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The Perceptions about ASD's Rising Rates: A Comparison between the General Public and ASD Professionals.

Anna Ernst
malandan@mnstate.edu

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The Perceptions about ASD's Rising Rates: A Comparison between the General Public and
ASD Professionals.

A Project Presented to

The Graduate Faculty of

Minnesota State University Moorhead

By

Anna Ernst

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CHAPTER 1 INTRODUCTION

Introduction

The cause of Autism Spectrum Disorder has been a very popular subject for the last five or ten years. Even with the facts and statistics that we have now, there are still people who have very different ideas as to why children and adults have autism. For instance, I have recently been diagnosed with autism. I am a very high-functioning adult with a career, a family, and advanced schooling. I went 24 years without being diagnosed and was only diagnosed after visiting a psychologist for my high anxiety. If you were to ask my mom, she would tell you I am completely normal and there's nothing about me that "says autism." My oldest nephew also has autism. He has grown a lot socially and is now in college making a lot of gains like having a big social circle, he has held a job all through college, he is thriving in his chosen program, and he has begun to show both empathy and sympathy and reaches out to me asking how I am on a regular basis. He had a very hard time in school as he was very sporadic with his emotions, would throw high volume fits, excelled in math but wasn't very good with any other subject, and was too anxious to be in any extra-curricular activities. My other nephew, 14, also has autism, but struggles with most subjects in school, is very quiet and reserved, talks in an inappropriate manner when in public using baby talk, needs to wear the same necklace every day for security, and carries a Lego rod with him at all times to fidget with as a stimulant. We are all on very different sides of the spectrum, and our upbringings were all very different. We do have a genetic connection that may have caused us to fall on the spectrum, but it wasn't because *we ate lunch meat* or *got a vaccine*, I wasn't *more religious* than my youngest nephew and so I got an "easier" form of ASD. There are a lot of mysteries that still surround ASD, but a lot of the public's perceptions on those with ASD hasn't changed.

Brief Literature Review

Anyone in the education field can tell you that the number of students with Autism Spectrum Disorder has increased dramatically in recent years. I believe this is due to an increased awareness as well as early intervention and better diagnostic testing. I find that autism still has a bit of a negative outlook maybe because of their portrayal in the media, or because of some of the erratic behaviors that can be displayed, like flapping, screeching, rocking, yelling, and sporadic violent behavior. With the rates rising, I feel being able to find out how the general public views autism VS. how those in an educational profession view autism will help in finding ways to normalize it and identify areas of need to educate the community about ASD.

All of the articles I found on ASD mentioned many of the same patterns that I did and came to the same conclusion: Autism isn't affecting more people, but because more people are aware of ASD, more children are being referred and diagnosed at a younger age. Over the course of two years, the rates rose over 30% alone (Cardon & Kelley, 2016). It has gone from being diagnosed in the 80s as 1 in 10,000 to now being diagnosed 1 in 150. In 1994, the average amount of school aged students with ASD was just over 22,000, by 2006 it was over 211,000.

Screaming, crying, running away, not speaking, sitting alone, no eye contact, and rocking are all traits that can be shown in a child with ASD. Laughing, intelligence, healthy relationships, and non-stop talking are also traits that can be shown in a child with ASD. Autism has such a broad scale and so many different traits. There is not a one-size-fits-all instructional or behavioral support for children and adults with autism. There is no chromosome to look at, no blood test to order, there is really no answer as to why autism is a part of our world or who can be affected. Some people are diagnosed at six months, others like me, have to navigate the world of adolescence and adulthood before getting the answer we needed to hear. Through countless

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observations and different testing, we are getting so much better at early diagnosis to better support kids with ASD. This can't truly happen until the world knows the stories of children with ASD, what makes them tick, what calms them down, why they may have different interests than a "typical" child. I can't wait to see a world that accepts them for what they are and works to support them all.

Statement of the Problem

The problem I researched is the different perceptions about autism spectrum disorders that exist among the public in general and the various professionals providing services to students with this diagnosis.

Purpose of the Study

I conducted this study because I was recently diagnosed with ASD. After sharing that with people, I get varying responses. I wanted to see, even with studies to back up why rates have gone up in recent years, why the public believes that Autism has been on the rise, and what they think about ASD, to see what stigma and ideas are still in the general public versus the perception of the professionals working with those with ASD.

Research Question(s)

What are the public's perceptions about ASD and its rising rates and how these compare to the perceptions of professionals providing services to children with ASD?

Definition of Variables

DV: Opinion – a judgment not based on fact.

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Profession: Professionals- people in a professional education setting that work with individuals with ASD vs. General Public - those with no contact, professional or otherwise, with individuals with ASD.

ASD: Autism Spectrum Disorder is a condition related to brain development that impacts how a person perceives and socializes with others, causing problems in social interaction and communication.

Significance of the Study

As someone who has autism, this is important to me to be able to see what the public believes so that I can help to better educate them. I did this with the participants of the study by sharing what other professionals in my field know about ASD with the general public. There is still such a stigma when it comes to autism, and I want people to know that I didn't do anything to myself, my parents didn't do anything to me to make my brain process things the way that it does. It isn't a negative thing saying that someone has autism, it is just a part of who they are. As a teacher of very young kids, that is something that I teach very often.

Research Ethics

Permission and Approval. In order to conduct this study, the researcher sought MSUM's Institutional Review Board (IRB) approval to ensure the ethical conduct of research involving human subjects (Mills & Gay, 2019). Likewise, authorization to conduct this study was sought from the school district where the research project took place (See Appendix A and B.)

Informed Consent. Protection of human subjects participating in research was assured. Participants were aware that this study was conducted as part of the researcher's Master Degree Program and that it would benefit her teaching practice. Informed consent means that

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participants have been fully informed of the purpose and procedures of the study for which consent is sought and that participants understand and agree, in writing, to their own participation in the study (Rothstein & Johnson, 2014). Confidentiality was protected through the use of pseudonyms (e.g., Participant 1) without the utilization of any identifying information. The choice to participate or withdraw at any time was outlined both, verbally and in writing.

Limitations.

Some of the limitations of this study include: dishonest answers as the answers were short answer, differences in understanding, and the difficulty of conveying feelings and emotions.

Conclusions

As a teacher, this was an important study for me to help erase the stigma of those with ASD being incapable of being independent, being "weird," erratic, moody, unemotional, and not friendly, that follows those with ASD. There are so many resources that back why ASD seems more prevalent now than it did five or ten years ago, but people have their own ideas like hormones in foods, vaccines, or even religions. My review of literature can be found in the following chapter.

CHAPTER 2

LITERATURE REVIEW

Introduction

I conducted this study because I was recently diagnosed with ASD. After sharing that with people, I get varying responses. I wanted to see what the general public believes ASD to be and why they believe it is so prevalent as well as how ASD professionals view ASD.

Body of the Review

It isn't just in the United States that the rate of ASD diagnoses have increased. Countries all over have been reporting the same rising statistics in all ages. In Germany, a study followed newly diagnosed people from ages 0-24 years (Bachmann, 2018). They reported that rates had gone from 20% to 30%. One thing I found very interesting was that while rates of diagnosing ASD are rising, girls aren't being diagnosed at the same rates as boys (Bachmann, 2018). This is due to gender roles and assumed personality traits, such as girls being more dramatic and emotional than boys. This large gap has formed only when diagnosing the milder forms. Some reasons why this is happening is because girls, starting in their early childhood years and continuing to adulthood, are much better at masking their symptoms. They tend to watch and mimic "typical" behavior so that those symptoms go unseen. They also tend to be a lot less repetitive than boys, as well as obsessive over things that younger girls typically play and interact with, so it is also overlooked. This is why girls, and women like myself, are often diagnosed much later in life, even after showing these ASD traits all of their lives.

Even though girls are diagnosed with ASD on a 1:4 ratio to boys, both diagnosis rates have grown in the last decade (Bachmann, 2018). This has caused speculation to the general

population, and many have wondered if the testing is accurate (Chawarska, Klin, Paul, Macari, & Volkmar, 2009). Many studies have been conducted on the accuracy of ASD testing for this reason, and they are consistently finding the same thing: the tests are accurate (Chawarska et al., 2019). Concerns have also come up with early testing. Many don't believe that the tests can be done accurately on young children, specifically toddlers. In one study, a group of 89 toddlers were taken between four and five months, and were studied through seven and eight months (Chawarska et al., 2019). The study found that the stability in the diagnosis was 100% accurate. There were under 20% of the kids whose symptoms changed in severity, but otherwise, the initial diagnosis with ASD and non ASD, was correct and held true (Chawarska et al., 2019). Social skills, cognitive skills, and communication skills were all profiled and helped with the accuracy of diagnoses. Studies on adults with the diagnosis have also been conducted and they have about the same success rate with the diagnosis being retained. Early testing leads to early identification, and early identification is so important because there is more likely to be more interaction with the child after diagnosis. During a study with a group of 79 low-risk toddlers, their diagnosis facilitated increased intervention hours (Suma, Adamson, Bakeman, Robins, & Abrams, 2016). They also found that, aside from the interaction in the intervention, they received more interaction with parents and family in general (Suma et al., 2016). This happens in later years as well, and opens up the dialogue on ASD and what it is because more people are coming into contact with them because they are seeing multiple interventionists, doctors, and their parents are paying closer attention after doctors make known the diagnosis.

There are more and more books and movies coming out with plot lines that include a character with autism. This increases the awareness and puts it in the realm of "typical" for students to discuss, which is a huge change, even in the last five years. Being able to include

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characters with ASD in media, which is such a huge part of kids' lives now, is important because they are able to learn about this diagnosis which I know was something never talked about when I was growing up, so that when they meet kids with ASD, they know what to expect. This helped them to learn about ASD, some of the behavior that comes along with it, how to navigate a friendship with a person with ASD when they are having a harder day, and the best ways to include them in their social lives. ASD wasn't very prevalent when I was growing up, in media or real life, but now, in 2020, it is much more prevalent. I was diagnosed with generalized anxiety disorder very young, and have dealt with it most of my life. About a year ago, the medication I was on to manage it was no longer helping and I was having multiple anxiety attacks a week. I started going to a therapist to talk about it and figure out what my next step should be. In our second session, she asked me about ASD and if there was any in my family. From there I was tested multiple times, and went to a few more sessions before she told me that I had scored off the charts on the ASD tests I was given. It makes a lot of sense to me. I am definitely a "perfectionist," I have very high anxiety, and many sensory issues. Knowing this hasn't really changed my life, most people don't know about my diagnosis, but it does give me peace of mind knowing why I do the things I do.

This research was conducted using survey research, asking for participants' opinions, whether they were formed based on facts or not is not of concern of this study. I did not "grade" their thoughts as a right or wrong, but I did conduct a content analysis of the responses.

Research Question(s)

What are the public's perceptions about ASD and its rising rates and how these compare to the perceptions of professionals providing services to children with ASD?

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Conclusions

There are a lot of statistics behind ASD and why it is on the rise, but there are also a lot of assumptions made by the public. Those are what this study was based on. You can see what my research design was in the following chapter.

CHAPTER 3

METHODS

Introduction

I conducted this research because I wanted to see how the public vs professionals working with ASD students view autism. Because of this, I used a survey as my research design.

Research Question(s)

What are the public's perceptions about ASD and its rising rates and how these compare to the perceptions of professionals providing services to children with ASD?

Research Design

I conducted survey research. The goal of the study was to recruit at least 50 participants.

Setting

This research was conducted via social media and email. This helped me to reach the largest amount of people in a fast way. I put my survey out to those on my social media page and my work email to complete it, based on how they felt about it. Those who completed it turned it into me via google forms. Afterwards I conducted a content analysis of the responses collected from the public versus responses collected from professionals providing services to individuals with an ASD diagnosis.

Participants

My ideal composition was 50% males, 50% females. I would have liked the participation to be 50% from those professionals that work with students with ASD and 50% from those that do not have a regular connection to those with ASD. I also wanted at least 50 participants. The answers also came from a range of ages.

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Sampling: This was a purposive sampling as I had an internet connection to those responded to my survey, but it was a fast and efficient way to conduct the survey.

Instrumentation

I used a survey as my instrument which I made on google forms. The questions aimed towards finding out how the public perceives those with ASD.

Data Collection. I put the survey out to the public and collect the responses. This didn't happen in a public setting as it was done over social media and my school email.

Data Analysis. I used descriptive statistics to summarize the quantitative data. I then conducted content analysis of the text responses.

Research Question and System Alignment. The table below (Table 1) provides a description of the alignment between the study Research Question and the methods used in this study to ensure that all variables of study have been accounted for adequately.

Table 1.

Research Question Alignment

| Research Question | Variables | Design | Instrument | Validity & Reliability | Technique (e.g., interview) | Source |
|--|---|-----------------|--------------|------------------------|-----------------------------|--|
| RQ1 What are the public’s perceptions about ASD and its rising rates? | DV: Opinions on ASD from those of professionals that work with students with ASD vs those with no regular contact with students with ASD. IV: Profession: Professionals working with students with ASD vs. those who have no regular connection to a student with ASD. | Survey Research | Google Forms | N/A | Survey | I sampled 50 random participants VIA survey on social media. |

Procedures

Over the course of one month I continuously collected data based on the answers I received from my survey. I collected them and stored the data in an excel spreadsheet until I had a minimum of 50 responses back.

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Ethical Considerations

There were no risks of harming any participants. The study focuses on individuals' opinions on ASD.

Conclusions

The following chapter presents the data collected from the survey.

CHAPTER 4

RESULTS

Introduction

I conducted this research because I wanted to see how the public vs professionals working with ASD students view autism. Because of this, I used a survey as my research tool.

Research Question

What are the public's perceptions about ASD and its rising rates and how these compare to the perceptions of professionals providing services to children with ASD?

Data Collection

The survey was sent out to my coworkers at my school as well as posted on my personal Facebook page. The survey was done on Google Forms and was only visible to myself. Everyone was invited to take the survey. I made sure they knew this was going to be used for a research paper for my master's program but would not give out any identifying information. I received 59 responses. (See Appendix C).

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What are the public’s perceptions about ASD and its rising rates and how these compare to the perceptions or professionals providing services to children with ASD?

Table 2.

49.5% of respondents were professionals that have contact with students that are diagnosed with ASD.

| What do you know about ASD? | Do you believe there has been a rise in ASD diagnoses? | If yes, why? |
|--------------------------------------|--|---|
| It is a spectrum. 34% | Yes 96.5% | It has become a catch all. 10% |
| A lot. 28% | No 3.5% | The definition has become much broader. 8% |
| Not a lot. 3% | | More awareness, knowledge, research, and early intervention. 64% |
| It’s Autism Spectrum Disorder. 8% | | Environmental reasons. 8% |
| Multiple symptoms. 24% | | Not sure. 10% |
| Being diagnosed earlier. 3% | | |

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Table 3.

50.5% of respondents were those from the general public with no regular contact with those diagnosed with ASD.

| What do you think about ASD? | Do you believe there has been a rise in ASD diagnoses? | If yes, why? |
|--------------------------------------|--|---|
| It is a spectrum. 33% | Yes 80% | It has become a catch all. 8% |
| A lot. 10% | No 3% | The definition has become much broader. 8% |
| Not a lot. 23% | I do not know 17% | More awareness, knowledge, research, and early intervention. 63% |
| It's Autism Spectrum Disorder. 7% | | Environmental reasons. 17% |
| Multiple symptoms. 17% | | Not sure. 4% |
| It's not good to have. 10% | | |

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Table 4.

Results from 100% of respondents.

| What do you know about ASD? | Do you believe there has been a rise in ASD diagnoses? | If yes, why? |
|--------------------------------------|--|---|
| It is a spectrum. 34% | Yes 88% | It has become a catch all. 9% |
| A lot. 19% | No 3% | The definition has become much broader. 8% |
| Not a lot. 13% | I don't know 8% | More awareness, knowledge, research, and early intervention. 63% |
| It's Autism Spectrum Disorder. 7% | | Environmental reasons. 12% |
| Multiple symptoms. 20% | | Not sure. 8% |
| Being diagnosed earlier. 2% | | |
| It is not good to have. 5% | | |

Table 5.

29 responses came from professionals that have contact with students diagnosed with ASD.

What do you think about ASD?

"I think children with ASD need additional support in ways to manage their emotions and coping mechanisms for how to deal with social cues."

"I think that it can be an overused diagnosis and that many of the strategies used with those students are beneficial for entire classes or typically developing folks as well. I believe that helping students and adults with Autism find their voice is very rewarding and important."

"I think people with ASD are all unique individuals with unique strengths, talents, and needs. One of my favorite quotes is, "If you've met one individual with autism, you've met one individual with autism"-Stephen Shore."

"I empathize parents who have to learn to deal with their children on a 24-7 basis. These children can be very challenging and very different to deal with compared to typically developing children as well as the long term parenting that is required well after typical children would be self sufficient. We should be spending much more money to try and find a cure. I feel that the cause of ASD has to be multifaceted; it must have a genetic factor as well as a factor that is influenced by the pollution in our water, food and air. Too much plastic in our world and bodies. What else has changed in the last 25 years?"

"I think it is very interesting how much of a spectrum it truly is and how the degree of severity can affect social skills and reasoning abilities."

"Every kid is different. You can't categorize a child by their diagnosis."

"I think that it can be an overused diagnosis and that many of the strategies used with those students are beneficial for entire classes or typically developing folks as well. I believe that helping students and adults with Autism find their voice is very rewarding and important."

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“It is a condition that needs to be addressed. And in doing so ones life can be so much better.”

“That it is a very interesting topic.”

“With the increase of screens in the home, children are not getting the necessary language and social stimulation from caregivers and this impacts development in all areas. Face to face interaction trumps a screen everytime. Screens don't cause ASD, but as caregivers turn on a screen they are not interacting with the child and ASD characteristics may be exacerbated.”

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Table 6.

30 responses came from the general public that has no contact with someone diagnosed with ASD.

What do you think about ASD?

"No idea."

"It takes patience and a loving person to work with these kids."

"I think it's a disease that affects a decent amount of people."

"I think that the culture surrounding ASD needs to be more person-centered rather than ability-centered. It's not something that is a problem that needs to be fixed, but rather a person who needs equitable care."

"I feel bad for people who have it."

"Needs more attention not only to the community but to those who help the community understanding autism and how to work with children and adults who have autism."

"I think it is legit, however sometimes over used."

"It's a very difficult illness that has no boundaries. It affects children from all economic and racial backgrounds."

"No idea."

"I believe it has been more of an issue than people realize. People need to be more aware of the problem and what can be done to help with education."

Data Analysis

Overall, the results were what I expected. There was an overwhelming majority that believes that ASD diagnosis rates have risen in recent years with 88% of 59 people saying “yes.” The reasons why they thought they were rising were very interesting. I thought it was interesting that professionals working with students on the spectrum believed that the rise in diagnoses was being caused by environmental factors such as screen time and additives in food and water. It was also interesting that several of them believed that ASD is now just a “catch-all” for difficult diagnoses. I didn't think professionals thought this way with all of the research that has been published. The majority of both professionals and the general public believed that it is because of more awareness, knowledge, research, and early intervention, which aligns with what I found in my research. There isn't necessarily a growing number of people with ASD, but there is a growing number of diagnoses because we can now better identify it. There was a decent number of the general public that still believe ASD is caused by environmental factors. Some listed by respondents were food additives, medications, vaccines, and parenting techniques.

I didn't really have any problems with my data collection, although I wasn't quite sure how to show the data of what the respondents think about ASD as not many answers were similar enough to group together for a percentage. That is one thing I would change if I were to redo this in the future. I also think it would have been interesting to include ages in the survey so that I could see if the older generation or the younger generation was the one to be more open minded when it comes to those with ASD or if it was a mixture of both. I thought the instrument I used for my survey was utilized well and was an easy tool to use for my respondents. I do wish that I would have gotten more surveys back to make the sample size larger.

Conclusion

As I read through the data I collected, I do believe that some of my points in my writings are reflected in the results, while others are not. The majority from both groups believe that the rising rates are because of more awareness, knowledge, research, and early intervention, which aligns with the literature. The number of those from both groups that believe ASD is rising because of environmental factors. I was expecting to see this from the general population, but not from the professionals as there is a lot of data that says otherwise.

CHAPTER 5

Action Plan

Even before this study, I always wanted to make sure that my classroom was a place where everyone felt equal and everyone felt welcome. Now because of this study, I want that even more. I want a stranger to come in and not be able to tell who might be on an IEP because all of the students are respected and treated equally. I want to have a conversation with the case workers these students have coming into my room and make sure that they are working privately and discreetly when they are with the kids in my classroom so that no one is singled out. There were many comments made in the data I collected that said I feel bad for those kids, it's a disease, or they are really challenging kids, and we as educators are the ones that can step up and make it normalized. Being labeled as someone with ASD does not mean that they are a challenging kid, it doesn't take "a real loving and patient person" to work with these kids, because a lot of these students have the biggest hearts out of any child I've ever met. It isn't a disease that someone is so unlucky to have, it is a disorder that is a part of them just like their eye color or the way they smile.

My school does notice Autism Awareness day which takes place on April 2nd of each year, but they don't do anything to celebrate it. Going forward, I would like to team up with my school's special education team, who are usually the only ones to recognize the day, to plan something that we can do school wide to bring awareness to Autism Spectrum Disorder. I believe that this will make our school climate a more inviting and inclusive one. It will help us celebrate our differences instead of dwelling on them or judging others for them. I would also like to add something into my monthly newsletter. It wouldn't necessarily need to focus on

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Autism, but just our differences as a whole, and celebrating those within our home and community. I feel that bringing awareness to ASD can make our students who are struggling to be more confident in themselves and to make others view each person as a person instead of a disorder.

Plan for Sharing

I plan to share my completed project in multiple ways so that others can learn from it and I can spread awareness. I will be sending out my completed research to those who took my survey through my work email as well as on Facebook. This will give those who took my survey as well as those who choose to read the research a chance to read the final product. I also have a blog that I write about my journey with being diagnosed with autism that I would like to share on as well to bring more awareness to the full spectrum that autism finds itself on. I would like to share this with my university as well so that others that may be curious about the perceptions of ASD and its rising rates may be able to find it.

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APPENDIX A

Institutional Review Board



DATE: February 27, 2020

TO: Ximena Suarez-Sousa, Principal Investigator
Anna Ernst, Co-Investigator

FROM: Lisa Karch, Chair
Minnesota State University Moorhead IRB *Lisa J. Karch*

ACTION: **DETERMINATION OF EXEMPT STATUS**

PROJECT TITLE: [1556010-1] The Perceptions about ASD's Rising Rates: A Comparison between the General Public and ASD Professionals.

SUBMISSION TYPE: New Project

DECISION DATE: February 27, 2020

Thank you for your submission of New Project materials for this project. The Minnesota State University Moorhead IRB has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations under 45 CFR 46.104.

We will retain a copy of this correspondence within our records.

If you have any questions, please contact the [Minnesota State University Moorhead IRB](#). Please include your project title and reference number in all correspondence with this committee.

This letter has been issued in accordance with all applicable regulations, and a copy is retained within Minnesota State University Moorhead's records.

APPENDIX B

Crosby-Ironton School District 182



Learning through relationships

January 27, 2020

To whom it may concern;

This letter is to grant Anna Ernst permission to conduct an action research study at Cuyuna Range Elementary during the 2019-2020 school year. I understand this study poses no risk to those persons involved or to the Crosby-Ironton School District. I also understand that all information received will be kept confidential and will only be used for purposes of this study.

Sincerely;

A handwritten signature in black ink, appearing to read 'Kurt Becker', is written over a light blue horizontal line.

Kurt Becker
Principal, Cuyuna Range Elementary

*Cuyuna Range Elementary School, 509, 6th Ave NE, Crosby, MN 56441
Kurt Becker – Principal - 218-545-8803 - kbecker@ci.k12.mn.us*

APPENDIX C

Assessment

For my masters program, I am conducting research on Autism Spectrum Disorder (ASD) and the perceptions of the general public and ASD professionals.

Do you agree to let me use your answers as a part of my research in my MSUM masters program? *

Yes

No

Please sign your name if you consent *

Short answer text

What is your profession? *

Long answer text

What do you know about ASD? *

Long answer text

What do you think about ASD? *

Long answer text

⋮

Do you believe there has been a rise in ASD diagnoses? Why or why not? *

Long answer text
