AN EXPLORATORY ANALYSIS OF CURRENT AUTISM TERMINOLOGY

USAGE, INCLUDING ITS IMPLICATIONS FOR PUBLIC HEALTH AND SPECIAL

EDUCATION IN THE STATE OF INDIANA

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I wish to dedicate this work to my future wife, Jessie. Her never-wavering encouragement, support, and love make all things possible and worthwhile.

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ABSTRACT

Consistent under-reporting of autism cases by Indiana physicians to the Indiana Birth Defects and Problems Registry (IBDPR) has made quality autism-related data very difficult to obtain (Indiana Birth Defects and Problems Registry [IBDPR], 2011). As a result, the Indiana State Department of Health (ISDH) currently also utilizes data from billing information that it receives from hospital discharges. However, such cases must be investigated further because autism is often merely suspected as a possibility in the discharge data. A chart auditor must therefore review the child's chart to determine if the condition is confirmed. Meanwhile, the Indiana Department of Education (IDOE) has a different diagnostic procedure from physicians for determining whether a student has an Autism Spectrum Disorder (ASD), which qualifies him or her for special education. A physician diagnosis of autism does not guarantee that a child will receive special education from public schools. With all of these current complications surrounding autism, announced changes in the definition of autism by the American Psychiatric Association (APA) will likely have effects on both the special education field and the public health field. There is a possibility that children who had previously received special education could cease to maintain their eligibility and may find it difficult to obtain benefits. The IDOE may find it necessary to reevaluate their criteria for determining special education eligibility. Additionally, public health officials may see the definition changes affect the number of autism cases they perceive their populations to have, thus impacting community and policy decisions.

This study was performed as an attempt to investigate and compare the sources used by the IBDPR to obtain autism data, and determine whether or not the resulting data creates an accurate depiction of the autistic population of Indiana.   It was also performed to speculate whether a stricter definition of autism will result in a higher quality of data for the IBDPR and a more consistent view on the disorder between the ISDH and the IDOE. Perhaps from such consistency and simpler definitions, future recorded data will more closely resemble that of reality, enabling the ISDH to utilize the IBDPR to its full extent. Using current definitions for an exploratory analysis of data from the past five years, a discrepancy clearly exists between the IBDPR and the reality of the population of Indiana.

1. Introduction

Autism Spectrum Disorder (ASD) is a childhood developmental disorder which current estimates claim affects roughly as high as 1 out of every 91 children (Kogan et al., 2009). Obtaining an ASD diagnosis early in a child's life is extremely important for the sake of attempting early intervention. Numerous studies have shown that ASD patients who have undergone a carefully planned intervention to address social, cognitive, and communicative skill developments have produced positive outcomes (Bryson, Rogers, & Fombonne, 2003). Unfortunately, diagnoses can be very difficult and time-consuming. The average time between the first examination of a child following the observation of suspicious symptoms and their diagnosis is approximately 13 months (Wiggins, Baio, & Rice, 2006). There are a number of different disorders that fall within the autism spectrum, and these disorders are often confused with similar ones that are outside of the spectrum. For example, children with Down syndrome are 10 times more likely to have some form of autism, but of course, the two are completely separate disorders although some symptoms are shared (Molloy et al., 2009). Additionally, there are often large numbers of discrepancies of diagnoses and classifications of individual children between different evaluators. One study in particular found that the rate of agreement for specific diagnoses among professionals was only 45% (Williams, Atkins, & Soles, 2009). Such inconsistencies are very troubling, because receiving two conflicting diagnoses or one incorrect one can be a major setback for successful early intervention.

The broad and often vague classification of disorders in and around the autism spectrum also makes needs assessment difficult for those in the special education sector. A lack of organization and a lack of understanding of the specific needs of individual children with autism can prohibit children with ASD from reaching their full potential. Health professionals have expressed great concern that gains being made in early interventions are not sustained once the children begin formal education (Bryson, et al., 2003). These unsustained gains result in a problem not only for families coping with ASD but also for the government as money is wasted on programs that are ineffective because of a lack of organization and overall understanding. With each passing decade, cases of ASD have been discovered with more frequency (Yeargin-Allsopp et al., 2003), and as the cases increase, there is an even greater need for better data classification in all sectors that deal with autism so that special education systems can better serve the needs of each individual child

As more children are born with autism, more information becomes available about specific cases of autism and the circumstances under which the disorder affects these children. For this information to become useful, it must be collected in databases or registries and analyzed. The surveillance of autism is important for public health entities to be able to become fully aware of the health of their populations and what the needs of those populations are. It has been shown that autism registries, in conjunction with other health department programs, can reach cases of autism that would not otherwise be detected (J. Pinborough-Zimmerman, Bilder, Satterfield, Hossain, & McMahon, 2010). Unfortunately, because of the broad and vague nature of ASD, it is very challenging for surveillance methods to account for all or even a vast majority of

autism cases (Nonkin Avchen et al., 2011). In addition to registries targeting autism cases, consistent physician reporting of autism cases must take place for more accurate ASD counts to be possible. Accurate counts also rely on physicians and other experts being able to detect and diagnose a problem early. A clear picture of the needs of autistic children and their families from an early age allows government programs to allocate funds and create policies that most significantly and efficiently benefit them. Thus, the ease of receiving a diagnosis must increase if benefits from early interventions are to be retained.

2. Problem Statement

The terminology related to autism and the classification of the various conditions within ASD is complicated and can lead to problems with both obtaining and maintaining a diagnosis. Children diagnosed with autism after 2001 are more likely to have their diagnosis lost or altered than were children diagnosed before 2001. This is likely because changes in the definitions of autism disorders caused confusion, often leading physicians to apply a diagnosis of a specific disorder within the spectrum of autism as a placeholder until a more definite diagnosis could be assigned(Daniels et al., 2011). In addition to convoluted terminology, autism also tends to have a high comorbidity, which can lead to symptoms similar to those of autism causing issues with a child's diagnosis (Matson, Matson, & Beighley, 2011). Although medical registries have been shown to be useful for information exchange and research, their usefulness relies heavily on data quality (the accuracy with which data represents a real population). One characteristic of registry data that can cause its quality to be diminished is unclear definitions of for its data items

(Arts, De Keizer, & Scheffer, 2002).   The unclear definitions and boundaries of autism, therefore, would make it difficult to maintain high quality data in an autism registry. This is exacerbated by prolonged periods of time leading up to a diagnosis caused by the time that passes before symptoms clearly exhibit themselves and the inability of experts to quickly place a child in one of several different ASD diagnosis groups (Wiggins, Baio, & Rice, 2006).

A lack of data, of a high quality or not, has made it difficult for researchers to perform studies of significance to explore trends, causes, and clusters of autism. It also has made it difficult for public health agencies to properly address the disorder in communities everywhere. However, it has been shown that well-maintained electronic registries can provide larger quantities of high quality data for researchers to interpret and public health officials to utilize (Daniels et al., 2012).

The Indiana State Department of Health (ISDH) maintains a birth defects registry called the Indiana Birth Defects and Problems Registry (IBDPR) which contains autism data. The primary purpose of the IBDPR is to prevent birth defects and childhood developmental disabilities as well as to help improve the quality of life for Indiana residents affected by them. Furthermore, the IBDPR exists to perform the following functions:

- Detect trends in birth defects
- Suggest areas for further study
- Identify epidemiological factors associated with birth defects
- Address community concerns about the environmental effects on birth outcomes

- Evaluate education, screening, and prevention programs

- Establish efficient referral systems that provide special services for children with identified birth defects and their families

Autism, like the other birth defects contained in the registry, is a reportable condition (a condition which is required to be reported to public health officials upon diagnosis) for healthcare providers. Therefore, physicians who diagnose a child with autism must submit a report using the IBDPR's web application, providing whichever of the four ICD-9-CM (International Classification of Disease, 9th Revision, Clinical Modification) codes for ASD disorder corresponds to the diagnosis. These codes work as a standardized way for clinicians, public health officials, and other people in the healthcare field to communicate about a condition using the same classification system. Unfortunately, low reporting rates for autism by physicians have caused the IBDPR to send multiple reminders to physicians to request that they submit their diagnoses of autism. They also attempt to ascertain further cases by targeting potential autism cases from hospital discharge data as it is received by the ISDH. Nonetheless, such data must be audited by public health officials to determine whether these children are at least a probable case of autism (IBDPR, 2011). This study hypothesizes that such difficulties obtaining data leads to a lack of information that is representative of the population of the state of Indiana, rendering it unable to properly perform its primary functions.

2.1 Purpose of Study

The primary objective of this study is to evaluate the IBDPR's autism data as a representation of the population of the State of Indiana while analyzing the terminology

that is used to define the data that is within the registry. The ideal outcome of this evaluation is to determine whether the IBDPR's ability to improve the quality of life for Indiana residents affected by autism is inhibited by a potential lack of knowledge about these affected residents, resulting from a lack of data.

2.2 Scope and Limitations

This study represents an exploratory analysis of ASD data sources for Public Health agencies and a potential taxonomy for the organization of ASD data. It also represents an attempt to hypothesize potential impacts of such data on other stake holders aside from Public Health agencies. The study is not, however, intended to be an analysis with statistical significance. The study's exploratory nature is intended to encourage further research and analysis rather than to reach significant statistical conclusions.

3. Background

3.1 Defining Autism Spectrum Disorders

Autism Spectrum Disorders are also known as Pervasive Developmental Disorders (PDD). As defined by DSM-IV-TR, they are disorders that are "characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities." This spectrum of disorders contains Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (APA, 2000). To receive a diagnosis of Autistic Disorder, a child must exhibit six or more symptoms from three specific

symptom groups. These symptom groups include qualitative impairment in social

interaction, qualitative impairments in communication, and restricted, repetitive, and

stereotyped patterns of behavior, interests, and activities. In addition, the child must

show delays or abnormal functioning in social interaction, language, or symbolic or

imaginative play before he or she reaches 3 years of age. The following figure visualizes

the classification of Autistic Disorder and the other Autism Spectrum Disorders:

Figure 1: Visualization of the DSM-IV-TRclassification of Autism Spectrum Disorders
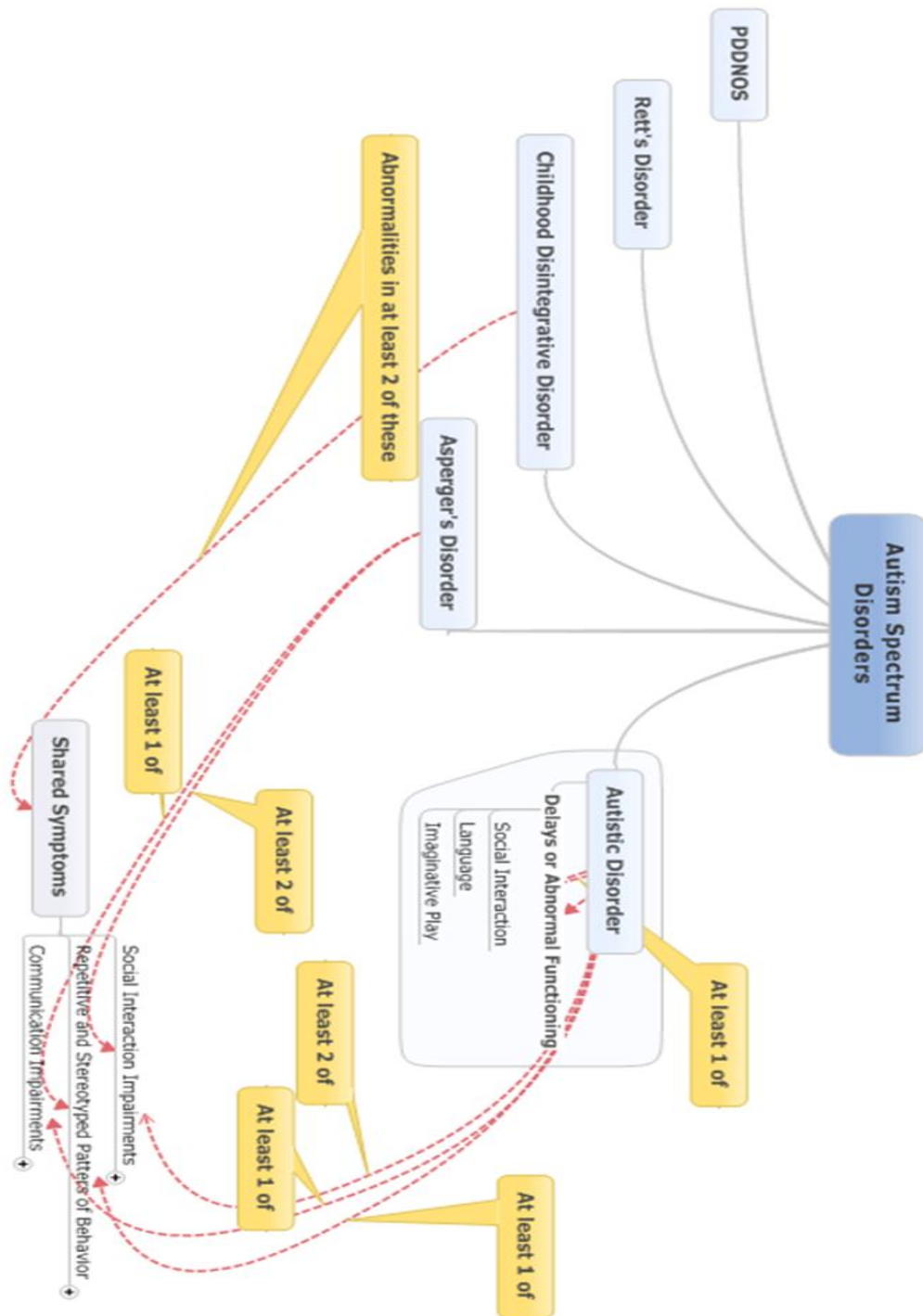
Asperger's Disorder consists of the "impairment in social interaction" and "restricted repetitive and stereotyped patterns of behavior" categories of symptoms, but does not exhibit the impairment in communication skills. Childhood Disintegrative Disorder (CDD) exhibits itself by apparently normal development in a child for the first 2 years of life followed by significant loss of previously acquired skills before the child reaches 10 years of age. These symptoms are also accompanied by symptoms from 2 of the 3 groups of symptoms in Autistic Disorder. Rett's Disorder is very similar to CDD in that it results in the loss of previously acquired motor and social skills, but is also exhibited by deceleration of head growth in the first few years of life and more severely impaired language development. Finally, Pervasive Development Disorder Not Otherwise Specified (Including Atypical Autism) is used to describe any disorder when a child shows evidence of severe and pervasive impairment in the development of social interaction or communication skills, but does not meet the criteria for another specific PDD (APA, 2000). The APA created these multiple definitions of PDDs in DSM-IV to compensate for a previous definition of autism which they thought was too broad. They were attempting to reduce the number of false positives and felt this justified the creation of multiple subcategories of autism(e. a. Volkmar, 1994). Unfortunately, these multiple subgroups of ASDs have caused physicians to be unable to diagnose autistic children in a timely manner, let alone diagnose them consistently. Many years of confusion have led many to make the assertion that clearer guidelines for diagnosis should be created for the benefit of potential research (F. R. Volkmar, State, & Klin, 2009).

3.2 Current Terminology Usage by Indiana State Department of Health

For the purposes of public health and the maintenance of autism data by the

IBDPR, ASDs are divided into four different categories by their ICD-9-CM codes. These

codes are 6-digit numbers which are part of a standardized classification for all diseases.

The four different groups are Autism, Childhood Disintegrative Disorder, other specified

Pervasive Developmental Disorders, and unspecified Pervasive Developmental

Disorders. Information about ASDs is received at the ISDH electronically in the form of

ICD-9-CM codes either from a physician or from hospital discharge billing data. Receipt

of a physician diagnosis report of any form of autism is taken as a confirmed diagnosis.

Receipt from billing data, however, results in a medical record review by a chart auditor.

Following the review, the auditor determines whether the report of an ASD can be

recorded as a confirmed case or at least a probable one. The IBDPR focuses not on the

strict definitions of autism, but rather on the targeted ICD-9-CM codes and whether a

perceived case is likely to be a true one. This is for the sake of attempting to maintain

data that is as accurate as possible. Failure to maintain accurate or adequate data would

prohibit the IBDPR from performing a majority of its (and the ISDH's) primary

objectives. It is difficult for the ISDH to determine where interventions should be

performed without data to guide them, and the needs of the autistic community cannot be

assessed properly without knowledge of the circumstances under which those in that

community live. To that end, further information is also held about the child who has

been diagnosed, such as age and sex of the child, and the location and date of the

diagnosis. However, no further autism terminology is used (IBDPR, 2011).

3.3 Special Education Eligibility in the Indiana Department of Education

With education, autism is essentially defined in terms of qualification for special education benefits. While the definitions of autism and other PDDs themselves are essentially the same as those used by the APA, in Indiana the child must also undergo what is called a Case Conference Committee (CCC) which assesses their eligibility. The first segment of a child's CCC includes an assessment of their current academic achievement, their functional skills or adaptive behavior, multiple different types of communication skills, and their motor skills. The CCC also includes analysis of the student's social and developmental history, a systematic observation of their interactions in various environments, and any other assessments and information that may be pertinent at the time of the CCC (Indiana General Assembly, 2012). A child only meets the criteria for ASD special education eligibility after the CCC determines based on all of these steps that the child is indeed autistic. As a result of these strict criteria, many children do not qualify for special education as autistic despite the fact that they have an ASD diagnosis from a physician.

4. Methods

Using an exploratory analysis of data from multiple sources, this study was intended to examine the use of autism terminology and classification in a practical setting. Its aim was to explore the implications of the data and terminology for the fields of education and public health, particularly on the IBDPR's ability to perform its desired functions.

A literature review was also performed to determine the impact that the new DSM-V definition of autism will have on those affected by the disorder in the future, both near and far.

4.1 Data Collection

The data for this study were obtained by an official request to the IBDPR at the ISDH. Following an IRB request for approval of exemption, which was approved, a formal letter of request was written to officials at the IBDPR. The requested items in the letter included de-identified data containing the following fields: city/town of the diagnosing physician, age (in years) of the patient at diagnosis, sex of the patient, the official diagnosis of the patient, and the source of each patient's data (physician or hospital discharge data). This initial request for data was denied, citing the potential identification of patients from specific fields that were requested as a result of a limited number of cases.

An additional request was written following the denial of the original. The subsequent request asked for fewer fields, but the following three items were requested:

- the number of children per county reported with each of the four autism-related diagnoses for each of the past five years
- the number that was obtained from hospital discharge data for each autism-related diagnosis for each county by year
- the number of children that originated from both physicians and hospital discharge data for each autism-related diagnosis for each county by year.

The four different diagnoses that the IBDPR receives and keeps record of based on their ICD-9 code are Autistic Disorder (299.00), Childhood Disintegrative Disorder (299.10),

other specified pervasive developmental disorders (299.80), and unspecified pervasive developmental disorder (299.90). This request was accepted, but it was recommended that the data be grouped by region (groups of counties) rather than county.

Following the request to the ISDH for data from the IBDPR, an attempt was made to obtain data from the IDOE which specified the number of autism cases by age and county. Upon discovering that such data was not maintained, letters of request were written to the Planning District Director for each school district to obtain autism data. Understanding that many districts likely have their special education data in different formats, the data were requested in any format that it would be available. This data search was not intended to be exhaustive, but merely a means to obtain samples of data to compare against IBDPR data to analyze potential differences between the information that the two stakeholders work with. Data in several different formats was sent in response by many Planning District Directors for the Special Education department of the IDOE. Some district numbers were divided into ages while others provided total numbers alone.

Finally, a literature review was performed to obtain information about changes that will likely be made with how autism is diagnosed when DSM-V is released and implemented beginning in May of 2013. This review was intended to aid with the speculation of potential impacts that the new definition could have for public health and special education stakeholders.

4.2 Data Analysis

Upon receipt of the requested data from the IBDPR, comparisons were made across the different data sources by each region. The numbers were analyzed to

determine the level of agreement between sources and unusual trends were noted. In addition to the data received directly from the ISDH, the IBDPR's Legislative Progress Report from June of 2011 was reviewed to analyze the overall numbers of live births from the year 2004 to 2008 that have been counted as confirmed or probable cases of autism. This data and its rates per 10,000 live births were compared to incidence rates that other studies have reported. Data received from the Planning District Directors for Special Education departments were also compared to the IBDPR data to determine the level of agreement between public health and education sources.

To perform the literature review of studies performed relating to the pending DSM-V release, the first reviewed item was the definition for Autism Spectrum Disorder that the APA currently plans to use in place of the previous definition found in DSM-IV-TR. Following this research, fifteen journal articles were found which pertained to potential effects that the new definition may have on different fields related to autism. The articles were found from links from the APA's official DSM-V website, PubMed, and Google Scholar using the key words "DSM-V", "autism", "Asperger Disorder", and "PDD". These articles were reviewed and several are discussed further in the results and discussion sections.

5. Results

The data were received on December 5, 2011 in the form of tables. The tables specify the number of cases (assuming there are 5 or more cases) for each of the 4 categories of autism for each year from 2004 to 2008 in each region of Indiana. Marion County is counted as its own region. The data were divided by source, with one table

created for physician reports, one table created for birthing facility reports, and one table for cases that were reported by both. Any county that has fewer than five cases is marked by an asterisk to indicate that the number of cases is too small to determine anything of significance. The table for cases received from both sources was not included because no region had 5 or more cases reported by both sources in any given year.

Table 1: Autism Cases Reported by Physicians

Birth year	Region	Report Source & Diagnosis	MD - Autism	MD - Childhood disintegrative disorder	MD - Other specified pervasive developmental disorders	MD - Unspecified pervasive developmental disorder
2003						
	Northwest		*	*	*	*
	Northeast		7	*	9	*
	East Central		7	*	*	*
	Marion		10	*	*	*
	West Central		*	*	*	*
	Southwest		*	*	*	*
	Southeast		*	*	*	*
	UNK		10	*	*	*
2004						
	Northwest		*	*	*	*
	Northeast		*	*	15	*
	East Central		7	*	*	*
	Marion		7	*	*	*

West Central	*	*	*	*
Southwest	*	*	*	*
Southeast	*	*	*	*
UNK	*	*	8	*
2005				
Northwest	*	*	*	*
Northeast	*	*	18	*
East Central	12	*	*	*
Marion	10	*	*	*
West Central	7	*	*	*
Southwest	*	*	*	*
Southeast	*	*	*	*
UNK	8	*	*	*
2006				
Northwest	*	*	*	*
Northeast	11	*	19	*
East Central	7	*	*	*
Marion	8	*	*	*
West Central	*	*	*	*
Southwest	11	*	*	*
Southeast	*	*	*	*
UNK	9	*	*	*
2007				
Northwest	6	*	*	*
Northeast	8	*	21	*
East Central	9	*	*	*
Marion	12	*	*	*
West Central	*	*	*	*
Southwest	6	*	*	*
Southeast	*	*	*	*
UNK	7	*	8	*
2008				
Northwest	*	*	*	*
Northeast	*	*	8	*
East Central	*	*	*	*
Marion	*	*	*	*
West Central	*	*	*	*
Southwest	*	*	*	*
Southeast	*	*	*	*
UNK	*	*	*	*

Table 2: Autism Cases Reported by Hospital Discharge Data

Birth year	Region	Report Source & Diagnosis HDD - Autism	HDD - Childhood disintegrative disorder	HDD - Other specified pervasive developmental disorders	HDD - Unspecified pervasive development disorder
2003					
	Northwest	*	*	*	*
	Northeast	*	*	*	*
	East Central	*	*	*	*
	Marion	*	*	*	*
	West Central	*	*	*	*
	Southwest	*	*	*	*
	Southeast	*	*	*	*
	UNK	*	*	*	*
2004					
	Northwest	9	*	*	*
	Northeast	*	*	*	*
	East Central	*	*	*	*
	Marion	5	*	*	*
	West Central	*	*	*	*
	Southwest	*	*	*	*
	Southeast	*	*	*	*
	UNK	*	*	*	*
2005					
	Northwest	22	*	*	*
	Northeast	11	*	*	*
	East Central	15	*	*	*
	Marion	9	*	*	*
	West Central	*	*	*	*
	Southwest	*	*	*	*
	Southeast	*	*	*	*

UNK	*	*	*	*
2006				
Northwest	21	*	*	*
Northeast	17	*	*	*
East Central	17	*	*	*
Marion	14	*	*	*
West Central	10	*	*	*
Southwest	*	*	*	*
Southeast	*	*	*	*
UNK	*	*	*	*
2007				
Northwest	19	*	*	*
Northeast	6	*	*	*
East Central	11	*	*	*
Marion	12	*	*	*
West Central	8	*	*	*
Southwest	*	*	*	*
Southeast	*	*	*	*
UNK	*	*	*	*
2008				
Northwest	13	*	*	*
Northeast	*	*	*	*
East Central	7	*	*	*
Marion	*	*	*	*
West Central	*	*	*	*
Southwest	*	*	*	*
Southeast	*	*	*	*
UNK	*	*	*	*

Using the data from these tables, bar graphs were created to visualize the number of cases reported to the ISDH from each of the two sources. There is a graph for each of the 6 regions of Indiana, as well as one for Marion County. Any year in which an asterisk is recorded in the table, that year is marked to have 0 cases reported on the graphs.

Figure 2: Reported Autism Cases in Northwestern Counties
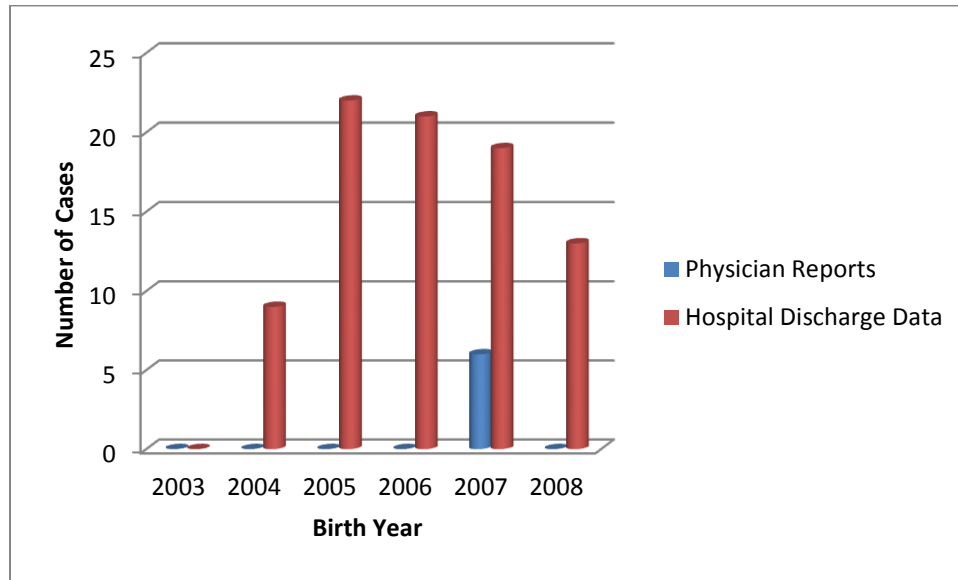

Figure 3: Reported Autism Cases in Northeastern Counties
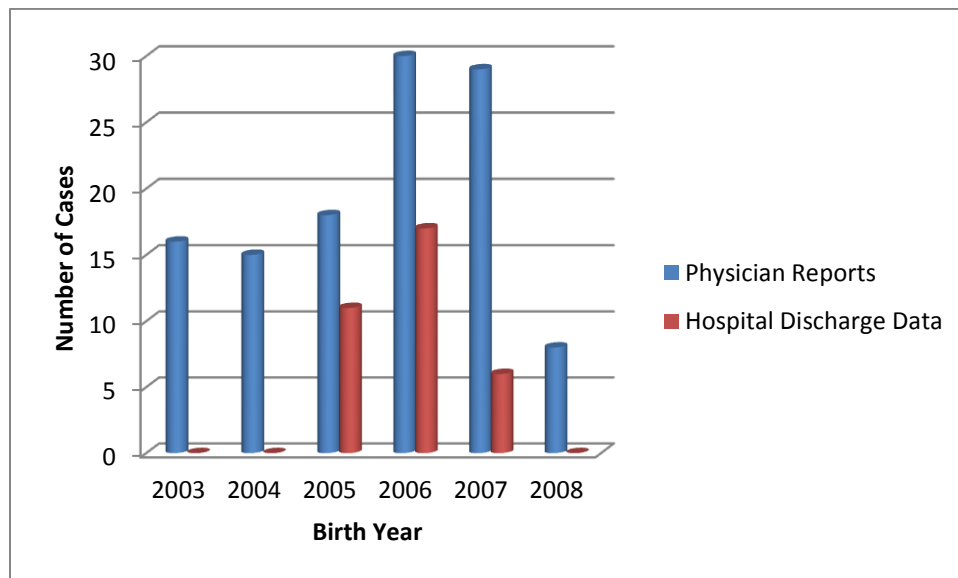
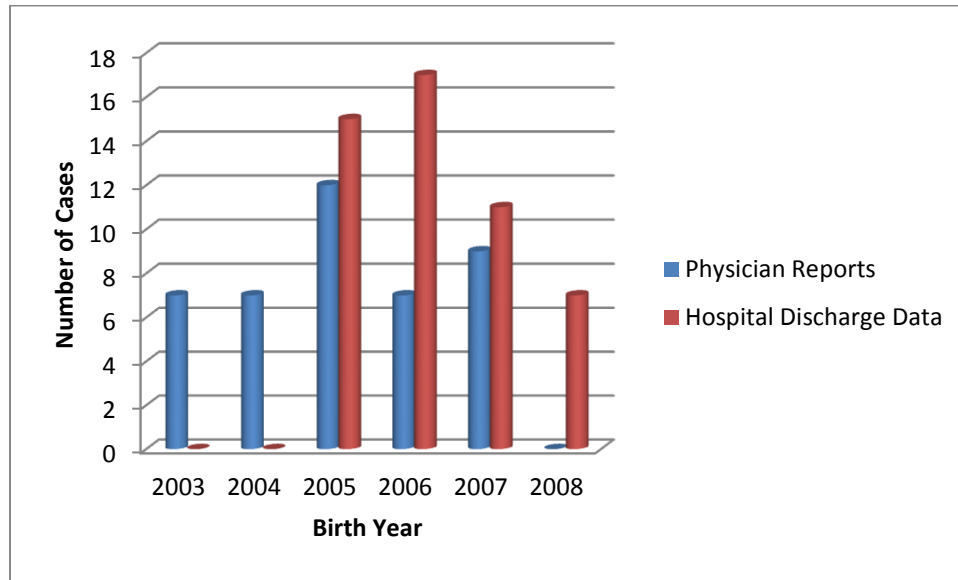**Figure 4: Reported Autism Cases in East Central Counties**

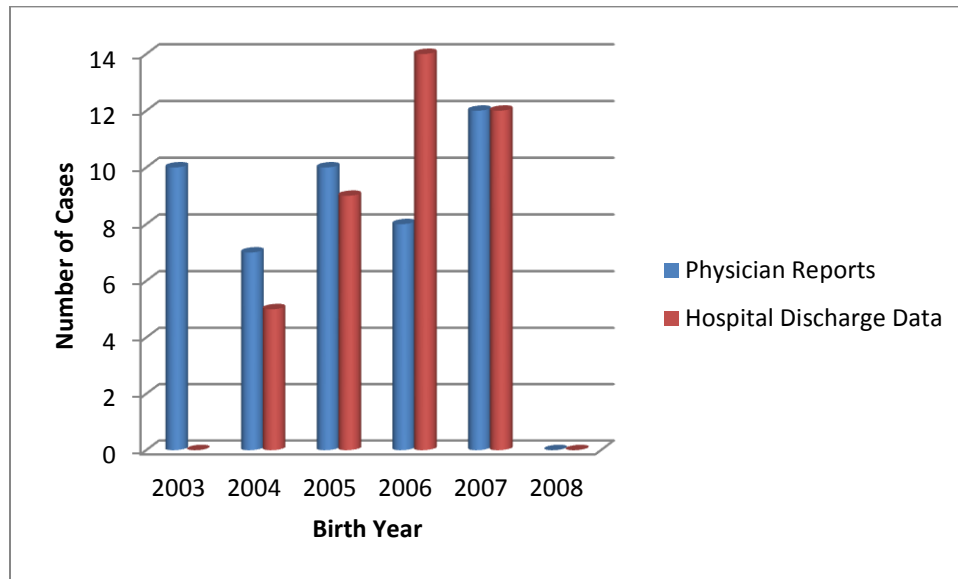**Figure 5: Reported Autism Cases in Marion County**

Figure 6: Reported Autism Cases in West Central Counties
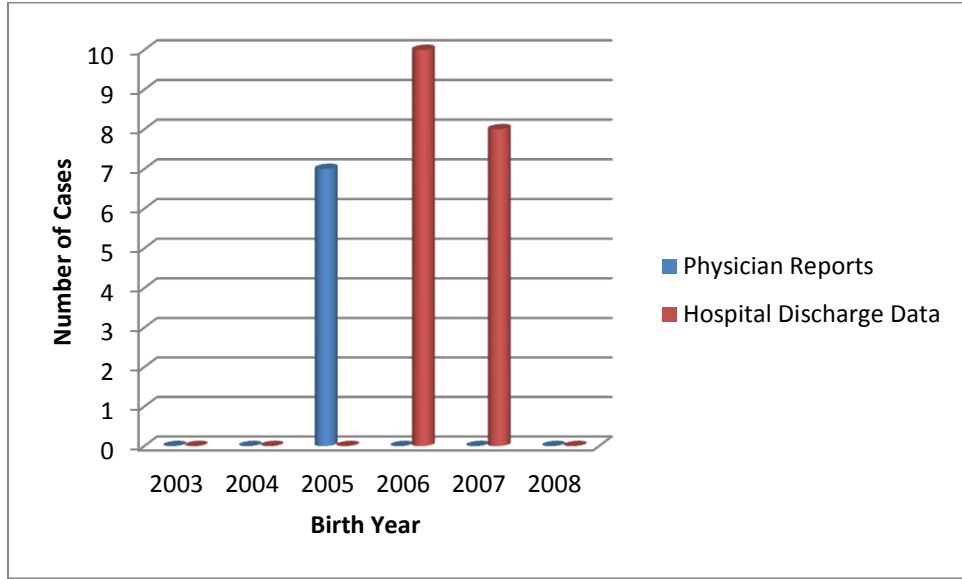
Figure 7: Reported Autism Cases in Southwestern Counties
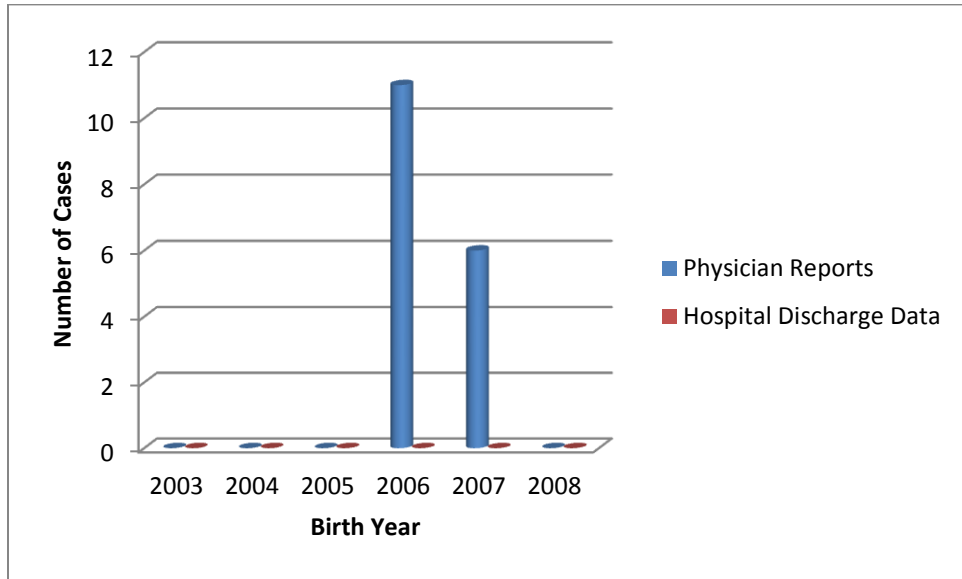
Figure 8: Reported Autism Cases in Southeastern Counties
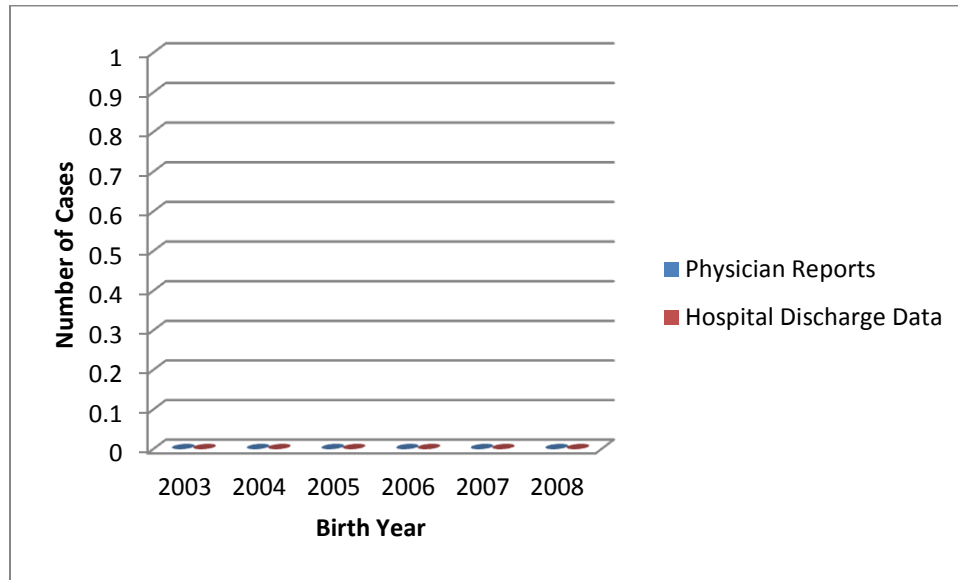
In addition to the data that were received divided by region and year, further data were obtained which indicate total numbers for the state grouped by source and by year. Also included with this data was the number of medical records that were audited to investigate whether a suspected case could be marked as confirmed or probable and how many cases were in fact confirmed. According to the IBDPR data, approximately 32 % of confirmed cases were reported only by physicians, 64% were reported only by hospitals, and 4% were reported by both for children born in the years 2004 through 2008. Of the 877 cases of autism reported by hospital discharge data, 328 were confirmed (some by physician diagnosis, some by medical record audit), or 37.4 %. All 174 cases reported by physicians (156 by only physicians, 18 by both physicians and hospitals) are taken as confirmed cases, bringing the total to 484.

The majority of school districts that were contacted were either not willing or not able to supply data for the number of autism cases at their schools. However, official state data do show that the number of children with ASD served by Indiana did rise from

10,643 in 2009 to 11,514 in 2010, which indicates higher totals than those obtained from the IBDPR. It also shows that funding for the special education disability level that autism is included in rose by $7,456,550 in that same time frame. Of the districts that did respond with data, most of the data were not separated by age in any way. Many districts or schools also had low numbers because they were such a small representation of the region or state, and it was therefore not possible to compare them to IBDPR data without corresponding data from other districts in their respective regions. However, two counties that did respond with quality data stood out. Despite only 16 confirmed or probable cases of ASDs in Elkhart County's region (Northeast) in the IBDPR for the birth years 2004 to 2008, the 7 school districts in that one county have 74 children in that corresponding age group (preschool to 3rd grade) that qualify for special education for ASD. Additionally, the IBDPR has negligible data for Clark County for these years (5 or less cases confirmed or probable cases of autism), while the 3 districts in this county provide special education for ASD to 78 children in grades preschool through 3rd.

6. Discussion

One statistic which indicates clearly that there is an issue with autism being under-reported in the state of Indiana is the incidence of autism per 10,000 live births based on the cases in the IBDPR. With 515 confirmed or probable cases for children born from 2004 to 2008, autism has a rate of approximately 11.81 per 10,000 or 1 in every 847 live births. Although more cases are sure to be reported as the average age of diagnosis ranges in studies from 3.9 to 5.7 years(Rosenberg, Landa, Law, Stuart, & Law, 2011), it is unlikely that the autism rate for live births from 2004 to 2008 will rise to what

is typically accepted to be the average rate of 1 in 110 (Lord & Bishop, 2010). Also, the higher rate of autism for children in the IDOE (1 in 90.95) negates the possibility that Indiana may have a low autism rate when compared to other states.

Although conclusions of statistical significance cannot be gained from the provided data, there are certainly areas of the state that are much less reliable than others with regards to physician reporting of autism. While hospital discharge data for each region provided the IBDPR with more reported cases than did physicians, this gap was wider for the Northwest region of the state than any other. Cases from hospital discharge data were higher in the Northwest region than in any other region for each of the five birth years. Conversely, the Northwest region only provided a physician report count of five or better for one of the five birth years. There could be many possible reasons for the physician reporting issue. It could possibly be that when physicians diagnose autism, they simply do not think of it as a birth defect because symptoms are not present at the time of birth. Therefore, it may not cross their mind to report a diagnosis of autism to the IBDPR. Also, although autism has been getting more and more attention in the medical field, it may be possible that because it is not seen as an illness like the flu, STDs, or other contagious diseases, it does not trigger the response of reporting.

Despite specified autism data being received from very few District Directors for Special Education departments, data from those few specific locations seem to indicate that schools are more aware of autism cases than the IBDPR. While the number of autistic cases in the Northeast region of the state of Indiana (which contains 16 counties) has no cases contained in the IBDPR data due to statistical insignificance for the birth year of 2003, Elkhart County alone has 23 cases for children of the corresponding age

(Grade 3). 2003 is a year in which all children born have now surpassed the average age of diagnosis by more than 2 years. Such a high number of cases in one county far surpasses the amount of cases found in the IBDPR for Elkhart County's entire Northeast region. Although data for the remaining counties of the Northeast region were not provided, it is likely that at least some number of additional cases exist elsewhere in the region.

Another county whose autism count from Special Education sources far exceeded that of its entire region from the IBDPR was Clark County from the Southwest region of Indiana. Despite the IBDPR's lack of any noted cases of autism (5 or less) for the Southwest region for children born in 2006 or 2007, Clark County schools alone have 17 autistic children in preschool. Although there is not enough data for such numbers to be statistically significant, the numbers do indicate that there are likely more cases of autism in any given part of Indiana than are found in the IBDPR.

It is certainly understandable that District Directors of Special Education would have more information on autistic children in their community than the ISDH, as schools and teachers deal with children on a daily basis while the ISDH typically only deals with them indirectly. However, more information about true child population and how autism is represented in it could be beneficial for the IBDPR to have and to utilize for further research. As the ISDH claims that the IBDPR's main goals are to "improve the quality of the data available on birth defects in Indiana and to provide information…to the parents/guardians and primary care providers of children with confirmed birth defects", it would stand to reason that obtaining further available data would be within its interests.

This low reporting of ASD makes it difficult for the ISDH to fully utilize the IBDPR for its intended purpose. Without significant amounts of data available for autism throughout the state, it becomes very difficult for the ISDH to detect trends, identify epidemiological factors, or address community concerns about the environmental effects on birth outcomes that result in autism. If there is not enough knowledge about the children that are affected by autism, where these cases take place, and when they take place, public health officials as well as other government officials cannot become properly informed to make decisions that will affect the autistic community. Analysis of more robust data would be able to show these trends and epidemiological factors that may be taking place as well as provide knowledge for establishing efficient referral systems, evaluating education programs, and suggesting areas for further study.

It is clear that efforts need to be made to obtain more data for the IBDPR to truly have high quality data on autism. One potential method for obtaining more data would be collaboration with the IDOE. Information about autistic children, which would remain confidential, could be provided by the IDOE to the IBDPR. Such information would be difficult to obtain because of restrictions placed on accessing student health data by the Family Education Rights and Privacy Act (FERPA). FERPA prevents agencies or people from outside of a child's school to access that child's health records. Nevertheless, permission can be obtained by meeting with the State's department of education and reaching a memorandum which can designate other governmental agencies as authorized representatives of a State-supported education program (Family Educational Rights and Privacy, 2011). Although such a memorandum could be difficult to reach, it has been shown that more data and a higher rate of case ascertainment can happen when education

and public health data are combined in a registry (Judith Pinborough-Zimmerman et al., 2011).

Beyond further collaboration between the IDOE and the IDSH on data sharing, further encouragement of physicians (particularly those who already report regularly) to report ASDs and further overall public awareness may also aid eventually in acquiring more autism data. An excellent time to conduct awareness and education campaigns and encourage physicians to be mindful of IBDPR reporting rules would be in May of 2013, when the new definition of ASD becomes official and researchers, clinicians, educators, and families alike can attempt a fresh start at comprehending ASD and what it means in our society.

The American Psychiatric Association's upcoming release of the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-V*) in May of 2013 could affect future diagnoses and how autism information is obtained and utilized for research. It also may have an effect on how families are able to cope, as it has been shown that many children who would have previously received a diagnosis of autism with *DSM-IV*-TR, will not qualify as autistic under the proposed *DSM-V* (Worley & Matson, 2012). The intention of the new DSM-V autism definition was to cause a higher specificity while maintaining the sensitivity of autism diagnoses (American Psychiatric Association [APA], 2011). The APA found the definitions of disorders within the spectrum to be inconsistent over time and across locations. It also believes that ASD is a common set of behaviors which allows a single category to be applied to all affected individuals while including specifiers that may describe a specific case (APA, 2011). Consequently, the proposed changes from *DSM-IV-TR* will eliminate the subcategories of

autism and define it solely as a single category (APA, 2011). This elimination of the subcategories results in the creation of a singular category and combines the social and communication deficits into a single symptom group rather than two separate ones. It also requires that all of the social and communication deficits be exhibited. Rather than requiring 6 symptoms across 3 different symptom groups, 5 symptoms are needed across 2 different symptom groups (APA, 2011). The following figure is a visualization of the simplified classification of ASD:

Figure 9: Visualization of the DSM-V classification of Autism Spectrum Disorder
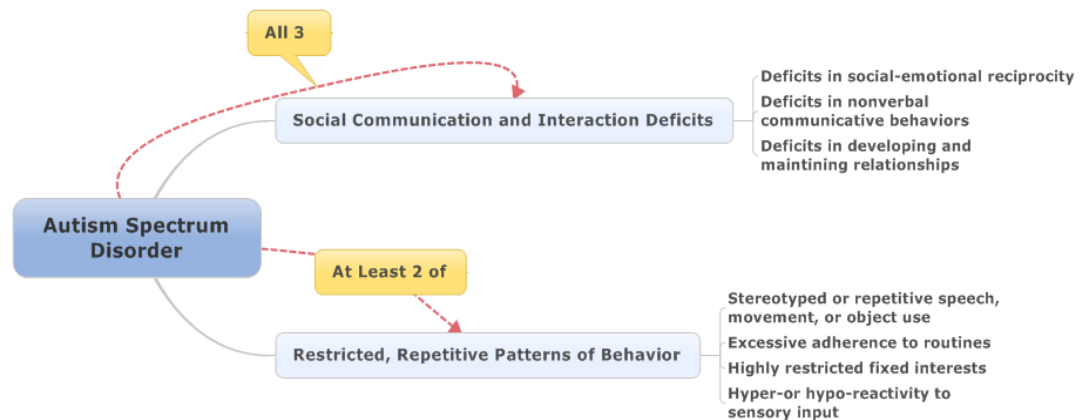
While these changes seem to simplify the classification of autism, it is impossible to know for sure whether it will impact the clinical, public health, and special education fields in a positive way until the changes are officially implemented. However, an increase in early detection of ASD as a result of the simplification of its definition could have many positive impacts, most importantly an early intervention for autistic children, with sustained improvements in their areas of impairment.

From the review of the literature covering the May 2013 release of DSM-V, one conclusion that seems to be agreed upon unanimously by researchers is that the pending new definition of Autism Spectrum Disorder will result in a higher specificity of diagnosis, with possibly four times less false positives (Frazier et al., 2012). However, studies have also shown that the APA's attempts to maintain sensitivity for diagnoses has not been successful (Frazier, et al., 2012) and that many children who meet the DSM-IV-TR autism criteria but not the DSM-V criteria may experience significant impairments related to the core ASD symptoms (Worley & Matson, 2012). The children most likely to be impacted by lower sensitivity of the DSM-V criteria would most likely be those who may have higher cognitive ability, but are still socially impaired and still have restricted repetitive and stereotyped patterns of behavior. Such children would probably not retain special education eligibility in the same form that they are accustomed to.

Other studies show that girls, women, or adults may go undiagnosed or become misdiagnosed despite their autism (Wing, Gould, & Gillberg, 2011). Nonetheless, there are studies that demonstrate that DSM-V is a vast improvement over DSM-IV-TR with regards to autism and that the model was consistent for children of any age or sex (Mandy, Charman, & Skuse, 2012). Others felt that although the amount of subgroups for ASD were excessive and confusing, the new definition could still benefit from having just two basic categories of severe and mild autism (Mattila et al., 2011). Some researchers are also of the opinion that Asperger Disorder is different enough from the new definition of autism that it should remain as its own entity (Nils, 2011).

Although there may be fewer false positives following the official release of DSM-V, there also seems to be evidence that indicates many children who previously

had diagnoses of a disorder on the autism spectrum will lose that diagnosis. While losing an official physician diagnosis would not necessarily cause a child to lose their special education eligibility based on Article 7, the IDOE could still potentially alter the eligibility requirements to more closely resemble the official DSM-V definition. Although many will likely be diagnosed with another disorder based on their symptoms, this possible loss of benefits is a situation which must be closely monitored to ensure that children who need support from special education and health insurance are not left without assistance.

7. Limitations

This study was initially intended to provide an extremely detailed analysis of the data contained within the IBDPR. The analysis was to include exploration into multiple data fields such as county and sex and to evaluate the demographics and location of autism cases with potential cluster areas. Limited fields and case numbers prohibited this sort of detail which caused the study to become more of a search for discrepancies between sources.

Although the under-reporting of autism is accepted as fact by many public health officials, there is a lack of previous research papers that discuss this topic or prove it with any significance. This lack of literature is the cause for the limited amount of papers cited to explain such under-reporting.

The insignificance of the IBDPR data that the IDOH was willing to provide for the study limited both the initial scope and the overall impact of the study. Additionally,

the elapsed time between the data request and the release of the data prohibited further inquiries for data from the IDOH from being an option. Finally, the speculation of the future impact of changes the autism definition in DSM-V is based on pending changes that are not yet official. Further changes are possible before DSM-V is officially released.

8. Future Research Recommendations

Further research into the effects the implementation of DSM-V has on autism incidence in the state of Indiana and beyond would be a beneficial study following its official release, focusing as well on its effects on education. The number of autism cases for the first 2 years would be compared against the 2 years prior to DSM-V implementation for the IBDPR and the IDOE. The level of increase or decrease in the years following DSM-V's adoption would be an indication of the true sensitivity and specificity of the new ASD definition and may also point toward a higher or lower percent reception of cases by the IBDPR. Whether or not the elimination of ASD subcategories increases the significance (fewer instances of insignificant totals as a result of the numbers no longer being divided into groups) of the numbers received by the IBDPR would also indicate whether the population is being more accurately presented. With regards to education, an exploration into the number of ASD cases combined with a comparison of the special education funding data across the 2 years prior to and after DSM-V implementation would clearly illustrate the impact that the new definition of autism has on children with special needs across the state. This study would determine whether DSM-V negatively or positively impacts autistic children and their families.

9. Conclusion

The results of this study indicate that the suspected under-reporting of autism cases by physicians is a reality in the state of Indiana. It is critical that more data are obtained by the IBDPR in order to make greater use of the information that has yet to be harnessed. More data is crucial for the ISDH to obtain a better understanding of the autistic community that it serves. In order for public health departments and other government agencies to make the correct choices when it comes to the lives of families that are impacted by autism, they must be well-informed. Other sources besides physicians and hospitals, especially schools, must be tapped into for information about the population. Improvement of the quality of life for those affected by autism starts with knowledge about these members of the community. Evaluating their needs and the needs of the State of Indiana requires data that better represent the population as a whole.

The impending release of DSM-V will be very important to the future of autism research, and it should be studied closely. Its effects on public health data organization, on special education funding, and most importantly on the lives of millions of children around the world, are of great significance to comprehend.

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11. Appendices

Appendix A: APA DSM-IV-TR definition of Autistic Disorder

A. Six or more items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

1. qualitative impairment in social interaction, as manifested by at least two of the following:

    a. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

    b. failure to develop peer relationships appropriate to developmental level

    c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

    d. lack of social or emotional reciprocity

2. qualitative impairments in communication as manifested by at least one of the following:

    a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

    b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

    c. stereotyped and repetitive use of language or idiosyncratic language

    d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

3. restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

    a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

    b. apparently inflexible adherence to specific, nonfunctional routines or rituals

    c. stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)

    d. persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

(APA, 2000)

Appendix B: APA DSM-V definition of Autism Spectrum Disorder

Autism Spectrum Disorder

Must meet criteria A, B, C, and D:

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

1. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction,

2. Deficits in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.

3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people

B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:

1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).

2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).

3. Highly restricted, fixated interests that are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)

D. Symptoms together limit and impair everyday functioning.

(APA, 2011)

Appendix C: IBDPR data by year for Birth Years 2004-2008

Table 1: Number of Children* Reported** to IBDPR by Birth Year

Condition Name / Category	ICD-9-CM Codes	2004	2005	2006	2007	2008
Acute myelofibrosis	289.80			1		
Adenoma of lung bronchus	212.30	1	1	1	1	2
Anomalies of jaw	524.00-254.10	62	57	67	72	71
Anterior horn cell disease	335.00-335.99	8	4	5	11	11
Autism, Childhood disintegrative disorder, Aspergers, Rett syndrome, and Pervasive developmental disorders not otherwise specified	299.00-299.99	338	361	325	214	82
Cardiovascular anomalies	745.00-747.99	1954	2082	2155	2119	2111
Central nervous system anomalies	740.00-742.99	343	391	415	387	381
Cerebral degenerations usually manifest in childhood	330.00-330.99	8	5	4	7	7
Chromosomal anomalies	758.00-758.99	205	218	250	246	275
Cleft palate and cleft lip	749.00-749.99	173	156	166	151	122
Coagulation defects	286.00-286.50	31	32	32	30	40
Congenital anomalies of integument	757.00-757.99	704	1118	1614	1551	1904
Congenital nystagmus	379.51	3	10	7	6	14
Constitutional aplastic anemia	284.00	1	1			
Diabetes mellitus	250.00-250.99	173	168	200	193	154
Diseases of white blood cells	288.00-288.99	779	843	859	912	814
Disorders involving the immune mechanism	279.00-279.99	64	80	75	85	54
Ear, face and neck anomalies	744.00-744.99	207	209	227	225	213
Eye anomalies	743.00-743.99	213	223	221	205	229
Fetal alcohol syndrome	760.71	39	34	35	41	32
Gastrointestinal anomalies	750.30-751.99	457	459	523	560	480
Genitourinary anomalies	752.00-753.99	1461	1503	1533	1625	1519

Appendix D: IBDPR data for Birth Years 2004-2008 by source

Table 4B: Sources of Case Ascertainment Data for Reportable Conditions* of 2004 - 2008 Births to Indiana Women

Condition Name/ Category	Reported by Physician Only	Reported by Hospital Only	Reported by Physician and Hospital	Total
Acute myelofibrosis	1	0	0	1
Adenoma of lung bronchus	0	6	0	6
Anomalies of jaw	7	373	4	384
Anterior horn cell disease	1	49	0	50
Autism, Childhood disintegrative disorder, Aspergers, Rett syndrome, and Pervasive developmental disorders not otherwise specified	156	310	18	484
Cardiovascular anomalies	36	5554	6	5596
Central nervous system anomalies	22	991	1	1014
Cerebral degenerations usually manifest in childhood	4	28	1	33
Chromosomal anomalies	145	591	12	748
Coagulation defects	1	195	0	196
Congenital anomalies of integument	12	7124	5	7141
Congenital nystagmus	2	37	1	40
Constitutional aplastic anemia	0	2	0	2
Diabetes mellitus	0	1053	0	1053
Diseases of white blood cells	0	4498	0	4498
Disorders involving the immune mechanism	2	433	0	435
Ear, face and neck anomalies	12	1148	3	1163
Eye anomalies	14	1014	1	1029
Gastrointestinal anomalies	5	921	1	927
Genitourinary anomalies	25	5570	6	5601
Glaucoma of childhood	1	0	0	1
Hearing loss	22	2976	0	2998
Hereditary hemolytic anemias	2	1108	0	1110
Hereditary retinal dystrophies	0	1	0	1
Mesothelioma of peritoneum	0	2	0	2
Muscular dystropies and myopathies	11	185	1	197
Musculoskeletal anomalies	150	9815	41	10006
Neoplasms of lip	3	1353	1	1357
Neoplasms of skin	1	824	0	825
Neoplasms-other	6	602	1	609
Other congenital anomalies	90	1322	37	1449
Other paraproteinemias	1	0	0	1
Other testicular dysfunction	0	5	0	5
Primary thrombocytopenia	0	44	0	44
Respiratory system anomalies	14	2098	1	2113
Retrolental fibroplasia	0	768	0	768

Appendix E: IBDPR data for confirmed case percentage

Table 5: Targeted Conditions Reported to IBDPR via Hospital Discharge Data for Children Born in 2004 - 2008 which are Confirmed or Determined as Probable by Medical Chart Audits or Physician Reports

Condition Name / Category	Number of Children Reported	Targeted Conditions Reported	Conditions per Child	Conditions Confirmed / Probable	Confirmed/ robable Percentage
Autism, Childhood disintegrative disorder, Aspergers, Rett syndrome, and Pervasive developmental disorders not otherwise specified	877	877	1	496	56.56
Cardiovascular anomalies	8732	13396	2	4958	37.01
Central nervous system anomalies	1211	1466	1	768	52.39
Chromosomal anomalies	708	718	1	554	77.16
Cleft palate and cleft lip	762	1225	2	681	55.59
Ear, face and neck anomalies	39	40	1	29	72.50
Eye anomalies	111	120	1	68	56.67
Fetal alcohol syndrome	111	111	1	83	74.77
Gastrointestinal anomalies	1802	1836	1	1473	80.23
Genitourinary anomalies	3486	3642	1	2486	68.26
Musculoskeletal anomalies	1240	1377	1	719	52.21
Respiratory system anomalies	94	94	1	51	54.26

Data compiled on 7/18/2011 1:26:17 PM

Appendix F: IDOE data for years 2008-2010 by condition

APC Level 1 - STATE TOTALS (AGES 5B-22) DEC 1 CHILD COUNT (DOE-SE)				
Exceptionality Category	2010 Count (A)	2009 Count (B)	2008 Count	Difference (A-B)
Multiple Disability	1,988	1,890	1,860	98
Orthopedic Impairment	1,524	1,548	1,570	(24)
Blind or Low Vision	951	912	807	39
Deaf or Hard of Hearing	2,186	2,194	1,910	(8)
Emotional Disability - FT	6,710	6,731	6,690	(21)
Severe Cognitive Disability	583	622	651	(39)
Deaf Blind	26	25	18	1
Autism Spectrum Disorder	11,514	10,643	9,726	871
Traumatic Brain Injury	501	525	526	(24)
Totals	**25,983**	**25,090**	**23,758**	**893**

* The increases to the Blind or Low Vision and Deaf or Hard of Hearing Categories is attributed to the 2009 expansion of the APC formula to include students enrolled at the Indiana School for the Blind and Visually impaired and the Indiana School for the Deaf.

APC Level 2 - STATE TOTALS (AGES 5B-22) DEC 1 CHILD COUNT (DOE-SE)				
Exceptionality Category	2010 Count (A)	2009 Count (B)	2008 Count	Difference (A-B)
Emotional Disability - All Other	6,857	7,051	7,578	(194)
Specific Learning Disability	55,316	56,912	59,100	(1,596)
Mild Cognitive Disability	13,101	13,815	14,625	(714)
Moderate Cognitive Disability	3,852	3,931	3,941	(79)
Other Health Impairment	14,091	12,940	11,943	1,151
Totals	**93,217**	**94,649**	**97,187**	**(1,432)**

APC Level 3 - STATE TOTALS (AGES 5B-22) DEC 1 CHILD COUNT (DOE-SE)				
Exceptionality Category	2010 Count (A)	2009 Count (B)	2008 Count	Difference (A-B)
Language or Speech Impairment	71,422	71,485	73,270	(63)
APC Level 3 (cont.) - STATE TOTALS (AGES 3 and up) DEC 2 - DEC 1 CHILD COUNT REPORT (DOE-HB)				
███████████████████████	2010 Count (A)	2009 Count (B)	2008 Count	Difference (A-B)
Homebound Funding Eligibility **	1,810	1,757	1,214	53

**Homebound funding eligibility numbers represent a cumulative total of all students who met the criteria to receive Homebound funding during a one year timeframe (Dec. 2 - Dec. 1).

STATE TOTALS (AGES 5B-22) DECEMBER 1 CHILD COUNT				
APC Category	2010 Count (A)	2009 (B)	2008	Difference (A-B)
APC Level 1 ($8,350)	$216,958,050	$209,501,500	$198,379,300	$7,456,550
APC Level 2 ($2,265)	$211,136,505	$214,379,985	$220,128,555	($3,243,480)
APC Level 3 ($533)	$38,067,926	$39,037,986	$39,699,972	($970,060)
TOTALS	**$466,162,481**	**$462,919,471**	**$458,207,827**	**$3,243,010**

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Appendix G: IDOE Eligibility Criteria for Autism spectrum disorder

Rule 41. **Eligibility Criteria**

511 IAC 7-41-1 **Autism spectrum disorder**
 Authority: IC 20-19-2-8; IC 20-19-2-16
 Affected: IC 20-19-2; IC 20-35

Sec. 1. (a) Autism spectrum disorder is a lifelong developmental disability that includes autistic disorder, Asperger's syndrome, and other pervasive developmental disorders, as described in the current version of the American Psychiatric Association's Diagnostic Statistical Manual of Mental Disorders. The disability is generally evident before three (3) years of age and significantly affects verbal, nonverbal, or pragmatic communication and social interaction skills and results in an adverse effect on the student's educational performance. Other characteristics often associated include the following:
   (1) Engagement in:
      (A) repetitive activities; and
      (B) stereotyped movements.
   (2) Resistance to:
      (A) environmental change; or
      (B) change in daily routines.
   (3) Unusual responses to sensory experiences.
   (b) Autism spectrum disorder does not apply if a student's educational performance is adversely affected primarily by:
   (1) an emotional disability;
   (2) blindness or low vision;
   (3) deaf-blindness; or
   (4) a cognitive disability;
unless the characteristics of autism spectrum disorder are demonstrated to a greater degree than is normally attributed to these disabilities.
   (c) Eligibility for special education as a student with autism spectrum disorder shall be determined by the student's CCC. This determination shall be based on the multidisciplinary team's educational evaluation report described in 511 IAC 7-40-5(e) and 511 IAC 7-40-5(f), which includes the following:
   (1) An assessment of the following:
      (A) Current academic achievement as defined at 511 IAC 7-32-2.
      (B) Functional skills or adaptive behavior across various environments from multiple sources.
      (C) The student's receptive, expressive, pragmatic, and social communication skills that must include at least one (1) of the following:
         (i) An individually administered norm-referenced assessment when appropriate for the student.
         (ii) If adequate information cannot be obtained via an individually administered norm-referenced assessment, a criterion-referenced assessment that:
            (AA) has been designed or may be adapted or modified for use with students who have autism spectrum disorder; and
            (BB) is administered by a professional or professionals with knowledge of assessment strategies appropriate for the student.
      (D) An assessment of motor skills and sensory responses.
   (2) A social and developmental history that may include, but is not limited to, the following:
      (A) Communication skills.
      (B) Social interaction skills.
      (C) Motor skills.
      (D) Responses to sensory experiences.
      (E) Relevant family and environmental information.
      (F) Patterns of emotional adjustment.
      (G) Unusual or atypical behaviors.
   (3) A systematic observation of the student across various environments.
   (4) Any other assessments and information, collected prior to referral or during the educational evaluation, necessary to:
      (A) exclude the disabilities listed in subsection (b);
      (B) determine eligibility for special education and related services; and
      (C) inform the student's CCC of the student's special education and related services needs.
(Indiana State Board of Education; 511 IAC 7-41-1; filed Jul 14, 2008, 1:24 p.m.: 20080813-IR-511080112FRA)

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