parents' expectations, awareness, and experiences of accessing evidence-based speech-language pathology services for their children with autism. *International Journal of Speech-Language Pathology, 14*(2), 109-118. doi:10.3109/17549507.2011.652673
- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., . . . & Dowling, N. F. (2018, April 27). Prevalence of autism spectrum disorder among children aged 8 years-Autism and Developmental Monitoring Network, 11 Sites, United States, 2014. *Morbidity and Mortality Weekly Report Surveillance Summaries, 67*(6), 1-23. Retrieved from <https://www.cdc.gov/mmwr/volumes/67/ss/ss6706a1.htm>
- Barrow, D. M. (2017). *A phenomenological study of the lived experiences of parents of young children with autism receiving special education services*. Retrieved from https://pdxscholar.library.pdx.edu/cgi/viewcontent.cgi?article=5044&context=open_access_etds
- Blane, K., & Borden, C. (2008). The importance of early intervention for autism. *The Brown University Child and Adolescent Behavior Letter, 24*(6), 1-7. Retrieved from <https://doi.org/10.1002/cbl.20068>
- Centers for Disease Control and Prevention (2018). *Learn the Signs. Act Early*. Retrieved from: <https://www.cdc.gov/ncbddd/actearly/index.html>
- Christon, L. M., & Myers, B. J. (2015). Family-centered care practices in a multidisciplinary sample of pediatric professionals providing autism spectrum disorder services in the

- United States. *Research in Autism Spectrum Disorders*, 20, 47-57. Retrieved from:
<https://doi.org/10.1016/j.rasd.2015.08.004>
- Corkum, P., Bryson, S. E., Smith, I. M., Giffin, C., Hume, K., & Power, A. (2014) Professional development needs for educators working with children with autism spectrum disorders in inclusive school environments. *Exceptionality Education International*, 24, 33-47.
 Retrieved from: <https://ir.lib.uwo.ca/eei/vol24/iss1/4>
- Education for All Handicapped Children Act, Pub. L. 94-142 (1975).
- Guthrie, W., Swineford, L, Nottke, C. & Wetherby, A. (2013). Early diagnosis of autism spectrum disorder: Stability and change in clinical diagnosis and symptom presentation. *Journal of Child Psychology and Psychiatry*, 54(5), 582-590. doi:10.1111/jcpp.12008
- Hill, C. E., Thompson, B. J., & Williams, E. N. (1997). A guide to conducting consensual qualitative research. *The Counseling Psychologist*, 25(4), 517-572. doi:
 10.1177/0011000097254001
- Iadarola, S., Hetherington, S., Clinton, C., Dean, M., Reisinger, E., Huynh, L., . . . & Kasari, C. (2015). Services for children with autism spectrum disorder in three large urban school districts: Perspectives of parents and educators. *Autism: The International Journal of Research and Practice*, 19(6), 694-703. doi:10.1177/1362361314548078
- Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004)
- Jenson, W. R., Bowen, J., Clark, E., Block, H., Gabrielsen, T., Hood, J., . . . & Springer, B. (2011). *Superheroes social skills: A multimedia program*. Eugene, OR: Pacific Northwest Publishing.

- Kogan, M. D., Vladutiu, C. J., Schieve, L. A., Ghandour, R. M., Blumberg, S. J., Zablotsky, B., . . . & Lu, M. C. (2018). The prevalence of parent-reported autism spectrum disorder among US children. *Pediatrics, 142*(6), e20174161. doi:10.1542/peds.2017-4161
- McKenney, E. (2017). Endrew, F v. Douglas County School District: Implications for teams serving students with autism spectrum disorder. *Communiqué, 46*(2), 11-12
- Murphy, M. A., & Ruble, L. A. (2012). A comparative study of rurality and urbanicity on access to and satisfaction with services for children with autism spectrum disorders. *Rural Special Education Quarterly, 31*(3), 3-11. doi:10.1177/875687051203100302
- Qualtrics. (2019). Provo, Utah, USA. Available at: <https://www.qualtrics.com>
- Rogers, S. J., & Vismara, L. A. (2008). Evidence-based comprehensive treatments for early autism. *Journal of Clinical and Adolescent Psychology, 37*(1), 8-38.
doi:10.1080/15374410701817808
- Rosenblatt, A. I., & Carbone, P. S. (2019). *Autism spectrum disorder what every parent needs to know* (2nd ed.). Itasca, IL: American Academy of Pediatrics.
- Shyman, E. (2012). Teacher education in autism spectrum disorders: A potential blueprint. *Education and Training in Autism and Developmental Disabilities, 47*(2), 187-197.
Retrieved from:
https://www.researchgate.net/publication/288249425_Teacher_Education_in_Autism_Spectrum_Disorders_A_Potential_Blueprint
- U.S. Census Bureau (2017). *QuickFacts*. (n.d.). Retrieved from
<https://www.census.gov/quickfacts/fact/table/sanjuancountyutah/PST040218>

APPENDIX A

Review of the Literature

ASD and Need for Services

According to the Diagnostic and Statistical Manual 5 (DSM-5), autism is defined as “Persistent deficits in social communication and social interaction across multiple contexts...” (American Psychiatric Association [APA], 2013). The prevalence of autism spectrum disorder (ASD) is increasing significantly, to the point where individuals with autism are found in every community; including rural communities. According to the Centers for Disease Control and Prevention (CDC), the current prevalence of individuals with ASD is one in 59 which is roughly double the prevalence from 2004 (Baio et al., 2018). The availability of educational services may not be keeping pace with this increase, particularly for students with autism who live in rural communities.

Along with the increased presence of these students in the classroom are the educators, paraprofessionals, and caregivers who may feel unprepared to adequately provide the necessary educational interventions and support. Research findings in an autism study completed in *urban* areas by Iadarola et al. (2015) found that students with autism’s educational needs were not being met reliably. Resources may be more available in an urban area, but needs are still not being met because of other barriers to accessing services. ASD related resources may be much more difficult to access in rural communities. Training emerged as an important theme in autism education in the urban study. In particular, paraprofessionals felt unprepared and unsupported in their role with the students on the spectrum. Findings also indicated a need for administrators to improve school wide support of all students and improve the culture of their building to be more inclusive of all students (Iadarola et al., 2015).

The Autism and Developmental Disabilities Monitoring (ADDM) Network also found that the prevalence of ASD is steadily increasing over time, suggesting that these trends may continue in the future (Baio et al., 2018). The substantial increase in the prevalence rates of ASD indicates a corresponding and enduring increase in the necessity for high-quality supports and interventions for persons with ASD dispersed throughout the United States. To best serve these students, educators must determine and be trained in educational best practices (evidence-based interventions) while taking into consideration that each student on the autism spectrum may have individual needs, strengths, and weaknesses. One size may not fit all, in terms of educational programming (Shyman, 2012).

Individuals with ASD struggle with social interactions. They may also tend to lack interest in making friends and may need social skills training to help them improve these skills. Social interactions may be used only to the extent of meeting their needs and even in this area they may have trouble communicating those needs effectively. Also, individuals on the autism spectrum may show fixations with various items (e.g., characters, toys, etc.) and engage in repetitive behaviors (National Autism Center, 2015).

Early classification and intervention are considered by many researchers to be of utmost importance. “Clear evidence now exists for the link between early diagnosis, access to early intervention services, and positive development outcomes” (Murphy & Ruble, 2012, p. 3; see also Blane & Borden, 2008; Rogers & Vismara, 2008). That being said, not only do these individuals need to begin early with educational interventions, but the interventions chosen should be effective. One study of ASD undertaken by Barrow (2017) interviewed families of young children with ASD in an effort to determine what interventions were needed by these

families. A common theme among the research indicated a need for effective early intervention services.

Earlier diagnosis of ASD was also identified as a necessary precursor to early intervention (Barrow, 2017). Autism identification and diagnosis has been shown to be possible and stable in children as young as 2 years old (Guthrie, Swineford, Nottke, & Wetherby, 2013), but treatment rarely begins before a child's third or fourth birthday (Barrow, 2017). Research by Baio et al. (2018), also found a gap in early evaluation of individuals with ASD, with only approximately 39% of the children with ASD having any comprehensive evaluation by 36 months of age (Baio et al., 2018). This shows a probable gap in the initiation of intervention services of one and a half to two and a half years. This is a great deal of lost educational time for a young child with ASD.

Educational Concerns for Students with ASD

Educational concerns and needs for students with ASD can be wide-ranging. Support with improved social skills to help with functional daily living activities comprise the range of supports and intervention that are likely to be needed for individuals with ASD to become independent and successful in academic settings.

Students with ASD are increasingly present in the classroom with educators, paraprofessionals, and caregivers who may feel unprepared to adequately provide necessary educational interventions. Research in an ASD study completed in urban areas by Iadarola et al. (2015) found that students on the autism spectrum have educational needs that are not being met reliably in their respective schools. Of particular importance is training for all educators that work within the school systems with increasing numbers of students with ASD. They found that paraprofessionals felt unprepared and unsupported in their role with the students on the

spectrum. The findings also indicated a need for administrators to improve school wide support of all students and improve the culture of their building (i.e., the school) to be more inclusive of all students (Iadarola et al., 2015).

Providing educational interventions for students living in a rural community can pose many daunting challenges. There are a variety of factors that contribute to these challenges; such as long traveling distances to professional support services and specialists, few highly trained professionals in education specific to ASD in the area, and families lacking financial resources to meet educational and other related needs of student with ASD. Geographic variables may also contribute to challenges in supporting students with ASD. The rural county of interest for this study is located in the western United States. It is not uncommon for a family in this county to travel from 70 up to 100 miles to shop at a Walmart or other large commercial institution. According to the U.S. Census Bureau, the median income for a family in this county between 2012-2016 was \$41,108 and >31% of individuals are considered to be living in poverty (U.S. Census Bureau, 2017). A vast proportion of the county residents live outside of city limits on dirt roads, many without electricity. Therefore, sources of support for students with ASD commonly found in more highly populated areas may not be an option given the lack of resources in a rural area. Of particular concern is the lack of highly trained educators in the area of ASD. Knapczyk Chapman, Rodes, and Chung (2001) found that “80% of the [rural] school districts did not have enough personnel in special education” (p. 402). Of the special education staff available, many lack knowledge of evidence-based interventions for students with ASD (Murphy & Ruble, 2012). Many students with a variety of special education classifications may be placed on a single teacher’s case load, and it is not realistic for that one teacher to be highly trained in each of the special education areas that can prove problematic (Williams, Martin, & Hess, 2010).

As part of the ADDM report, data were gathered about students with ASD being serviced in special education but classified under other categories such as; speech impairment, SLD, and so on (Baio et al., 2018). This is the perceived scenario in this rural school district. There is a concern that many students that may have ASD are not being served for that disability because they are being served under a different classification or possibly not receiving any special education services at all (K. Perkins, personal communication, October 17, 2018). Therefore, many students with ASD may very well be missing the appropriate intervention for their specific needs and educational concerns (Baio et al., 2018).

Educational Laws

Individuals with Disabilities Education Act (IDEA). The Education of All Handicapped Children Act of 1975 (now known as IDEA) was created to guarantee that all children with disabilities had the opportunity for a free and appropriate education which places emphasis on special education and its related services, which are intended to meet the student's unique needs. As well as guaranteeing that the educational plans are effective. An important piece regarding the heart and intent of IDEA is the protection of the rights of both the student and the parents (IDEA, 2004).

IDEA legislation went through several updates and revisions, including adding four new components in 2004. These included Part A-Revisions, Part B-Assistance for Education of All Children with Disabilities, Part C-Infants and Toddlers with Disabilities, and Part D-National Activities to Improve Education of Children with Disabilities (IDEA, 2004). We will address IDEA's Part B and Part C and the significance they have in the lives of students with ASD.

Part B of the Individuals with Disabilities Education Improvement Act (IDEA, 2004) includes provisions for state educational plans. These state plans should include descriptions of

how the state will provide and assure a free and appropriate public education (FAPE) for all children with disabilities residing within the state between the ages of 3 and 21 (Individuals with Disabilities Education Improvement Act, 2004). As determined in the *Endrew F. v. Douglas County School District* case, education agencies should strive to find and appropriately educate students with ALL disabilities, including ASD (*Endrew F. v. Douglas County School District*, RE-1, 2017).

Of particular importance to students with disabilities, including those with ASD, is IDEA's Part B regarding education in the least restrictive environment in school settings. To the extent possible, students with ASD should be educated alongside mainstream students and only removed from the mainstream if the severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. (Individuals with Disabilities Education Improvement Act, 2004). Oftentimes in rural settings, students with ASD may be placed in general education classrooms due to a lack of adequate teaching staff and fewer resources. These students, although placed in the mainstream, may not be getting their needs met appropriately by teachers that are unaware of the educational interventions necessary for these students to meet their potential. Also, rural schools may lack the resources that would allow a wide variety of intervention opportunities for students with ASD (Williams et al., 2010).

Part C of the Individuals with Disabilities Education Act was added to include early intervention services for infants and toddlers. The rationale in adding this amendment to the IDEA act was for the following reasons:

- (1) to enhance the development of infants and toddlers with disabilities and to minimize their potential for developmental delay;

- (2) to reduce the education costs to our society, including our Nation's schools, by minimizing the need for special education and related services after the infants and toddlers with disabilities reach school age;
- (3) to maximize the potential for individuals with disabilities to live independently in society;
- (4) to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities; and
- (5) to enhance the capacity of state and local agencies and service providers to identify, evaluate, and meet the needs of all children, particularly minority, low-income, inner-city, and rural children, and infants and toddlers in foster care (Pub. L. No. 105-17; § 631; 118 Stat. 2644 [2004]).

Part C of IDEA was developed by the federal government to support the needs of infants and toddlers with disabilities. Before this time, “IDEA addressed the special education needs of children between three and twenty-one with no provisions for infants and toddlers” (Barrow, 2017, p. 66). IDEA Part C could be a great benefit to students with ASD in giving them a better educational beginning in their early years when they are experiencing intense brain development and growth (CDC, 2019). Additionally, there is the hope that the early intervention may relieve some of the suffering and later financial burden of educating students with disabilities who have not acquired basic life skills (e.g., speech and language). Research supports the idea that early educational interventions are beneficial in helping students to improve their lacking skills. Of particular interest to this research study is the need expressed in Part C for meeting the educational needs of children in rural communities (IDEA, 2004).

The underlying premise for IDEA Part C is that early intervention services can greatly enhance the student's outcomes in upcoming educational endeavors. Because of IDEA – Part C, federal money was given to special education programs to fund early intervention efforts. IFSP's or Individualized Family Service Plans were put into place to meet the needs of infants and toddlers with various disabilities, including those who are at risk for delays because of their medical history. The impressive piece to IFSPs is the fact that the parent and/or family are

central to the planning, creation, and implementation of these plans. Parents and families are taught how to help the infant or toddler with their learning needs as they work as a team with the service coordinator (Barrow, 2017).

However, one concern with ASD and IDEA-Part C is the conundrum that by the time the diagnosis of ASD has been made, the child has already aged out of Early Intervention services. After this time the child is able to participate in early childhood special education interventions, but these Part B programs tend to miss the family and caregiver piece found in early intervention through Part C (Barrow, 2017). Another issue with IDEA and students with ASD is the level of services that is considered to be “appropriate.”

Andrew F. v. Douglas County School District. The Supreme Court’s ruling in the case of *Andrew F. v. Douglas County School District* (*Andrew F. v. Douglas County School District*, RE-1, 2017), has important implications for the education of all students of disabilities, but in particular of students with ASD, considering that public education may be the primary vehicle for a rural student with ASD to receive intervention services (Murphy & Ruble, 2012).

On March 22, 2017, the Supreme Court unanimously ruled that schools are obligated to provide more than de minimus services for students with disabilities. The core issue in “*Andrew F. v. Douglas County Schools*” is how schools are to define the “A” in FAPE: What is an appropriate public education? Douglas County schools held that they were upholding their legal responsibility in providing de minimus benefit to Andrew, as that was their interpretation of the precedent-setting case previously litigated around this issue (“*Rowley v. Board of Education*”). However, the current court disagreed, determining that “*Rowley*” spoke to the issue of what is appropriate in the case of a child who was succeeding in the general education setting with accommodations, whereas the issue in the “*Andrew*” case is the nature of FAPE when a student is demonstrating little to no progress year upon year, despite having an IEP. Furthermore, Andrew F.’s parents argued that IEP-based services should be designed to enable achievement and a level of independence that is “substantially equal” to those provided to students without disabilities, but the Court did not uphold this high standard, referring to the “*Rowley*” precedent, in which it was determined that such a standard would be impossible to measure and, therefore, impossible to enforce. For those familiar with the needs of students with autism spectrum

disorder (ASD), and especially those who have worked with students with ASD during the early education and elementary school period, it is perhaps not surprising that this issue (defining FAPE for students with intensive needs) arose around a child with ASD (McKenney, 2017, p. 11).

Therefore, educators are put in a position to determine what constitutes FAPE or a Free and appropriate education for each of their students. In 1993, the United States Court of Appeals, Sixth Circuit, defined FAPE as a “serviceable Chevrolet and not a Cadillac” (*Doe v. Bd. Of Educ. Of Tullahoma City Schools, 6th Cir., 1993*). In providing this level of service to a student with ASD, there may be no guarantee of an optimistic educational outcome for the child.

Educators and parents alike would do well to have an understanding of case law as it pertains to students with disabilities, including ASD. This understanding may benefit stakeholders in having the necessary knowledge to provide services that are appropriate and least restrictive and therefore will benefit students with ASD (Adams & Taylor, 2017).

Other pertinent case law. The Rowley case (Board of Education of the Hendrick Hudson Central School District v. Rowley, 1982) was one of the early attempts at determining what was meant by a free and appropriate education. Two questions were set forth in an effort to determine if an educational program was appropriate. Those questions include “Were IDEA procedures followed in developing the IEP?” and, “Is the program reasonably designed to benefit the child?” To determine the answers to these two questions, the individual student and his or her needs should be taken into account. This case law has significance for students on the autism spectrum as well; does the IEP being developed for the student with ASD meet his or her needs, will the program being implemented help the student with ASD have the best chance at meeting his or her potential?

In the case of *Pennsylvania Association for Retarded Children (P.A.R.C.) v. Commonwealth of Pennsylvania* (1972), educators and other stakeholders were compelled to see the obligation to educate all students despite the severity of their disabilities or the magnitude of their educational needs. In the case of *Mills v. Board of Education of District of Columbia* (1972), the courts ruled that schools were obligated to provide each handicapped child of school age a free and suitable publicly supported education regardless of the degree of the child's mental, physical or emotional disability or impairment. Therefore, if schools are under the obligation to ensure an education, furthermore an appropriate education, measures need to be taken to determine the needs of students on the autism spectrum and implement those efforts towards that end.

Necessity of educational interventions. Kucharczyk et al. (2015) researched the long-term educational needs of high school students with ASD and how their education ought to be designed to meet those needs. The researchers found that within 4 years of leaving high school only 57% of the students with ASD had enrolled in any form of post high school educational program, only 47% were employed, and only 11% were living in an independent setting. Therefore, the researchers recommended the need for improved educational services to support these students' post high school needs, stating, "many [students with ASD] leave school without the skills, experiences, supports, and linkages that will prepare them well for college and future careers," (Kucharczyk et al., 2015, p. 329).

Parents' Educational Concerns

When addressing parent and stakeholder concerns regarding educational needs, Kucharczyk et al. (2015) developed the following indicators about their perspectives of the education experience for high school students with ASD. They separated the indicators in terms of positive and negative indicators and nonexistent efforts and ineffective efforts. Their research accumulated 192 references in relation to ASD, out of those only 16 (8.3%) were considered positive responses. Of these references, these 16 stated that they felt the efforts being made by schools were leading to positive educational outcomes for students with ASD. The most common parent and/or stakeholder messages were negative in nature, suggesting that schools were ineffectively educating these students. Other responses suggested the schools' efforts were nonexistent or most often ineffective. "It depends on..." was a common statement across respondents, suggesting schools' efforts were more or less effective depending on such things as consistency, "buy-in," feasibility, warnings of using the "one-size-fits-all" educational approach, and so on (Kucharczyk et al., 2015).

Barrow's (2017) research also determined concerns and perspectives of families with children with ASD who resided in the metropolitan areas of the Northwest. The participating families were able to share their views on family life, interventions, and medical care. The families were also followed as they navigated the educational service systems. Families felt that they had experienced stress in accessing services, felt inadequate, felt the ASD had an impact on family life, and felt they needed to make adaptations in their situations (Barrow, 2017).

The parents in Barrow's (2017) study felt that they needed to learn to navigate the system for themselves and their child with ASD. They also felt some compulsion to improve the system for other parents who would need to follow in their footsteps. Beyond feeling the need as parents

to tread their own way in this unknown territory of adequate services for children with ASD, these parents also felt some confusion in what this disorder meant and how to cope with it. Furthermore, these parents felt there was a detrimental lag in services for their child with ASD. Parents were concerned that they were seeing the signs of a problem in their child's development anywhere around a year before they were able to access specialized treatment (Barrow, 2017).

Parents of children with a disability, and in the case of Barrow's (2017) study, ASD, struggle with a variety of worries in relation to their child. They worry over developmental lags, health problems that may be associated with the ASD, as well as the stress related to finding appropriate services to support their child's developmental and educational needs. These parents also felt worry over the lag in waiting for a confirming diagnosis; as well as the lack of good information in terms of services for their child and support in connecting with those services. However, in the face of all these challenges, the parents continued to advocate for their child and other children with ASD. These parents proved to be sources of encouragement and confidence for other parents finding themselves in the same situation (Barrow, 2017).

Essential dynamics that affected families with ASD experience include socio-economic and family support issues, among other things. According to Barrow's (2017) research, these factors play a role in the perspectives of parents towards ASD as well as their perspective on early intervention and other interventions. Parents felt comfortable if served by a caring service provider, and frustration if serviced by an unreliable and unresponsive service provider. Parents wanted direction and support and felt dissatisfied if this service wasn't provided. Parents appreciated being involved in decision making and being treated as if they were valuable members of the intervention team (Barrow, 2017).

To summarize Barrow's (2017) findings in terms of parent needs, research found that these parents felt they, by necessity had to learn to navigate the systems, help their children receive the interventions they required, and create the path for parents that would follow in their footsteps (Barrow, 2017). These parents also felt very strongly that they wanted to and should be included in their child's educational interventions and serve as a fundamental partner on their child's educational team. Families felt that the opportunity to bond with other families with children with ASD was also valuable and proved to be a positive support (Barrow, 2017).

Of particular interest to this research in the rural county of interest in the western United States, wherein approximately 49.4% of the population are American Indian people (U.S. Census Bureau 2017), was a study by Applequist and Bailey (2000). Applequist and Bailey interviewed 52 Navajo parents whom had children receiving early intervention services. The researchers interviewed the Navajo families regarding their satisfaction towards early intervention services. They were more likely to respond positively about the services when they found the service to be "family-centered" and that their needs were met by that program. Interestingly, they were less concerned with services being provided by someone of a similar cultural background, than they were by the characteristics of the program in use (Applequist & Bailey, 2000).

Stakeholder Concerns

Educator concerns. After analysis of the data was completed by the research team of Iadarola et al. (2015), the same primary themes rose to the top with each focus group and amongst each category of respondents (e.g., educators, parents, paraprofessionals). As stated earlier those themes include the following; tension amongst the various groups, need for improved training for all school personnel, and the need to create a culture shift which is more accepting of others with differences (Iadarola et al., 2015).

In regard to the tension experienced by each group, there was evidence of tension between special education and regular education teachers, tension from teachers towards administrators, and paraprofessional tension towards the teacher. One paraprofessional stated, “They assume we know, but sometimes you know, we do know, but other times we’re unfamiliar with and they won’t take the time to explain it...why we’re doing it this way” (Iadarola et al., 2015, pp. 698-699). Probably not surprising, there is also tension sensed between the parents and the school. It would appear as though the greatest source of the tension from parents was about the lack of administrative support.

The need for professional training and ASD awareness for educators was a recurring theme in the research completed by Kucharczyk et al. (2015) as well. However, not only was the need for greater ASD awareness a concern, but sharing that awareness beyond the educators to the peers of the students with ASD (Kucharczyk et al., 2015) was also important. In terms of training for the educators, stakeholders conveyed the need to understand an individual student’s need(s) for intervention, rather than developing one intervention and assuming all will be successful in that one educational practice. Furthermore, the special educators who responded discussed a need for general classroom educators to increase their knowledge of and interventions for students with ASD (Kucharczyk et al., 2015).

In working towards improved educational interventions for students with ASD, teachers need improved training opportunities to meet the needs. In 2012, Eric Shyman examined the needs of educators and in particular educational training programs to prepare educators to manage the complexities involved in educating students on the autism spectrum. Shyman stated that individuals with ASD present with complex behavioral, social, and linguistic patterns

necessitating specialized educational needs. Therefore, in-service teachers must become better prepared to meet such challenges (Shyman, 2012).

Shyman (2012) also addressed the issue of one size of educational intervention not fitting all students with ASD. He proposes the obligation for educators to be well-versed and trained in a variety of approaches, so they have a whole menu of interventions at their disposal when working with students with ASD. Further, he admonishes educators and education preparation programs to focus less on reactive strategies for dealing with behavioral problems that have occurred, but more on effective interventions and preventions before the behavior presents itself (Shyman, 2012).

Community care providers' concerns. There may be some debate over who should take responsibility for interventions such as speech therapy, occupational therapy, and mental health services. Does the responsibility for these services lie solely or primarily with the educational institution? Or do community care and health services have some or any responsibility in the delivering of these interventions? Bilaver, Cushing, and Cutler (2016) researched the access and usage of community services by children with ASD for further understanding of this complex issue. Their findings suggest that a majority of the services are provided by the education agency, with differences of service provisions depending on the student's socioeconomic status. For example, children from wealthier homes (with annual income above \$50,000) were more likely to receive occupational therapy services from their education institution as well as community care providers (Bilaver et al., 2016). This being the case, a coordinated intervention effort between school and community care may be a viable solution. If it is, how do we provide the community care service to the uninsured and/or economically challenged families? Or do we continue to provide the services solely through educational agencies?

One hurdle to educational agencies taking the lead on the behavior therapy is the high caseloads on a school's behavior therapist, assuming the school has such an employee, which is unlikely in the case of rural communities. Therefore, with this high case load, or no behavior therapist, the behavior therapy intervention falls upon the special education teacher. This teacher is most likely not trained in appropriate intervention (Bilaver et al., 2016).

In the case of a rural community, community care providers may be unprepared to provide the specific interventions as needed by individuals with ASD. Brookman-Fraze, Drahot, and Stadnick (2011) found that "there are gaps in the quality of CMH [Community Mental Health] services for children with ASD... [they] do not have enough specialized knowledge about ASD to effectively treat this population" (p. 1652). These gaps in the necessary skills by CMH have been found, yet their research also suggest that "approximately 70% of children with ASD meet criteria for at least one additional psychiatric disorder" (Brookman-Fraze et al., 2011, p. 1651).

Educational Needs of Students with Autism Spectrum Disorder

A recurring theme in research with regard to the educational needs of students with ASD is the definite need for educational interventions, with the caveat that one intervention may not fit all students' needs. Educators need training in a variety of interventions, as well as planning for the use of varying interventions with varying students. In other words, a student's educational needs may be as varied as that student is diverse from other students. Students' needs are also likely to change over time.

As stated in previous portions of the literature review, we are aware that lacking social skills is a common indicator of ASD. As we look at post high school needs for education, work, and adult living, we see the need for a level of competency in social skills as key to successful

outcomes. Fengfeng, Whalon, and Yun (2018) described the need for social competence in children and the link to post high school experiences in this way, “. . . difficulties with social competence are linked to the persistent reports of un- or underemployment and dependence in adulthood” (p. 4).

Post high school statistics provided by Fengfeng et al. (2018) are particularly bleak. According to their research, there is a 50% to 56% range of employment for individuals with ASD and the percentages at which these individuals are seeking out post high school education are between 31.9% to 50% in self-reports (Fengfeng et al., 2018).

Autism Interventions

Early screening. The need for early screening and early interventions for students with ASD is ever increasing. Many researchers have stressed the importance of the necessity for this early screening of children with ASD, followed up by evaluations, diagnosis, and effective interventions. The earlier an individual with a disability can receive interventions, better yet effective interventions, the more promising the outcome for their improvement and gaining of necessary skills. Furthermore, early intervention services are likely to provide the greatest benefit for the child when there is a united front amongst the family and the various service providers (Barrow, 2017). Early intervention services may be impeded in rural area by the possibility of later diagnosis and consequently later access to specialized intervention services (Murphy & Ruble, 2012).

McKenney indicated that “Children with ASD are uniquely sensitive to their environments, including the rigor and quality of their early academic and communicative instruction” (2017, p. 11). Therefore, since research suggests that early screening and interventions are of the utmost importance, it is a concern to understand that many interventions

put in place for young children with ASD are not for their specific classification. One study found that 65% of states reported that they were not providing autism-specific interventions for infants and toddlers with ASD (Stahmer & Mandell, 2007).

Use of data. Educators and members of the Individualized Education Program (IEP) or Individualized Family Service Plan (IFSP) teams have a mandate to make use of data when determining educational planning and goals for the student with ASD. Present Levels of Academic Achievement and Functional Performance (PLAAFP) are a key component to preparing and developing a data-based IEP for a student with a disability. Using data to determine where the student's performance is currently and then using data to determine next step planning and goal setting with the use of evidence-based practices may help to develop an appropriate and ambitious intervention for the child (Parent Companion, n.d.). The use of data would also be beneficial in handling the educational quandary of one size does not fit all in terms of educating students with ASD.

Implications from the case of *Andrew F. v. Douglas County School District* (2017) suggest the use of data to “make positive predictions about student progress” (McKenney, 2017, p. 11). McKenney provided this example of a valuable IEP team recommendation based on appropriate application of data, “Based on Timothy’s recent rates of response...in the home setting, the IEP team expects Timothy to gain 8 to 12 words per minute...Thus the IEP team recommends that Timothy receive rigorous individualized behavior analytic reading instruction...” (2017, p. 11).

Connecting recommendations and goals made with data will help to ensure that the best practices are put in place for students. Parents and educators alike ought to feel more confident with the planning that is developed for the students when data is a driving factor in the creation

of goals. Also, the use of data, can be invaluable in helping the team understand what progress is being made and whether or not that progress is sufficient and appropriate or if the team needs to reconsider their plans.

Evidence-based practices. The National Autism Center has done an abundant amount of research in the area of effective interventions for people with ASD, available to the public as the National Standards Report, Phase 1 and Phase 2. Their qualifications for determining the effectiveness of an intervention took into account the amount of evidence available for the intervention, peer-reviewed publications, and the effects on a particular targeted behavior. The researchers noted 10 skills that the intervention should increase; academic skills, communication, higher cognitive functions, interpersonal, learning readiness, motor skills, personal responsibility, placement, play, and self-regulation (National Autism Center, 2015).

An effective intervention would show change in one or more of these areas. There were also target areas in which they hoped to see behaviors decreasing from use of the interventions. The researchers found 14 interventions to meet their criteria for effective. Those interventions include the following; behavioral interventions, cognitive behavioral intervention, comprehensive behavioral treatment for young children, language training, modeling, natural teaching strategies, pivotal response training (PRT), visual schedules, scripting, self-management, social skills package, and story-based intervention (National Autism Center, 2015). Though these interventions have been found to be effective, the researchers warn against the assumption that they will all work with all children on the autism spectrum. One intervention may not fit all, or several interventions may be combined in a package that is benefitting the individual student.

McKenney suggests that the progress made by the student with ASD will depend a great deal upon how well the services are delivered (McKenney, 2017). When a school and IEP team plan with care, use data, and implement evidence-based practices with fidelity, their efforts are more likely to be appropriate and meet the educational needs of the student with ASD. The bleak reality of schools not providing this appropriate education will most likely result in the child not making acceptable growth and improvement (McKenney, 2017).

As stakeholders determine best practices to put into place, they should also take into consideration the ecological situation of schools. Is the school staff able to manage the interventions requested in the IEP? Or does the school staff need further training to prepare for the interventions? For an intervention to be effective there needs to be competent staff with appropriate training. Funding is another important variable in the decision making. Not having the necessary amount of funding may present problems in obtaining or maintaining various interventions.

Student to teacher ratios. The best-case scenario in education for any student is a low student to teacher ratio. Combine this with the unique and complex needs of a student with ASD, the necessity for a low student to teacher ratio is of the highest priority. A student with ASD may require a great deal of individualized support to meet their specific needs.

Though the goal for students with disabilities is to be provided an education in the least restrictive environment, a student with ASD may need their teaching provided on a one to one basis or perhaps a small group. These determinations should be made based on the needs of the student to meet their IEP goals. From findings related to the case of Andrew F., careful observation, monitoring, and planning are needed to make the most appropriate educational

placement decisions for students with ASD, as well as revisiting the goals and placements regularly, possibly more than the one time per year mandated (McKenney, 2017).

In addressing students with ASD's social and communication needs, education teams ought to contemplate ideas to give these students opportunities in regular education classrooms and with regular education peers. These efforts, combined with an appropriately sized classroom may help the student to work in the direction of improved social and communication goals (McKenney, 2017).

Individualized Education Program (IEP). The development and implementation of Individualized Education Plans is another essential component of IDEA-Part B. The implementation of an IEP for a student with a disability is regarded as a protection for those students, to ensure that their rights to a free and appropriate education are met. An IEP team should include parents or legal guardians of the student, at least one general education teacher, at least one special education teacher, an LEA (local education agency) representative, the student may also attend, and any other individuals the parents and/or LEA feel would be a helpful participant on the team (Jacob, Decker, & Lugg, 2016). The school is responsible for implementing and following through on the services and interventions outlined in the IEP. Individualized Education Plans are meant to be reviewed at least annually, which is a vital component in determining if satisfactory progress has been made and if the goals and services are meeting the needs of the student.

Create realistic goals. As the IEP team meets to set goals, data should be used to create realistic goals at each level. The creation of realistic goals will be valuable to all stakeholders, most especially the child with ASD. The educators, parents, and child will all feel less frustration with appropriate and realistic goals. In the event of transition planning, the team would be wise

to consider the child's levels of functioning and adaptive skills, more so than IQ scores, to determine next step planning and goal setting for the future (McKenney, 2017).

Team-based approach. Individualized education plans (IEP) are meant to be designed with the understanding that a team of stakeholders will be creating the educational plans. An IEP team should include parents, special education teachers, regular education teachers, and so on. The opportunity for inclusion of these key players, has the power to create meaningful, appropriate, and attainable goals for the child with ASD. Additional benefits may include minimizing frustration for key individuals who ought to be involved in the creation, implementation, and monitoring of these goals and interventions. The team-based approach may also help to ensure the child receives ambitious, but attainable skills within their zone of proximal development. A functioning and organized team would also be able to consistently evaluate the progress of the student and determine if interventions were continuing to meet the needs or if adjustments should be made. Also, if the team began to notice a gap in the student's progress, the team could determine the next course of action necessary to address and improve outcomes for the struggling student with ASD (McKenney, 2017).

Summary and Critique

The educational needs of students with autism spectrum disorder may be very complex. One intervention and approach may not work for each student classified on the spectrum. Of particular concern is meeting the needs of students with ASD in rural communities. Communities which often lack resources for students with ASD. Oftentimes, rural communities also lack access to the opportunities that are generally more available in urban or suburban areas. These

issues combined can prove disadvantageous for the families and students that wish to access a variety of services aimed at helping their student receive appropriate interventions and make appropriate progress.

Much of the research suggests that educational interventions for students with ASD need to be implemented with fidelity, and implemented as early as possible (Barrow, 2017). The interventions implemented need to come from evidence-based practices. It is important to note that in the case of rural areas, these interventions may be implemented by educators who have less training in the area of ASD. Consequently, more preparation and training may be essential for all educators involved in rural schools with these students.

Statement of the Problem

According to Iadarola et al. (2015), students with ASD educational needs may not be met reliably. This may be even more of a concern in rural communities with fewer resources and less availability of specialized education opportunities. Researchers Murphy and Ruble (2012) noted a need for further research in the area of resources and services for families and children in rural areas. In an effort to determine the educational needs of students with ASD in rural communities, researchers conducted needs assessment via questionnaire among all stakeholders who could be considered to be part of an individual's care and education team, including the individual, to determine perceived strengths and weakness in a rural school district according to their various perspectives. From these findings, recommendations were made to the school district for improvements to current services for students with ASD.

References

- Adams, D., & Taylor, J. (2017, Winter). Significant outcomes in case law in the United States: Autism and IDEA in 2013, transition issues and changes in diagnostic evaluation criteria. *Journal of the American Academy of Special Education Professionals*, 85-102. Retrieved from: <https://www.naset.org/index.php?id=4619>
- Appelquist, K. L., & Bailey, D. B. (2000). Navajo caregivers' perceptions of early intervention services. *Journal of Early Intervention*, 23(1), 47-61, doi:10.1177/10538151000230010901
- Barrow, D. M. (2017). *A phenomenological study of the lived experiences of parents of young children with autism receiving special education services*. Retrieved from https://pdxscholar.library.pdx.edu/cgi/viewcontent.cgi?article=5044&context=open_access_etds
- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., . . . & Dowling, N. F. (2018, April 27). Prevalence of autism spectrum disorder among children aged 8 years-Autism and Developmental Monitoring Network, 11 Sites, United States, 2014. *Morbidity and Mortality Weekly Report Surveillance Summaries*, 67(6), 1-23. Retrieved from <https://www.cdc.gov/mmwr/volumes/67/ss/ss6706a1.htm>
- Bilaver, L. A., Cushing, L. S., & Cutler, A. T. (2016). Prevalence and correlates of educational intervention utilization among children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46(2), 561-571. Doi: 10.1007/s10803-015-2598-z
- Blane, K., & Borden, C. (2008). The importance of early intervention for autism. *The Brown University Child and Adolescent Behavior Letter*, 24(6), 1-7. Retrieved from <https://doi.org/10.1002/cbl.20068>

- Brookman-Fraze, L. I., Drahota, A., & Stadnick, N. (2011). Training community mental health therapists to deliver a package of evidence-based practice strategies for school-age children with autism spectrum disorders: A pilot study. *Journal of Autism and Developmental Disorders, 42*, 1651-1661. Doi: 10.1007/s10803-011-1406-7
- Centers for Disease Control and Prevention (2019). *Learn the signs, act early*. Retrieved from <https://www.cdc.gov/ncbddd/actearly/index.html>
- Doe v. Board of Education of Tullahoma City Schools, 9 F.3d 455, 459-460 (6th Cir. 1993).
- Andrew F. v. Douglas County School Dist. RE-1, 580 US _ (2017)
- Retrieved from: https://www.supremecourt.gov/opinions/16pdf/15-827_0pm1.pdf
- Fengfeng, K., Whalon, K., & Yun, J. (2018). Social skill interventions for youth and adults with autism spectrum disorder: A systematic review. *Review of Educational Research, 88*, 3-42. doi: 10.3102/0034654317740334
- Guthrie, W., Swineford, L, Nottke, C. & Wetherby, A. (2013). Early diagnosis of autism spectrum disorder: Stability and change in clinical diagnosis and symptom presentation. *Journal of Child Psychology and Psychiatry, 54*(5), 582-590. doi:10.1111/jcpp.12008
- Iadarola, S., Hetherington, S., Clinton, C., Dean, M., Reisinger, E., Huynh, L., . . . & Kasari, C. (2015). Services for children with autism spectrum disorder in three, large urban school districts: Perspectives of parents and educators. *Autism: The International Journal of Research and Practice, 19*(6), 694-703. doi:10.1177/1362361314548078
- Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004)
- Jacob, S., Decker, D. M., & Lugg, E. T. (2016). *Ethics and law for school psychologists* (7th ed.). Hoboken, NJ: John Wiley & Sons, Inc.

- Knappczyk, D., Chapman, C., Rodes, P., & Chung, H. (2001). Teacher preparation in rural communities through distance education. *Teacher Education and Special Education, 24*(4), 402-407. Retrieved from <https://doi.org/10.1177/088840640102400415>
- Kucharczyk, S., Reutebuch, C. K., Carter, E. W., Hedges, S., Zein, F. E., Fan, H., & Gustafson, J. R. (2015). Addressing the needs of adolescents with autism spectrum disorder: Considerations and complexities for high school interventions. *Exceptional Children, 81*, 329-349. doi: 10.1177/0014402914563703
- McKenney, E. (2017). "Endrew, F. v. Douglas County School District": Implications for teams serving students with autism spectrum disorder. *Communiqué, 46*(2), 11-12
- Mills v. Board of Education of District of Columbia, 348 F. Supp. 866 (D.D.C. 1972)
- Murphy, M. A., & Ruble, L. A. (2012). A comparative study of rurality and urbanicity on access to and satisfaction with services for children with autism spectrum disorders. *Rural Special Education Quarterly, 31*(3), 3-11. doi:10.1177/875687051203100302
- National Autism Center. (2015). *Findings and conclusions: National standards project, addressing the need for evidence-based practice guidelines for autism spectrum disorder Phase 2*. Randolph, MA: Author.
- Parent Companion. (n.d.). *Present levels of academic achievement and functional performance (PLAAFP). Understand the PLAAFP statement and its importance in special education*. Retrieved from <https://www.parentcompanion.org/article/print/present-levels-of-academic-achievement-and-functional-performance-plaafp>.
- Pennsylvania Ass'n, Retard. Child. v. Commonwealth of Pa., 334 F. Supp. 1257 (E.D. Pa. 1971)

Rogers, S. J., & Vismara, L. A. (2008). Evidence-based comprehensive treatments for early autism. *Journal of Clinical and Adolescent Psychology, 37*(1), 8-38.

doi:10.1080/15374410701817808

Rowley v. Board of Education of Hendrick Hudson Center School District, 458 US 176 (1982)

Shyman, E. (2012). Teacher education in autism spectrum disorders: A potential blueprint.

Education and Training in Autism and Developmental Disabilities, 47(2), 187-197.

Retrieved from:

https://www.researchgate.net/publication/288249425_Teacher_Education_in_Autism_Spectrum_Disorders_A_Potential_Blueprint

Stahmer, A. C. & Mandell, D. S. (2007). State infant/toddler program policies for eligibility and services provisions for young children with autism. *Administration and Policy in Mental Health and Mental Health Services Research, 34*, 29-37. doi: 10.1007/s10488-006-0060-4.

U.S. Census Bureau (2017). *QuickFacts*. (n.d.). Retrieved from

<https://www.census.gov/quickfacts/fact/table/sanjuancountyutah/PST040218>

Williams, J. M., Martin, S. M., & Hess, R. K. (2010). Personnel preparation and service delivery issues in rural areas: The state of the art. *Rural Special Education Quarterly, 29*(4), 31-39.

APPENDIX B

Instrument

██████████ County Autism Needs Assessment

Start of Block: Default Question Block

Q You are invited to participate in the ██████████ County Autism Needs Assessment as a part of Brigham Young University. The needs assessment will begin with questions regarding who you are and your relationship to individual(s) with Autism. Responses will be kept anonymous and used for the purpose of improving the educational needs of students with ASD. By checking the following circle you indicate your consent to participate in this research project. (You may stop participating at any point, but only questionnaires that are more than 50% completed will be included in research)

I give my consent to complete this questionnaire. (1)

Q1a Are you currently a resident of ██████████ County, ██████████? (Research intends to include current residents or those who have resided in ██████████ County in the past 5 years)

Yes (1)

No, but I have lived in ██████████ County within the past 5 years (2)

No (Research intends to include current residents or those who have resided in ██████████ County in the past 5 years) (3)

Q1b How long have you been a resident of ██████████ County, ██████████? (Even if you don't live in ██████████ county currently)

Less than 5 years (1)

6 - 10 years (2)

11 - 15 years (3)

16 - 20 years (4)

21+ years (5)

Q2a What is your relationship to person(s) with Autism Spectrum Disorder (ASD)? (Check all that apply)

- Parent/Guardian (1)
- Other Caregiver (2)
- Educator - teaching role - special education (3)
- Educator - teaching role - general education (4)
- Educator -- administrative role (5)
- Educator - support role (e.g. paraprofessional, secretary, counselor, psychologist, therapist, librarian) (6)
- Community care providers (e.g. Medical Care providers, Community Health, Mental Health) (7)
- I have an autism spectrum disorder (8)

Display This Question:

If What is your relationship to person(s) with Autism Spectrum Disorder (ASD)? (Check all that apply) = I have an autism spectrum disorder

Q2b If you are an individual with autism spectrum disorder, how would you like to answer this questionnaire?

- As a parent, I have a child with ASD (1)
- As an individual, I am/was a student in [REDACTED] School District with ASD (4)
- I am both (individual with ASD & have a child with ASD) (5)

Skip To: Q27 If If you are an individual with autism spectrum disorder, how would you like to answer this questio... = As an individual, I am/was a student in [REDACTED] School District with ASD

Display This Question:

If If you are an individual with autism spectrum disorder, how would you like to answer this question... = I am both (individual with ASD & have a child with ASD)

Q28 If you are an individual with ASD and have a child with ASD, please complete this survey as a parent and if you wish to take the survey again as an individual, please return to email and click on link again.

During your second time through survey click on "as an individual, I am/was a student in [REDACTED] School District with ASD"

Q3 What is the age group of person(s) with Autism Spectrum Disorder that you interact with?
(Check all that apply)

- Birth to 2 years (1)
- Preschool -Kindergarten (2)
- Elementary (3)
- Middle/Junior (4)
- High School (5)
- 18-21 year olds (still in High School) (6)
- Adults (out of High School) (7)

Q4 What is your gender?

- Male (1)
- Female (2)
- Other response (3) _____

Q5 Race (you may check more than one):

- White (1)
- Black or African American (2)
- American Indian or Alaska Native (3)
- Asian (4)
- Native Hawaiian or Pacific Islander (5)
- Other (6)

Q6 Ethnicity:

- Hispanic (1)
- Non-Hispanic (2)

Q7 Marital Status:

- Single (1)
- Married (2)
- Widowed (3)
- Divorced (4)
- Separated (5)
- Cohabiting (6)

Q8 How many years have you been involved with Autism Spectrum Disorder? (caregiving or educating)

- Less than 5 years (1)
- 6 - 10 years (2)
- 11 - 15 years (3)
- 16 - 20 years (4)
- 21+ years (5)

Q9 Educational Background:

- Some High School (1)
- High School Completion (2)
- Some College (3)
- Technical School (4)
- Associate's Degree (5)

Q14 What do you think may prevent good communication with █SD regarding the autism services provided (e.g. too busy, lacking internet, remote location, no responses from █SD, etc.)?

Q15 What do you need the most help with in terms of your student with ASD (e.g. toilet training, aggression, peer relationships, community acceptance, etc.)?

Q16 In your opinion, what has worked well in educating students with Autism Spectrum Disorder in █SD?

Q17 In your opinion, what has NOT worked well in educating students with Autism Spectrum Disorder in █SD?

Q18 If any, what changes should be made to better serve students with Autism Spectrum Disorder?

Q19 Thank you for completing this needs assessment. WHEN YOU CLICK ON THE ARROW BELOW, You will be automatically redirected to a separate place that will allow you to request that we contact you about your answers. This is completely optional, YOU DON'T HAVE TO GIVE ANY INFORMATION if you don't wish to. (Your answers above will not be connected to your name and phone number with this link). PLEASE CLICK ON THE ARROW TO SUBMIT YOUR ANSWERS TO THIS QUESTIONNAIRE.

Display This Question:
If you are an individual with autism spectrum disorder, how would you like to answer this question... =
As an individual, I am/was a student in [] SD with ASD

Q27
If you have autism, click on this link to go to a new survey.
https://byu.az1.qualtrics.com/jfe/form/SV_aWPX7ja2Lw7bAKF

End of Block: Default Question Block

C Autism Needs Assessment-- Students Version

Start of Block: Default Question Block

Q1 What kind of school do you go to now?

- Elementary School (3)
- Middle School (4)
- High School (5)
- Adult (out of school) (6)

Q2 Are you a ?

- Boy (1)
- Girl (2)
- Other response (3) _____

Q3 Is your family (you can mark more than one).

- White (1)
- Black or African American (2)
- American Indian or Alaska Native (3)
- Asian (4)
- Native Hawaiian or Pacific Islander (5)
- Other (6)

Q4 Is your family:

- Hispanic (1)

class (Get Ready)
(3)

Speech/Language
Therapy (4)

Improving
sensory
sensitivities
(Tactile
Defensiveness
Interventions) (5)

Social Skills
Training (6)

Learning a new
skill through
watching video of
that skill (Video
Modeling) (8)

Other Intervention
(from Q13a) (7)

Q7 What has worked well in helping you learn in school?

Q8 What has NOT helped you learn in school?

Q9 If you could change something about the way teachers teach you at school, what would it be?

Q10 Thank you for completing this needs assessment.
WHEN YOU CLICK ON THE ARROW BELOW, You will go to a new survey.
YOU DON'T HAVE TO answer the new survey if you don't want to.
PLEASE CLICK ON THE ARROW TO FINISH.
End of Block: Default Question Block

APPENDIX C

Consent Form

**BRIGHAM YOUNG UNIVERSITY-- Provo, Utah
Consent Form for Research Participation**

Study Title: Educational Needs of Students with Autism Spectrum Disorder

Principal Investigator: Terisa Gabrielsen, PhD.

Student Researcher: Kari Pugh, MS

IRB Study Number: X19016

My name is Kari Pugh, I am a student at Brigham Young University and I am conducting this research under the supervision of Professor Terisa Gabrielsen, PhD. You are invited to participate in the research study of the educational needs of students with autism spectrum disorder (ASD). This form contains important information about the study and what we will ask you to do if you decide to be in this study.

The purpose of the study is to determine the educational needs as perceived by parents, educators, community care providers, and individuals on the Autism spectrum. The responses will be de-identified and shared with educational leaders of [REDACTED] School District to celebrate successes and make plans for any potential improvements that need to be made.

Your participation in this interview will require approximately one hour or less during one session. Your participation will be anonymous and you will not be contacted again in the future. You will not be paid for this study.

Study Location: Interviews will take place at the [REDACTED] High School office of Kari Pugh or at the home of participant if that is their request. Phone interviews may also be conducted at the participant's request. **Interviews will be audio recorded, de-identified, and analyzed by BYU students who are not associated with [REDACTED] School District for coding.**

Possible risks/discomforts: To the best of our knowledge, this activity will have no more risk of harm than you would experience in everyday life. We will take steps to minimize the risk of confidentiality being breached, to the extent possible.

Possible benefits for participation: Participants are not likely to have any direct benefit from being in this research study. The study is designed to learn more about educational needs of students with ASD. The study results may be used to help other people in the future.

How will information collected be protected, and how will that information be shared: Results of the study may be used in publications and/or presentations. Your study data will be handled as confidentially as possible. If results of the study are published, names and identifiable information will not be used. To minimize the risks to confidentiality, we will store data and interview information in a locked cabinet, within a locked office.

Rights of participant: Participation in the research study is voluntary. You are not compelled to answer any question you choose not to answer. If at any time and for any reason, you would prefer to end your participation, please tell me. We may take a break or stop all together. You may withdraw from this study at any time and will not be penalized for withdrawing.

Any questions or concerns you may have regarding this research study: You do not have to be in this study if you do not want to be. You do not have to answer any questions that you do not want to answer for any reason. We will be happy to answer any questions you have about this study; you are free to ask them now. If you have

questions later, you may contact the researchers by means of email at: [REDACTED] or terisa_gabrielsen@byu.edu.

If you have any questions about your rights as a research participant you may contact the IRB administration at A-285 ASB, BRIGHAM YOUNG UNIVERSITY, Provo, Utah 84602; IRB@BYU.EDU; (801) 422-1461. The IRB is a group of people who review research studies to protect the rights and welfare of research participants.

As part of this research, I will be making an audio recording of you during your participation. Please indicate that you permit audio recording, by initialing next to the use of recording and sign at the end. The choice is completely up to you. I will only use the audio in the ways you agree to. In any use of the audio, you will not be identified by name.

_____ Audio can be studied by the research team for use in the research project.
(Initial)

*I give consent for audio recording of this interview _____
PARTICIPANT SIGNATURE

*I do not consent for audio recording of this interview, I understand that the interview could take longer, as all comments will need to be transcribed verbatim by the interviewer

PARTICIPANT SIGNATURE

CONSENT:

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above, including audio recording of my participation, and will receive a copy of this consent form.

Participant's Name (printed)

Participant's Signature

Date

APPENDIX D

Interview Script**█ Autism Needs – Interview Script:**

Thank you for being willing to meet with me today. I have provided you with a consent form. Please feel free to read through the consent form and let me know if you have any questions before you sign the form giving your consent to participate in this interview. (Participant read consent form)

This interview will be recorded (audio only). As I am an employee of █ School District, I want to assure you that your responses will be de-identified and reviewed by a team of students at Brigham Young University. Their goal will be to find common themes and concerns in regards to education for students with autism in █ County among interviewees. There findings will be returned to me without attached names or identifying information to help participants maintain confidentiality. If at any point during the interview, you feel you would prefer to leave a question unanswered or you need to discontinue the interview all together, please let me know.

The purpose of this interview and the previous online questionnaire is to obtain perspectives on the educational experiences of students with ASD and create a summary of concerns and needs for █ School District.

Any questions?

As we proceed, you are encouraged to avoid using your/the child with autism's name, as well as your own name and/or educators' names. To retain confidentiality and privacy of individuals. Let's begin...

- (1) Please clarify any concerns you were unable to share on the online questionnaire.
- (2) What services do you feel that your child/student needs, include services that aren't currently being offered?
- (3) What services are you being provided or were provided previously?
- (4) How effective do you feel the services being provided or that were provided were?
- (5) Any final concerns/thoughts regarding effective education services for students with ASD?

Thank you for your time.