The increasing prevalence of autism spectrum disorders

Johnny L. Matson*, Alison M. Kozlowski

Louisiana State University, USA

1. Introduction

Autistic disorder, herein referred to as autism, and the related disorders that comprise the autism spectrum disorders (ASD) are characterized by varying levels of deficiencies in social behavior, communication, and rituals and stereotypies (Eikeseth, 2009; Fabio, Giannatiempo, Antonietti, & Budden, 2009; Matson & Boisjoli, 2007; Matson & Mahan, 2009; Matson & Neal, 2009; Matson, Nebel-Schwalm, & Matson, 2007; Matson & Wilkins, 2007, 2009). Previously believed to be environmentally caused, this group of disorders is now known to have a strong neurodevelopmental component (Lacroix, Guidetti, Rogé, & Reilly, 2009; Matson & LoVullo, 2009b; Niklasson, Rasmussen, Öskarsdóttir, & Gillberg, 2009). These conditions are believed to be present at birth and are diagnosable by 18 months of age (Kuban et al., 2009; Matson, Wilkins, Sevin, et al., 2009; Matson, Wilkins, Sharp, et al., 2009; Watson, Baranek, & DiLavore, 2003). Additionally, the course of ASD symptoms appears to be lifelong, at least for a substantial number of cases (Matson, Mayville, Lott, Bielecki, & Logan, 2003). Finally, deficits in impulsivity (Matson, Mahan, Hess, & Fodstad, 2010), challenging behaviors (Kuhn & Matson, 2002; Matson, Bamberg, Cherry, & Paclawskyj, 1999; Matson & Boisjoli, 2009; Matson, Dixon, & Matson, 2005; Matson & LoVullo, 2009a; Matson, Mayville, et al., 2005; Paclawskyj, Matson, Rush, Smalls, & Vollmer, 2001; Rojahn, Aman, Matson, & Mayville, 2003; Rojahn, Matson, Naglieri, & Mayville, 2004), and psychopathology accompany the ASD in much higher numbers than what is seen in the general population (Holden & Gitlesen, 2009; LoVullo & Matson, 2009). These deficits make it difficult for many with ASD to live independently (Matson, Dempsey, & Fodstad, 2009). Thus, the heightened interest in the study of this topic is understandable.

Recently, there has been great debate over whether or not the prevalence of ASD is increasing (Chakrabarti & Fombonne, 2001, 2005; Herbert, Sharp, & Gaudiano, 2002; Nicholas et al., 2008; Tidmarsh & Volkmar, 2003; Willemsen-Swinkels & Buitelaar, 2002; Williams, Mellis, & Peat, 2005; Wing & Potter, 2002). Once considered rare, ASD is being identified in higher and higher numbers (Mandell, Thompson, Weintraub, DeStefano, & Blank, 2005; Nassar et al., 2009). Early estimates of the prevalence of this spectrum of disorders identified less than 10 in 10,000 individuals as possessing some form of ASD.
2. Prevalence figures

A considerable literature has developed on exactly how frequently autism and ASD occur in the general population. Given that rates are reportedly increasing in the general population, we have chosen to review a sample of these studies in chronological order. They span the time period of 1997 to 2010. A number of countries are represented within this review including the United Arab Emirates, the United States of America, Norway, Canada, Germany, Sweden, France, Iran, Iceland, Finland, Israel, and Britain. However, it should be noted that these studies are not all inclusive and only represent a sample of recent prevalence findings that demonstrate the increases that are presently being observed.

Arvidsson et al. (1997) screened all of the 3- to 6-year-old children, for a total of 1941 children, residing in a community outside Goteberg, Sweden for autism. Prevalence figures of 31 per 10,000 were identified as autistic while 15 per 10,000 were noted to meet many but not all of the criteria to receive a diagnosis of autism. Fombonne, Du Mazaubran, Cans, and Grandjean (1997) assessed 325,347 French children born between 1976 and 1985. They detected a prevalence rate of 5.37 per 10,000 children with autism and 16.3 per 10,000 for all pervasive developmental disorders.

In Northern Finland, Kielinen, Linna, and Moilanen (2000) found the lowest rates of ASD in older children (6.1 per 10,000 for 15–18 year olds). The highest rates were in the youngest age group (20.7 per 10,000 for 5–7 year olds), thereby demonstrating an increase in prevalence over time. Webb et al. (2003) also found rates of 20 per 10,000 in a British sample of 11,692 children. These data are consistent with prevalence rates found in a meta-analysis (Williams, Higgins, & Brayne, 2006). A similar trend was noted in an Icelandic study. A cohort born between 1974 and 1983 had a prevalence rate of 3.8 per 10,000 while a cohort of children born from 1984 to 1993 had a prevalence rate of 8.6 per 10,000 (Magnusson & Saemundsen, 2001). Similarly, in data collected in 1996, Yeargin-Allsopp et al. (2003) reported the prevalence of autism at 34 per 10,000 in a sample of children 3–10 years of age collected in Atlanta, Georgia (U.S.A.).

Fombonne, Simmons, Ford, Meltzer, and Goodman (2001) assessed the prevalence of pervasive developmental disorders (PDD) in a nationwide survey in Britain. A randomized, stratified sample of 12,529 children between 5 and 15 years of age was studied. The investigators identified two girls with Rett syndrome while children with other PDD were identified at 26.1 per 10,000. The authors note that the rates they found were higher than what was noted 30 years earlier. Bertrand et al. (2001), in a study of 8,896 children 3 to 10 years of age (also a 10 year spread as with Fombonne and associates), found much higher rates. They reported 67 cases per 10,000 or approximately 2(1/2) to 3(1/3) times more than what was reported by Kielinen et al. (2000) or Fombonne et al. (2001). However, Bertrand et al. (2001) did note that their prevalence figures were higher than what had been reported in most studies up to that point. Honda, Shimizu, Imai, and Nitto (2005) completed an excellent review of studies from Japan, the United States of America, Canada, the United Kingdom, West Germany, France, Sweden, Norway, Finland, and Israel. They reported a cumulative incidence of autism of 27.2 per 10,000 and make several important points about prevalence studies, which will be addressed later.

In Australia, Williams, MacDermott, Ridley, Glasson, and Wray (2008) reported rates of autism from 2003 to 2004 for 6–12 year olds to be 9.6–40.8 per 10,000. Baird et al. (2006) also found higher rates than in earlier prevalence studies. They studied 56,946 children 9–10 years old from South Thames, United Kingdom. Rates were 38.9 per 10,000 for autism and 77.2 per 10,000 for other ASD for a total figure of 116.1 per 10,000. Eapen, Mabrouk, Zoubeidi, and Yunis (2007) studied 694 three-year olds in the United Arab Emirates. They reported 58 children per 10,000 with autistic features. High prevalence rates have also been noted by Nicholas et al. (2008) who looked at 47,726 children in South Carolina (U.S.A.) who were 8 years old. These authors noted a prevalence rate of 62 per 10,000. Chanzizadeh (2008) reported rates of autism and Asperger’s disorder at 250 per 10,000 when examining a sample of 2000 children in Iran. In perhaps the largest prevalence study to date, Kogan et al. (2009) reported data from the U.S. National Survey of Children’s Health. Children and adolescents from 3 to 17 years of age (N = 78,037) were studied. They reported a rate of 110 per 10,000. Finally, the most recent estimates provided by the Center for Disease Control and Prevention (CDC, 2009) have suggested a prevalence of 90 per 10,000.

While some variability in prevalence figures has occurred over time, what is unmistakable is that the numbers are increasing. We have described here some sample studies in a chronological fashion to give some sense of how these changes appear to be occurring. The fact that the numbers are increasing, that they are increasing rapidly, and that these changes in figures occurred over a relatively few number of years, is not in debate. However, the reasons for these differences have been debated and are sometimes quite contentious. Parent groups have in some instances sided against the scientific community, even in the face of overwhelming evidence. The Measles–Mumps–Rubella (MMR) vaccine debate is one striking example of this situation (Lingam et al., 2003). In our next section we review more plausible explanations for these ever increasing rates. Fombonne (2002) points out that it is hard to pinpoint exact causes of increased rates due to different methodologies and
definitions of ASD across studies. This statement is undoubtedly true. And, in fact, others have made similar points (Baird et al., 2006). However, while specifically how each factor affects rates of ASD may be difficult to pinpoint at this time, there is a good deal of consistency in the potential factors which may impact these changing rates. Increases in prevalence rates have important implications for service providers and for the structure of service provision (Webb, Lobo, Hervas, Scourfield, & Fraser, 1997). However, the issues are varied and complex, and considerable controversy exists as to whether true increases are occurring, and if so, what the causes of these increases are (Newschaffer, 2006). Therefore, looking at these factors in some detail would appear to have merit.

We address these factors next.

3. The changing prevalence

3.1. Diagnostic criteria and assessment

Among one of the most common factors cited for the increase in ASD is the ever changing diagnostic criteria for this spectrum of disorders (Croen, Grether, Hoogstrate, & Selvin, 2002; Fombonne, 2002, 2005; Honda et al., 2005; Lingam et al., 2003; Waldman, Nicholson, Adilov, & Williams, 2008; Williams et al., 2005; Wing & Potter, 2002). Although autism was first discovered by Kanner (1943) and received some attention in the literature at this point, formal diagnostic criteria for ASD did not emerge until the publication of the Diagnostic and Statistic Manual of Mental Disorders, Third Edition (DSM-III; American Psychiatric Association [APA], 1980). Therefore, all diagnoses made prior to this publication were not assigned according to the same, if any, set criteria. Following this initial classification system, ASD criteria were then modified and expanded throughout the successive versions of the DSM (APA, 1987, 1994) up until its current issue, the DSM-IV-TR (APA, 2000). Throughout these updated classification editions a number of changes occurred including what diagnoses were categorized as ASD, symptom inclusion, the number of symptoms needed for a diagnosis, and age of onset criteria. These periodic revisions resulted in studies utilizing different criteria when assessing the prevalence of ASD, thus increasing the possibility for a misinterpreted increase (Williams et al., 2005; Wing & Potter, 2002).

Furthermore, the International Classification of Diseases series is another popular classification system that possesses separate diagnostic criteria from most of the DSM. In fact, the criteria set forth in one version of the DSM in particular, the DSM-III-R (APA, 1987) was decidedly different from that which was presented in the International Classification of Diseases (10th Edition; ICD-10) (World Health Organization [WHO], 1992), which was also commonly used for diagnosis and classification of mental illnesses at the same time (Tidmarsh & Volkmar, 2003). Fortunately, the criteria set forth in the DSM-IV (APA, 1994) and DSM-IV-TR (APA, 2000) were found to be comparable to those set forth in the ICD-10 (WHO, 1992), which may have led to more consistent diagnoses world-wide. Although not yet published, the task force has already begun to develop the newest version of the DSM to be released in 2013 (APA, 2010). Proposed changes with respect to ASD include a complete removal of Rett’s Disorder and collapsing the remaining four diagnoses into one – ASD. Socialization and communication deficits will be combined into one set of symptoms with endorsement of all three symptoms (i.e., deficits in verbal and nonverbal communication during social interactions, lack of social reciprocity, and inability to develop and maintain developmentally appropriate peer relationships) being required for a diagnosis of ASD. Additionally, individuals will need to meet two of the following three restricted and repetitive behaviors, interests, and activities criteria: stereotyped verbal, motor, or other sensory behaviors; adherence to routines or ritualized patterns of behavior; and restricted interests. Finally, the age of onset criterion will be expanded to include early childhood in general. Such changes will no doubt further impact the prevalence of ASD.

However, the changes to occur may actually go in the opposite direction of the trend to date, with many individuals becoming seemingly cured of an ASD despite still evidencing significant impairments that would have previously warranted a diagnosis. Some have suggested that symptom severity may have led to more consistent diagnoses world-wide. According to Coo et al. (2008), they report that 1/3 of the diagnoses of autism from 1996 to 2004 may not have emerged until the publication of the DSM-IV-TR (APA, 2000). In fact, King and Bearman (2009) calculated rate changes of ASD with changes in diagnostic criteria in the state of California (U.S.A.) between 1992 and 2005. They estimate that 26.4% of cases can be directly attributed to this factor. Further support for this hypothesis is provided by Coo et al. (2008). They report that 1/3 of the diagnoses of autism from 1996 to 2004...
in British Columbia, Canada resulted in a switch from a diagnostic category other than autism to autism, a phenomenon referred to as diagnostic substitution (see Shattuck, 2006 for an excellent in depth review of this topic). Nassar et al. (2009) also report diagnostic substitution. They note that as incidents of severe intellectual disability decreased in the state of Washington (U.S.A.), rates of autism increased.

3.2. Inaccurate diagnosis

Another potential cause of increased prevalence can be linked to inaccurate diagnosis. Barbaresi, Colligan, Weaver, and Katusic (2009), for example, found a 22.1-fold increase in clinically derived diagnoses of ASD from 1995 until 1997. However, for research-identified ASD the increase was 8.2-fold or almost a third of the clinically derived diagnoses. Clinically derived diagnoses are often made following brief observation using DSM or ICD guidelines but not with systematic testing. However, even when tests are employed, they may vary widely in which test or tests are used as well as in who the respondents are (Posserud et al., 2009). Additionally, a range of clinicians including clinical psychologists, school psychologists, psychiatrists, and neurologists may conduct these evaluations. The amount of experience and training they have with ASD children varies widely. Thus, inconsistent diagnoses should not be surprising. Conversely, those employing research criteria would more likely employ homogenous protocols with a standard test battery conducted by professionals with specific training and experience in ASD. It is interesting to note then that the research diagnoses would likely be more accurate and that less accurate diagnoses result in higher reported rates of ASD.

Leonard et al. (2010) further point out that in the current climate, a child with ASD and intellectual disability is more likely to receive an ASD versus intellectual disability diagnosis than in the past. More resources and attention are now focused on ASD which may further account for this phenomenon. Furthermore, and in line with Barbaresi et al. (2009), Leonard et al. (2010) stress that an ASD diagnosis can be difficult and can lead to confusion in the diagnostic process due to overlapping symptoms between ASD and other conditions such as communication disorders. Given the difficulty and expertise required to arrive at accurate diagnoses, researchers and policy makers should be particularly cautious about reliance on data sets where children are identified as having ASD based on administrative diagnoses and clinical reviews, data abstracted from existing records, or client registers from regional centers (Hillman, Kanafani, Takahashi, & Miles, 2000; Pinborough-Zimmerman et al., 2010). These data may be over or under representations (Lauritsen, Pedersen, & Mortensen, 2004).

3.3. Research methodology

Prevalence estimates are derived in a number of ways including using data from registrars, retrospective accounts, telephone interviews, and whole-area surveys. Clearly, differences among research methodologies would inevitably result in differences in prevalence estimates. Fombonne (2002) asserts that the research conducted to date with respect to increases in prevalence over time cannot be viewed as evidence either for or against an increase because different diagnostic criteria and assessment methods were utilized across studies. In the most recent study conducted by the CDC (2009), different records were available dependent on the individuals being assessed with some only having medical records available while others also had accessible education records. Such a difference resulted in higher prevalence rates in the regions with access to both medical and education records. Therefore, it appears obvious that rates would differ for similar reasons across studies if such differences occurred within the same single study.

Finally, autistic regression is important to consider when very young children are assessed. Thus, if data are on children under the age of 3 years, then actual numbers later in childhood are likely to be higher (Matson & Kozlowski, 2010). Also, one aspect of many prevalence studies involves the age range studied. Nicholas, Carpenter, King, Jenner, and Charles (2009), for example, only looked at children who were 4 or 8 years old. They found rates of 80 per 10,000 for each year. Williams et al. (2008), on the other hand, evaluated children 6–12 years of age. Extrapolating from the Nicholas et al. (2009) data would need to multiply the 80 by 8 (years). Thus, their 6 to 12 year old cohort would result in a rate of 640 per 10,000.

3.4. Environmental components

Environmental insult has also been hypothesized as a cause for ASD. The MMR vaccine and the now notorious findings reported by Wakefield et al. (1998) assert that patchy chronic inflammation in the colon of 11 of the 12 children studied could result in developmental delays. While most observers know this paper for the declaration that these physiological effects could cause autism, the authors also claimed that the MMR vaccine could lead to other “behavioral disorders” as well, including disintegrative psychosis and encephalitis. These findings have been debunked (Taylor et al., 2002) and The Lancet recently retracted the paper, making international news. However, belief by many parents that the vaccine causes autism will just not go away (Waterhouse, 2008). Others have been more blunt about the general public’s understanding of the actual versus misattributed factors leading to the “epidemic” of autism cases. Gernsbacher, Dawson, and Goldsmith (2005) assert that public belief in unfounded factors is an “uncritical acceptance of illogical sources” and due to a lack of awareness with respect to true causes. Having said that, children with ASD are in fact at high risk for chronic gastrointestinal symptoms (Molloy & Manning-Courtney, 2003).

Additionally, major improvements in perinatal and neonatal care have resulted in much greater survival rates for premature infants. These babies evince neurodevelopmental disorders, including autism, at much higher rates than the
general population (Limperopoulos, 2009). Johnson et al. (2010) found similar results in 11-year-old children who had been born extremely premature with these children presenting with ASD more frequently than regular term children. Perinatal risk factors and high rates of neonatal hospitalization have also been suggested as possible causes of ASD (Guillem, Cans, Guinchat, Ratel, & Jouk, 2006). Kinney, Miller, Crowley, Huang, and Gerber (2008) have even suggested that tropical storms and hurricanes may cause autism by disrupting development during sensitive gestational periods. Sikora, Petit-Kekel, Penfield, Merkens, and Steiner (2006) found that in 14 children, 3–16 years of age with Smith–Lemli–Opitz Syndrome, all had an ASD (autism or PDD-NOS). Finally, while not known at this time, some have posited that toxic chemicals or metals could cause autism (Grether, 2006). However, none of these possible environmental causes have been validated to date (Fombonne, 2008; Wing & Potter, 2002).

3.5. Cultural factors

Kamer et al. (2004) and others note that rates of ASD have risen dramatically in the West over the last decade (now over a decade and a half) (Bresnahan, Li, & Susser, 2009; Charman, 2002; Senecky et al., 2009). Our previously reported data underscores the fact that these prevalence rates have risen dramatically in most of the developed nations (e.g., Nassar et al., 2009; Newshaffer, Falb, & Gurney, 2005; Plubrukarn, Piyasil, Moungnoi, Tanprasert, & Chutchawalitsakul, 2005; Yeargin-Allsopp, 2002). Kamer et al. (2004) make a good point in their study which demonstrated that Israeli born children evinced higher rates of ASD than Ethiopian born children. Furthermore, Israeli children of Ethiopian extraction evinced rates of ASD at much higher levels than the children born in Ethiopia. Thus, acculturation and related social factors appear to play an important role in the identification of children with ASD and thus overall reported rates of the disorder. Others have gone further and have suggested that ethnic bias on the part of the majority culture may account for these diagnostic differences (Begeer, El Bouk, Boussaid, Terwogt, & Koot, 2009). This factor may be true in some cases but it does not account for the data of Kamer et al. (2004).

Sun and Allison (2010) suggest that ASD is a relatively new concept in the Eastern world. They reviewed epidemiology studies that had been conducted from 1971 to 2008 in six Asian countries (China, Japan, Indonesia, Israel, Iran, and Taiwan). They noted considerable variability across countries, but overall, they note a general increase in prevalence rates over time (see also Lin, Lin, & Wu, 2009). Thus, in line with Kamer et al. (2004), some of the differences may be by country, groups of countries, or ethnic groups. However, despite the discrepancies between these Asian countries, all cultures studied demonstrated increased prevalence over time.

3.6. Awareness

Another noteworthy factor to consider when reviewing research demonstrating increases in the rates of ASD is the substantial increase in autism awareness and service provision in recent years. As ASD are frequently discussed in the media, especially with the concern over vaccinations being the cause or trigger of such disorders, parents are becoming more aware of ASD (Wing & Potter, 2002). This increased awareness may lead parents to have their children assessed when they may have not previously done so. Additionally, since services have simultaneously increased and improved with this awareness, an ASD diagnosis may now also be more accepted by both parents and clinicians. Furthermore, Ouellette-Kuntz et al. (2007) suggest that this development may contribute to ensuring that ASD are not under diagnosed. Finally, Gurney et al. (2003) note that changes in federal law and findings in the U.S. appear to have resulted in marked increases in ASD diagnoses.

4. Conclusions

Reported rates of ASD have been growing steadily for years. Additionally, there appears to be no end in sight with respect to these growing numbers (Hertz-Picciotto & Delwiche, 2009). Some authors attribute the bulk of the change to differences in criteria and efforts to make ASD a higher priority when multiple diagnoses are present (Hertz-Picciotto & Delwiche, 2009; Wing & Potter, 2002). Others are more of the opinion that a multitude of factors impact increased prevalence (Bearman & King, 2009). And still others focus on a few, but not all factors. For example, Wazana, Bresnahan, and Kline (2007) assert that broadening diagnostic criteria, making diagnoses at younger ages, and improving efficiency of case ascertainment are the primary factors resulting in these changes. Obviously, more research directly testing these hypotheses is needed. However, despite there being a lack of concrete answers regarding the rise in prevalence of ASD, some opinions can be offered based on the current literature.

First, there is no doubt that current ASD prevalence estimates are significantly higher than those that had been found in previous years. However, though a portion of this documented increase may be attributed to a true increase in the prevalence rate, it is doubtful that such a significant increase actually occurred. It is not a mere coincidence that utilizing different diagnostic criteria provides researchers with varying numbers. As was previously described, the relatively frequent change in diagnostic criteria appears to be at the core of the increasing prevalence of ASD. Such changes may have also allowed for inaccurate diagnoses to have previously occurred. Therefore, current studies are not comparable to those that had been conducted previously which had found lower rates of ASD. Without controlling for the changes in diagnostic criteria, researchers simply cannot make such claims that increases are being observed. Furthermore, the increased awareness of ASD has drastically changed not only the assessment process, but also who seeks out such assessments. The media has exploded...
with references to ASD assessment, treatment, and awareness in general. With this boosted awareness have come greater resources for testing children with assessment now being available for children as young as 1.5 years of age. As such, more and more parents are having their children assessed who may not have previously done so.

Although true increases, different research methodologies, cultural factors, and environmental contributions may also play a role in the significant increases seen within recent years, it appears the changes in diagnostic criteria and increased ASD awareness have had a stronger impact on the field. Variations in research methodologies are going to be seen across a multitude of studies and are not specific to ASD research. Therefore, it is unlikely that this factor alone would have raised the prevalence to such degrees. Although cultural factors may explain variations seen across cultures and regions of the world, they do not explain the observed increase seen within cultures and regions. Finally, thought environmental components do exist, research is lacking with respect to its influence.

Clearly, more researched is needed but this is not to say that conducting numerous prevalence studies will assist in solving the current debate. Research needs to be conducted using as uniform diagnostic criteria and assessment instruments as can be managed. Unless researchers are able to control for previously used diagnostic criteria, comparisons to previous prevalence estimates hold little information. Therefore, to solve this debate, researchers are encouraged to standardize their diagnostic criteria and attempt to determine prevalence estimates in the past using the current diagnostic system. Furthermore, those researchers presently attempting to determine prevalence estimates may wish to simultaneously assign diagnoses based on the prospective ASD diagnostic criteria, thus allowing for a comparison across diagnostic systems. Unfortunately, many other possible contributing factors, such as increased ASD awareness, may be more difficult to control in prevalence studies. However, if controlling for the multitude of potential factors influencing the perceived increase in ASD is not attempted, the rates of ASD will continue to rise without known cause.

References


