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Wolgemuth

Chemistry

### The Effects of Autism on the Individual and their Family

1. Provost, Beth, Brian R. Lopez, and Sandra Heimerl. "A Comparison of Motor Delays in Young Children: Autism Spectrum Disorder, Developmental Delay, and Developmental Concerns." *Journal of Autism and Developmental Disorders* 37.2 (2007): 321-28. UNM Center for Development and Disability. University of New Mexico Center for Development and Disability. Web. 12 Dec. 2010.  
<<http://cdd.unm.edu/ec/pubs/pdfs/comparisonofmotordelays.pdf>>.
  - a. This is the lab report from a study on kids 21-41 months old with autism spectrum disorder (ASD). It assessed their motor skills and compared the data to kids without ASD who were also experiencing motor delay. It looked at three groups: kids with ASD, kids with developmental delays, and kids with developmental concerns with no motor skill delays. The scientists used the Bayley Scales of Infant Development-2<sup>nd</sup> Edition to test motor skills. This test scores kids on 3 scales, a mental scale, a motor scale and a behavior rating scale. They also used the Peabody Developmental Motor Scales-2<sup>nd</sup> Edition test which has 6 scales: reflexes, stationary balance, locomotion, object manipulation (can they squeeze a ball), grasping skills and visual-motor integration (hand-eye coordination). The Bayley Scale test showed that 84% of the kids with ASD were classified as significantly delayed. The Peabody test showed a majority of the kids with ASD were below average or worse. The study concluded by stating that the research showed that although motor skill delays aren't used to diagnose ASD, all the kids with

ASD showed motor skill delays and therefore kids with ASD should be tested for motor skill problems. The study also concluded with saying that motor skill delays in children with ASD wasn't any different than motor skill delays in kids with other developmental disabilities.

b. I found this article interesting because it addressed possible delays experienced by autistic kids that haven't previously been studied. They didn't used to associate motor delays with autism but now this study proves there is a correlation. If I am aware that my cousin Owen, who is only 6, has motor skills delays, than it could help me give him instructions he could follow or understand his limitations. I liked learning about what the different tests measured because usually you just hear that kids are diagnosed with something, not how they are diagnosed. Some of the specific point differences in the data tables I didn't quite understand, but the percentages of where kids ranked were easy to understand. The study also made me realize the gravity of Autism or ASD because it really affects many areas of a kids life. This article also directly answered my question of what effects Autism had on the individual.

c. My article was published in 2006 right after the study was done, so it was covering recent discoveries and took into account all data available at the time. Although the study wasn't done this year, it is still very relevant because data about Autism hasn't changed much in the last decade. If the article had been from before 2000, I would have known it was outdated. The date proves my article credible, as does the authors. One author, Beth Provost has a PhD in Psychological Foundations of Education from UNM, works for the University of New Mexico (UNM) as an associate professor. She is also a physical therapist, so she works with people with motor skill delays and is knowledgeable on the

subject. Plus, one of her many research articles won an award as the best article in Pediatric Physical Therapy, an international journal. She has been published by many respected science journals. Another author, Brian R. Lopez has his PhD from the Department of Pediatrics at UNM and also works there. Plus, he has his MD so he is qualified to be doing medical research. The final author, Sandra Heimerl, is a discipline coordinator for the LEND program at the UNM and has a Bachelor of Science, Certificate in Physical Therapy from University of Michigan, and a Master in Science from the University Wisconsin. This article was published from a credible source, The Journal of Autism and Developmental Disorders which is a scholarly, peer-edited journal that specializes in my topic, Autism. Plus their website describes the journal as “the leading peer-reviewed, scholarly periodical focusing on all aspects of autism spectrum disorders and related developmental disabilities.”

2. Meadan, Hedda, James W. Halle, and Aaron T. Ebata. "Families with Children Who Have Autism Spectrum Disorders: Stress and Support." *Exceptional Children* 77.1 (2010): 30-37. *ProQuest*. Fall 2010. Web. 2 Dec. 2010.

a. This article uses many research articles from the last decade that were published in peer-edited science journal and based on studies to draw conclusions about the effect of autism on the autistic child's family. A study by Risdal and Singer in 2004 found a negative impact on parents, and so did a study by Higgins in 2005. Higgin's study reported that parents of kids with ASD had “lower levels of marital happiness, family adaptability, and family cohesion” meaning that the families of autistic kids aren't as flexible or as connected as the families of other kids. Other studies found out family

harmony was lower in parents of autistic kids compared to parents of kids with other types of developmental disabilities. A study by Benson in 2006 also showed that parents of kids with ASD had more stress and were susceptible to depression or other mental health problems. Another study found that contributing factors to stress are how permanent the condition is, whether other family members accept it or not and what level of support the parents receive. Many studies show that mothers experience more stress from parenting a child with ASD because they take on more responsibilities than fathers do. Some studies have even found that parenting a kid with ASD can have a positive effect on fathers. However, the more time spent caring for the child, the more stress fathers usually had. There have been mixed results on the effect on the siblings of a kid with Autism. Some studies show negative effects, and some positive effects. However, even studies that show positive effects report that siblings still experienced stress from the relationship. Most studies show that siblings of kids with ASD have more problems when they were part of a small family, there was marital stress or the kids with ASD had problem behaviors.

b. I found this source very interesting because as I spend a lot of time with not just my cousin, but his 3 siblings and his parents, I wanted to know what effect he was having on them. I thought it was interesting that the study found that they were usually more of a negative impact on mothers, because my uncle always seems more stressed out than my aunt. I think the study is probably right; it's just that my uncle is more susceptible to stress. I have definitely seen my aunt and uncle's stress levels rise since they found out Owen had autism, which I think is a pity because sometimes I worry they will miss out on the positive things in life, and all the things Owen does well at. Owen has two older

brothers and a younger sister, so I was glad to find out that since they are a larger family there is less chance of a negative impact on my other cousins. I also found the article interesting because I feel like often the family members of people with health problems are overlooked in studies and I feel like their needs must be addressed. For example, I can see clear effects of how my aunt with Down Syndrome has affected my other aunts and uncles and my sister's hip injury definitely impacted me.

c. This article is credible because it was published just a few months ago this fall and therefore took all recent discoveries into account when drawing conclusions about the effect of autism on the family. The studies talked about in the article are also all fairly recent, and are looking at autism from a modern perspective. The authors also make the article credible. Hedda Meadan graduated from Illinois State University with a PhD in special education and is a consulting editor of a peer-edited journal called "Focus on Autism and Other Developmental Disabilities." If she edits a magazine, she has to pick out credible articles herself, and would write a credible article. She also works as an assistant professor of special education at Illinois State University and has researched social and communication behavior of kids with disabilities. She has a background in kids with disabilities, which is what she is writing about in this article. Another author, James W. Halle, used to be an editor of the Journal of the Association for Persons with Severe Handicaps and right now he is the Associate Editor of the Journal of Applied Behavior Analysis. He is credible enough that he has been hired by scholarly journals to pick out other relevant articles. He also has a background in the field of autism and developmental disorders because he has a PhD in special education from The University of Illinois and teaches there as a professor. The last author, Aaron T. Ebata also works for

the University of Illinois and has been published by other scholarly peer-edited journals like the Journal of Applied Developmental Psychology, so he has checked out to be credible according to the scientists who edit the magazine. The journal this article comes from also proves its credibility. Exceptional Children has been published for over 65 years and has published many pioneering research articles. It is a peer-reviewed journal that only publishes original research on the development of infants, children and youth. It is an official quarterly publication of the Council for Exceptional Children. Its website calls it “the most respected scholarly journal in special education.” Such a prestigious, respected journal is a very credible source.

3. Bilgin, Huyla, and Leyla Kucuk. "Raising an Autistic Child: Perspectives From Turkish Mothers." *Journal of Child and Psychiatric Nursing* (2010). ProQuest. 2 Dec. 2010. Web. 09 Dec. 2010.

a. The article described the disease of Autism. It hurts a child’s ability to socially interact, inhibits their imagination, communication skills and causes unusual behavior habits. These behaviors impact every part of a kid’s life, including their daily living skills, relationships with their family and their home life. This study’s purpose was to investigate the effect on mothers by structuring interviews with 42 mothers from Turkey. Their children ranged from 6-17 years old with a mean age of 9. They asked questions about the mother’s role in the family, what they found stressful about parenting, their expectations for the future and for their child, what supportive services they received, and their general experiences. They then organized the data and grouped it using common

themes and calculating the percentage of mothers with similar experiences. Over all, the study showed that mothers felt burdened by their autistic child and experienced high stress. 44% of the mothers said they had trouble fulfilling their “role” in the family and needed more support from their husbands. Almost half of the mothers experienced stress from trying to treat the illness and frustrations that there wasn’t a cure. Only 23% of mothers said their families supported them in their struggles and disappointment with life was reported by 11.6% of them. Many stated that support from other mothers in similar situations substantially helped. 18.6% experienced grief and talked of depression. 14% went through shock and denial after hearing the diagnosis. 46.6% of them could only imagine a future linked to autistic children. Many felt ostracized by society and felt that others didn’t understand their child’s needs. 21% of mothers felt they didn’t have any support, although most said they received some financial support from their families. After analyzing the data, it was clear that the effect on mothers is great, and requires support from healthcare organizations and family members as well as society in general. It was also concluded that parents need training programs conducted by professionals and the need for education is significant.

b. One thing I found interesting in reading this source is that it was set up similarly to our lab reports. It was much longer, but followed a similar structure of methods, discussion, background information etc. I was surprised to learn how little support was given to parents, but I think this might have been because the study was done in Turkey. However, the underlying conclusion, that such support is necessary, seems very true to me. Support for the child is commonly found, but you don’t always find support for the emotional stress and marginalization the parents go through. I can’t imagine what it would be like to

not have the support of my family. I know my aunt and uncle would have a lot more trouble if they didn't have so much support. Even my grandma from the other side of my family helped my aunt figure out what therapies to do and how to approach raising Owen. The data makes me feel grateful for my family, which I know will always support me. I was also struck by the plight of mothers of autistic kids and all that they have to go through. This article is also useful because it gives us specific strategies to help the problem: increased education and support systems, and training programs so parents know what to expect.

c. This article is very credible. This article doesn't need a very recent date, because it is not detailing recent discoveries or findings and the experiences of mothers have not changed much in the last few years. However it was published very recently, this December, which improves its credibility because it means that all recent studies will be taken into account and that the study will reflect the current situation for mothers. Also, the author's are all qualified and credible. The first author, Bilgin, Huyla has her PhD and is a registered nurse. She is Assistant Professor at Istanbul University in Turkey. The other author, Leyla Kucuk, also has a PhD, a RN degree and is an Assistant Professor for the Department of Psychiatric Nursing and went to the Florenc Nightingale School of Nursing. Obviously, both authors have a background in the medical field, psychiatry and know the area they are studying in, Turkey. The journal is also highly credible. It is the official journal of the Association of Child and Adolescent Psychiatric Nurses (ACAPN) Division of the International Society of Psychiatric-Mental Health Nurses (ISPN). The sponsors of this journal increase its prestige and credibility. It is a primary resources for profesionales in the field. The journal only includes peer-reviewed scientific articles.



According to their website, it is also “the only nursing journal to focus exclusively on issues of child and adolescent mental health around the world.”

4. Smith, Laura O., and Jennifer H. Elder. "Siblings and Family Environments of Persons with Autism Spectrum Disorder: A Review of the Literature." *Journal of Child and Adolescent Psychiatric Nursing* 23.3 (2010): 189-96. *ProQuest*. Web. 2 Dec. 2010

a. This is a literature review that combines studies of kids with siblings with ASD to try and come to conclusions of the literature and see what needs to be studied next. Scientists systematically looked through research from the past ten years in peer-edited journals and picked out the 12 best studies to answer questions about sibling behavior, relationships and adaptation. A study by McCubbin, Thompson, and Kaston in 1993 showed that siblings may be at more risk for problems depending on their cultural background because different cultures used different coping methods. For example, parents who spoke English as a second language turned to religion as their main form of support more than verbal praise. Studies also show that there are some positive effects of having an autistic sibling. When families gathered resources and worked together they became closer and found greater meaning in their lives. However, some negative responses included money problems, fights for healthcare coverage, behavior problems, delays in career plans for parents and concerns about the child's future. Positive effects on siblings were noted in some studies. Studies about sibling behavior showed that siblings of kids with ASD had more self-confidence than sibling of kids with other disabilities. A study from 2007 created criteria to test the susceptibility of siblings for mental health problems

and indicated that because of the sense of responsibility many siblings feel for their brother/sister, negative effects on the siblings social life, and because of being exposed to scary, strange behavior that may be violent, kids were more likely to have mental health problems. Another study found that siblings were able to cope well if their parents adapted well. Studies also concluded that older siblings were closer to their ASD sibling and adapted better than younger siblings. A 2006 study showed that most siblings, 84% reported at least one aggressive incident between them and their sibling. Also, comparisons of behaviors of siblings of ASD kids and siblings of normal kids showed that their behavior was 40% worse and the differences in behavior is enough to conclude that siblings of ASD kids need attention to address behavior problems. The article concludes by saying that further studies are needed to identify useful coping strategies for siblings and effective treatment plans. The article also concluded that siblings of those with ASD are at risk for negative health problems.

b. This article seemed to agree with other studies I have looked at that concluded that having an autistic family member can have negative effects. The only positive aspect was higher levels of self-esteem, which makes sense to me because kids would compare themselves to their sibling and see themselves as more talented. The conclusions shocked me because there were so many negative impacts. The data showing higher chances of mental illness and behavior problems make me concerned for my cousins that don't have Autism but are affected by it. I don't want them to end up with problems. What encourages me is that my cousin Owen is functioning well, doing well in school and relates to people better than most kids with Autism, so hopefully there will be less negative effects on his siblings. I also know that Owen isn't prone to violent behavior as

described by some of the studies. The reports of violent behavior did remind me of one of the kids in my neighborhood. He is a 3<sup>rd</sup> grader and has a younger brother with Autism and talks of him being violent and hitting him. He also talked about how his parents didn't give him much attention. I feel like just from the brief talks I have had with him, he has already experienced negative impacts because of his brother. My cousins don't seem to have any behavior problems influenced by Owen, but I do feel like sometimes the middle cousin may get less attention and feel a little neglected. Overall, I found this source very interesting and I feel like it shows how we need to do more to help the families of individuals with Autism or ASD. I also found it interesting that even though this article was technically a review of other data, it was still set up like an investigation and went through the whole scientific process before drawing conclusions.

c. This article is from August 2010 making it credible because all recent discoveries can be taken into account. It is also important in this case because the investigation included pieces of data from the last few years, and since it was recent, that meant that the scientists could eliminate data that was no longer relevant or true so only the most credible, relevant sources were left. The authors also prove the article's credibility. One author, Laura O. Smith is a nurse practitioner which means she is highly educated in the medical field and would know the proper background information. She also is a PhD student in the College of Nursing for the University of Florida in Gainesville. The other author, Jennifer H. Elder, is qualified because she has a PhD, RN, FAAN and is Professor/Associate Dean for Research College of Nursing, part of the University of Florida. Both authors clearly have a background in the field and experience in medical research, improving the credibility of my source. The journal is also very credible. I used

the Journal of Child and Adolescent Psychiatric Nursing for this article too. It is the official journal of the Association of Child and Adolescent Psychiatric Nurses (ACAPN) Division of the International Society of Psychiatric-Mental Health Nurses (ISPN). The sponsors of this journal increase its prestige and credibility. It is a primary resources for professionals in the field. The journal only includes peer-reviewed scientific articles. According to their website, it is also “the only nursing journal to focus exclusively on issues of child and adolescent mental health around the world.”

5. Rellini, E., D. Tortolani, S. Trillo, S. Carbone, and F. Montecchi. "Childhood Autism Rating Scale (CARS) and Autism Behavior Checklist (ABC) Correspondence and Conflicts with DSM-IV Criteria in Diagnosis of Autism." *Journal of Autism and Developmental Disorders* 34.6 (2004). *SpringerLink*. Springer, Part of Springer Science+Business Media, Dec. 2004. Web. 2 Dec. 2010.

a. The purpose of this study was to determine whether the Childhood Autism Rating Scale (CARS) and the Autism Behavior Checklist (ABC) are good tests for screening autism and to see if they fit the DSM-IV criteria. Effects of Autism start to be seen before the child reaches 3 years of age. Autism hurts an individuals ability to interact socially, to communicate, and is usually characterized by repetitive patterns of behavior and limited interests and activities. The scientists hypothesized that CARS would turn out to be more accurate because of a previous study done in 1993 by Eaves and Milner which found such results. 65 kids were involved in the study from ages 18 months to 11 years old, with a mean age of 4.9 years. The study took place in Rome. All of the kids were tested using CARS and ABC after being diagnosed by doctors. CARS tests 15 categories:

imitative behavior, relating to people, emotional response, body use, object use, adaptation to change, visual response, listening response, perceptive response, anxiety, verbal communication, non-verbal communication, activity level, intellectual relations, general impressions. The scale for each category goes from 1 to 4 with 1 being age-appropriate behavior. Then the items are added together, with a score of above 30 diagnosing autism. ABC lists 57 typical autistic behaviors in 5 areas: sensory, relating, object use, language, and self-help and social. The score is determined by adding up the severity of each behavior, with a score of 53 or above indicating autism. The DSM-IV criteria diagnosed 54 with Autism and 9 children with ASD. All 54 children diagnosed as autistic by the DSM-IV criteria were also diagnosed autistic by CARS. However, only 29 were diagnosed autistic by ABC. This meant CARS had a sensitivity of 100% but ABC had a sensitivity of only 54%, meaning almost half were misdiagnosed. Both tests did not successfully differentiate between Asperger's Disorder and other developmental disorders, but this was attributed to the fact that Asperger's Disorder was not included in the autistic spectrum when the tests were created. The scientists concluded that CARS is an accurate test and can be used to do more research on Autism.

b. I found this source interesting and relevant. Although it was talking more about testing strategies than the direct effects of Autism, the descriptions of the areas kids are tested in lets you know the effects of Autism. It really is surprising to find out how many areas are affected. From body language to fear/anxiety to how well kids interact with objects, Autism really affects all parts of a kid's life. It lets you know the gravity of the situation and how serious this disease is. I was also surprised to learn that a test, ABC, which was being used by professionals didn't actually work. It lets you know that even if doctors or

others pretend like everything is fact, in fields like Autism that are still being studied, there can often be errors or things that go wrong. It's a serious problem that some of the tests don't work because then kids who need help won't get it. Misdiagnosis is a big problem in this field. If parents could accurately assess their child's behavior and intervene early, their kids could make huge improvements. Even though Autism is not fatal like cancer and doesn't require immediate attention, early diagnosis is really important to help improve the child's life. Catching the problem early is the best way to solve it. I know it has helped my cousin Owen a lot because he has gone to a lot of therapists and now is able to function in a regular kindergarten class. I have been able to personally see how much progress he has made in communication skills, as well as seen how smart he is. He started to read and recognize words before kindergarten! Plus, he could already do math problems I couldn't do at 5.

c. This article is very credible. The date is recent enough for the article to be credible, 2004. No major changes to the DSM-IV have been made that would affect the results of the study and no new studies have disproved this. The information is still valid and true. In fact, it is probably the most recent study on CARS and ABC because it isn't something often examined. From what I can tell the authors are credible. All the authors are affiliated with an Italian hospital named Ospedale Pediatrico Bambino Gesù, or the Mission Pediatric Hospital of the Child Jesus in English. This means they have a background in the field they are studying and are qualified, credible authors. However, I wasn't able to find any more information about the authors because they are from Italy and information about them was written in Italian, which I can't read. I found the hospital they were associated with from the article. Even though I couldn't verify the author's

credibility, I still feel confident using this source because the journal it comes from is very credible. It does make me a little nervous about the qualifications of the authors. The Journal is also very credible. The Journal of Autism and Developmental Disorders is a respected Journal with an editor who is a graduate of Yale University of Medicine. It has been published for over 30 years since 1971 which means that it has stood the test of time and proved reliable. The journal's website called it "the leading peer-reviewed, scholarly periodical focusing on all aspects of autism spectrum disorders." This means that not only is the source a credible journal, it also specializes in the subject I am studying, Autism, making it especially relevant for my source.