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## Developing a Data Compilation for the Marin Autism Collaborative

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Developing a Data Compilation for the Marin Autism Collaborative

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A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree Master of

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School of Health and Natural Sciences

Dominican University of California

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This thesis, written under the direction of the candidates' thesis advisor and approved by the Chair of the program, has been presented to and accepted by the Faculty of the Occupational Therapy department in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy. The content, project, and research methodologies presented in this work represent the work of the candidates alone.

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## Abstract

There is a documented need for better services for those with autism spectrum disorders. Various barriers, such as availability and accessibility of services and financial barriers, prevent those who need services from obtaining them. According to the literature, using data, particularly population level data, leads to improved services. Understanding the effectiveness and ineffectiveness of services helps healthcare providers identify areas for improvement and/or capitalize on past successful methods. The purpose of this project was to provide a data compilation containing autism statistics including but not limited to prevalence, trend data, service use, and needs for the Marin Autism Collaborative (MAC). The compilation is meant to aid the various organizations that comprise MAC in improving existing supports for the autism community to better meet this population's needs. The presented data compilation follows the trend in data-driven service development, while taking an occupational justice perspective on the various trends in autism data at the county, state, and national levels. In addition, it highlights the gaps in current autism statistics. A survey including a Likert scale and open-ended questions was sent to MAC agencies to evaluate the data compilation, the results of which were overall positive.

DEVELOPING A DATA COMPILATION FOR THE MARIN AUTISM  
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## **Introduction**

Approximately 36,500 of every four million children born each year in the United States will be diagnosed with an autism spectrum disorder (Centers for Disease Control and Prevention [CDC], 2009). Furthermore, the prevalence of autism spectrum disorders (ASD) is rapidly growing each year. The aforementioned statistic, in fact, is based on an earlier prevalence, meaning that a larger number of children from each birth cohort will be diagnosed with an ASD. Statistics from the U.S. Department of Education and other government agencies indicate that autism diagnoses are increasing at the rate of 10 to 17 percent per year (National Human Genome Research Institute, 2012). Currently, about one in 88 children have been identified with an ASD according to estimates from the Centers for Disease Control and Prevention's (CDC) Autism and Developmental Disabilities Monitoring Network (CDC, 2012). Also according to the CDC (2011), ASD is almost five times more common among boys (one in 54) than among girls (one in 252). Compared to data from the last decade, the prevalence has increased from one in 150 in the year 2000, to one in 125 in 2004, and to one in 110 in 2006 (CDC, 2012). Additionally, the growing prevalence of autism from 1994 to 2003 was associated with corresponding declines in the usage of other diagnostic categories (Shattuck, 2006).

Autism spectrum disorders is an expensive group of disorders that costs society almost \$90 billion per year (Lord & Bishop, 2010). Despite a small prevalence rate of autism in special education, it is among the top three most expensive diagnostic expenditures, costing an average of \$18,790 per student (Special Education Expenditure Project, 2003). The lifetime per capita incremental societal cost of autism is

approximately \$3.2 million. Lost productivity and adult care are the largest components of costs. The distribution of costs over the life span varies by cost category (Ganz, 2007).

The rise in the prevalence of ASD has led to new legislative changes.

California's Senate Bill 946 requires health insurance plans and healthcare service plans to provide coverage for behavioral health treatment for pervasive developmental disorder or autism (Official California Legislative Information, 2011). The Affordable Care Act covers ASD screening for children at 18 and 24 months of age, as well as well-child visits ("Affordable Care Act", 2012). Job-based and new individual health insurance plans are no longer allowed to deny, limit, or exclude coverage to any child under age 19 based on a pre-existing condition, including children on the autism spectrum under the Affordable Care Act (U.S Department of Health and Human Services, 2012). Starting in 2014, individuals on the autism spectrum and their families will have expanded access to affordable insurance options through new Affordable Insurance Exchanges and improvements in Medicaid (U.S Department of Health and Human Services, 2012). Insurance companies will no longer be able to impose lifetime dollar limits on coverage. Prior to the Affordable Care Act, many plans set a dollar limit on what providers would spend for covered benefits during the time individuals were enrolled in the plan, leaving individuals on the autism spectrum and their families to pay the cost of all care exceeding that limit (U.S Department of Health and Human Services, 2012).

The diagnostic criteria for ASD has changed in the Diagnostic and Statistical Manual (DSM) 5<sup>th</sup> edition, however, which will be important for service providers to consider when allocating funds and services (Lord & Bishop, 2010). The revised criteria include only the two symptom domains of social-communication and fixated, repetitive

interests, and eliminate subtypes of ASD (Lord & Bishop, 2010). While the DSM provides nationally-accepted definitions for Autism and ASD, under federal law, special education criteria for Autism services varies by state (MacFarlane & Kanaya, 2009).

Individuals with ASD require a variety of services, but face multiple barriers obtaining these services. There is a documented need for better services for this population. Using data, however, may reduce or eliminate these barriers. Service providers must be aware of the barriers to services, as well as the current and projected needs of the service recipients. While the information is available, it is not readily accessible in one location, meaning that the relevant data is not being utilized fully. Based on the needs of autism service providers in Marin County, particularly the Marin Autism Collaborative, data and statistics were compiled and organized in order to aid them in developing and focusing their services to better meet the community needs.

## **Literature Review**

In this literature review, the service use patterns of individuals with ASD, the gaps in and barriers to accessing services, and the importance of data-driven healthcare will be covered. Since service use varies due to age, the first section of the literature review has been divided into four age groups. It is important for organizations who serve individuals with ASD to note the differences between the age groups so they can ensure that they are meeting their clients' needs.

### **Service Use by Age Group**

#### **Pre-education (0-4 years old).**

In the pre-education age group, a wide variety of services are accessed, including in-school, outside of school, clinic-based, and childcare services. According to the literature, in-school therapies are the most commonly used services (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Speech and language therapy, reported to be used by 91 percent of families, is the most highly utilized in-school service in this age group. Occupational therapy and social skills training are also frequently accessed by this age group in the school setting. Physical therapy, adaptive physical education, and music therapy are also utilized by this age group in the school setting, but not as frequently (Thomas et al., 2007).

Outside of school, the most frequently accessed services are applied behavioral analysis, occupational therapy, speech and language therapy, and sensory integration therapy (McLennan, Huculack, & Sheehan, 2008; Thomas et al., 2007). Play therapy, social skills training, hippotherapy, music therapy, and physical therapy are also utilized, but by fewer than half of this population (Thomas et al., 2007). Clinic-based services that

are frequently utilized in this age group include using a case manager, a developmental pediatrician, and a neurologist (Thomas et al., 2007). Some individuals in this population also seek services from a psychologist or a behavioral specialist. Individuals with ASD between the ages of zero and four also utilize childcare services (Thomas et al., 2007). The majority of this population receives childcare services from friends and family members. Respite care services and day care services are also used to assist with childcare, as well as special summer camps (McLennan et al., 2008; Thomas et al., 2007).

#### **Elementary school age (5-11 years old).**

In the elementary school age group, services received in the school setting make up a large portion of the services used by individuals with ASD. Among the in-school services utilized by this age group, speech and language therapy and occupational therapy are the two most commonly used services (Thomas et al., 2007). However, these two services are used less than in the previous age group. This shows that as children get older, the types of in-school services they receive changes. Social skills training is also used in this age group, and it is used more frequently than in the pre-education age group. Other in-school services that are utilized by this age group include sensory integration services that are separate from occupational therapy services, cognitive behavioral modification therapy, TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children), and music therapy (Hess, Morrier, Heflin, & Ivey, 2008).

While a wide variety of therapies are utilized by this age group outside of school, their service use patterns differ from the previous age group. Occupational therapy services, speech and language therapy services, and play therapy are used by this age

group, but they are not utilized as much as they are in the pre-education age group (Thomas et al., 2007). Other services received outside of the school setting in the elementary school age group include sensory integration therapy and hippotherapy. A change in the service use patterns between the pre-education and elementary school age groups was also seen with childcare services. There was a decline in the percentage of families who utilized respite care services and received childcare services from family and friends. There was also a decline in the percentage of families that utilize day care (Thomas et al., 2007). This is likely because the elementary school age group is attending school during the day and no longer need day care services. There was an increase in the number of families who utilized after school care and special summer camps. Since the pre-education age group may not have access to after school care services, the increased usage of this service may be due to accessibility. The literature also reports a decline in the number of families that use clinic-based services, such as using a case manager or a developmental pediatrician. However, more children in the elementary school age group receive services from a neurologist than children in the pre-education age group (Thomas et al., 2007). Overall, the literature shows that as children grow older, their service use patterns begin to change.

### **Secondary school age (12-17 years old).**

The literature available on service use in the adolescent age group is limited. Brookman-Frazee, Baker-Ericzén, Stadnick, and Taylor (2012) reported that outpatient therapy and medication management were the most frequently utilized services according to parents of adolescents with ASD. However, the literature does not state exactly which types of outpatient therapy are used. Applied behavioral analysis is a type of therapy that

could greatly benefit adolescents with ASD, but it has not been set up properly to meet the needs of this age group (Gerhardt & Lainer, 2011). Mental health services were reported to be used by adolescents with ASD (Narendorf, Shattuck, and Sterzing, 2011) with up to 46 percent of families reporting that their adolescent has utilized a mental health service in the past year. Almost half (49 percent) of those adolescents accessed the service through their school district. However, the specific types of mental health services that are used are not mentioned in the literature. Nonetheless, this information is valuable to service providers in order to ensure that mental health services are accessible to adolescents with ASD through their school districts.

#### **Post-education (18 years and older).**

In the post-education age group, the most commonly utilized services are case management services, mental health services, and medical services (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). However, the literature does not specify the type of mental health or medical services that are being used. A small percentage of adults with ASD utilize speech and language therapy services (9.1 percent) and up to 39 percent report that they do not use any services. The percentage of adults with ASD that utilize speech and language therapy services is dramatically smaller than the percentage of children that utilize this service. In addition, the percentage of adults who do not use any services is significant. This shows that as individuals with ASD age, their need for certain services decreases. Conversely, there are services used in this age group that are not used in the younger age groups, such as adult day services and supported employment services. Up to 56 percent of adults report using adult day services and 38 percent of those adults also use supported employment services for 10 hours or less a week (Taylor

& Seltzer, 2011). The adults that use day services typically attend sheltered workshops or day activity centers. This information is useful to autism-focused organizations because it allows them to reassess the list of services available to their adult clients and decide whether or not the services they currently offer meet their needs.

### **Barriers to Receiving Services**

#### **Availability and accessibility of services.**

Parents of children with ASD reported more problems accessing services than parents of children with other special health care needs and were more likely to be dissatisfied with the services they did receive (Montes, Halterman, & Magyar, 2009). The types of services provided to children with autism spectrum disorders vary by state (Dymond, Gilson, & Myran, 2007). Children who change school districts may lose services that they were receiving at their previous school (Dymond et al., 2007). Parents have expressed frustration that services were not in a convenient location, that enrollment processes were lengthy, that their child often was placed on a waiting list, and that their child did not receive services in what was considered a timely manner after their child received a diagnosis (Dymond et al., 2007).

Facilities that offer services are often concentrated near large cities, meaning that some families had to travel a long distance in order to receive the services (Kalkbrenner, Daniels, Emch, Morrissey, Poole, & Chen, 2011). Just over fifty-six percent of the sample in a study conducted by Montes et al. (2009) reported that the services needed were not available in the area. Families with children with ASD living in South and West geographic regions are more likely to have unmet service needs (Chiri & Warfield,

2012). This indicates that health care resources are not distributed evenly throughout the nation.

Children are often not eligible for services they may need or could benefit from without an ASD diagnosis. In a study conducted by Montes et al., (2009), 45.8 percent said their family member is not eligible to receive the services that they need. A child's impairments and behaviors must affect his or her educational functioning in order to qualify for services under the autism category, meaning that high-functioning students who have a clinical ASD diagnosis but perform at grade level may never be tested by a school psychologist (MacFarlane & Kanaya, 2009). Additionally, a state's eligibility requirements can change at any time (MacFarlane & Kanaya, 2009). Parents also struggle with identifying and obtaining services from multiple organizations where the eligibility criteria vary (Dymond et al., 2007).

Waiting lists also cause difficulty in obtaining services. Families may encounter waiting lists for Medicaid waiver services, community services, and residential services (Dymond et al., 2007). More than 55 percent of one sample said long waiting lists prevented them from getting the services they need (Montes et al., 2009). Parents also find that the amount of paperwork and "red tape" that they experienced delayed the start of services for their child (Dymond, et al., 2007). In a study by Montes et al. (2009), 77.6 percent of the sample said there was too much paperwork to fill out in order to obtain necessary services.

Additionally, accessibility to services has been found to be limited for racial and ethnic minorities, those with lower levels of education, and those who were not using a major treatment approach (Thomas et al., 2007). Particularly, those who are African

American or Latino have less access to services than those who are Caucasian (Liptak et al., 2008). Nineteen percent of Caucasians experienced a problem obtaining specialty care, for example, compared with 40 percent of American Indian/Alaska Natives (AIAN), about one-third of African-Americans and Latinos (Flores & Lin, 2013).

A study by Flores and Lin (2013) aimed to identify racial/ethnic disparities in access to care. Sociodemographic characteristics, or non-financial characteristics, were examined. Three percent of Caucasian children live in households in which the highest attainment of education was less than a high school diploma, compared with 25 percent of Latino children and more than 10 percent of African American and AIAN children (Flores & Lin, 2013). Latino and AIAN children were also more likely to live in households in which English was not the primary language spoken. Only seven percent of Caucasian parents reported needing an interpreter to communicate with a primary care physician, compared with more than one-third of Latino children (Flores & Lin, 2013). Latino, AIAN, and African Americans households are more likely to have more than three children, and all minority households are more likely to have more than two adults as well as adult unemployment (Flores & Lin, 2013). Most studies tend to agree that limited access to healthcare services is correlated with socioeconomic status, and many report that compared to Caucasians, racial minorities are more likely to be of a lower socioeconomic status, leading to potential financial barriers.

### **Financial barriers.**

Shimabukuro, Grosse, and Rice (2008) found that individuals with an ASD had average medical expenditures that exceeded those without an ASD by \$4,110–\$6,200 per year. On average, medical expenditures for individuals with an ASD were 4.1–6.2 times

greater than for those without an ASD (Shimabukuro et al., 2008). In addition to medical costs, intensive behavioral interventions for children with ASD cost \$40,000 to \$60,000 per child per year (Centers for Disease Control and Prevention, 2012).

Because of the costs of autism services, the financial status of families can easily hinder service use. Not all families have the money to pay for services that would be beneficial for their family member with an ASD. Of a sample of 2,123 in a study by Montes et al. (2009), 43.5 percent of the sample reported not having enough money to pay for necessary services, with 3.4 percent of the sample being uninsured. Families who live in poverty and are uninsured, for example, are more likely to have unmet needs (Chiri & Warfield, 2012). Those living in poverty and those who are uninsured are more likely to be racial and ethnic minorities (Flores & Lin, 2013). Only eight percent of Caucasian children are considered poor, compared with almost one-third of Latino and AIAN households, and over 25 percent of African-American households. Over one-half of Latino, African-American, and AIAN children live in low-income households, compared with less than 25 percent of Caucasian children (Flores & Lin, 2013). Only six percent of Caucasian children are uninsured, compared with 19 percent of Latino, 13 percent of AIAN, and nine percent of African-American children (Flores & Lin, 2013). Latinos, AIANs, and African-Americans are also more likely to be sporadically insured.

Additionally, recent reports from the United States and the United Kingdom have estimated costs to families of children with autism to be more than three to five million dollars more than the ordinary lifetime costs of raising a child without autism (Lord & Bishop, 2010). Children with ASD were more likely to live in families that report

financial problems, need additional income for the child's medical care, and reduce or stop work because of the child's condition (Kogan et al., 2008).

While autism is diagnosed in children, costs of autism care continue into adulthood. In fact, adult care has the largest lifetime cost of all direct costs, typically more than five times larger than the next three largest costs, which include care incurred during childhood (Ganz, 2007). It was also determined by Ganz (2007) that the typical American spends about \$317,000 over his or her lifetime in direct medical costs, 60 percent of which are incurred after the person reaches 65 years of age. In contrast, an individual with autism spends about twice as much as the typical American over his/her lifetime and spends 60 percent of those direct medical costs after age 21.

#### **Other barriers to utilization of services.**

Parents of children with ASD perceive that a lack of communication between service providers, lack of accountability, and lack of provider training lead to decreased quality of services, or children not receiving services they need. Parents report limited communication between providers from different organizations and schools, as well as between providers within one organization (Dymond et al., 2007). An additional complaint included lack of communication between the providers and the parents (Dymond et al., 2007). Professionals do not always consider the parents' points of view, reducing the effectiveness of services (Dymond et al., 2007). Fifty-five percent of the sample in another study said they experienced communication problems among providers, making it difficult to access services, either by not providing the services the parent felt they needed or by not providing the services often enough (Montes et al., 2009).

Parents also have expressed dissatisfaction about the accountability among school and community services for student progress (Dymond et al., 2007). Parents find that school personnel do not always adhere to students' individual education programs or to the Individuals with Disabilities Education Act, nor do they face consequences when they do not (Dymond et al., 2007). Concerns were also expressed about the accountability of employees providing community services, including Medicaid waiver and residential services (Dymond et al., 2007).

Families of children with ASD are more likely than other parents to report inability of providers to treat the child as a barrier in obtaining therapy and mental health services (Chiri & Warfield, 2012). Routine preventative care was also reported as more difficult to receive, due to trouble obtaining referrals. In another study, parents expressed their concerns that lack of specialized educator training presented a barrier to their child receiving an appropriate education (Starr & Foy, 2012).

The majority of parents indicate that providers who work with children with ASD are not as qualified or experienced as they would like (Dymond et al., 2007). Lack of understanding, awareness, and training was perceived to affect the child with ASD's educational performance and the quality of services they received. Parents also found that some organizations claimed that their employees had experience working with children with ASD when in reality they did not (Dymond et al., 2007). People named as needing more training included medical professionals, including pediatricians, physicians, general practitioners, family doctors, neurologists, dentists, mental health providers, and therapists; and nonmedical providers, including respite staff, childcare

providers, community service boards, experts, advocates, early childhood educators, and staff (Dymond et al., 2007).

## **Data-Driven Health Care and Continuous Quality Improvement**

### **Reasons for using data.**

The healthcare industry has evolved into an enterprise that is powered by sophisticated knowledge and information resources. Abidi (2001) argues that data-derived knowledge can equip health care managers and policy makers with operative principles, values, know-how, and strategies relevant to the improvement of the operational efficacy of the healthcare system.

According to Abidi (2001), effective delivery of healthcare services is contingent upon the ability of agencies to deliver appropriate services in a timely manner.

Healthcare services must be determined by needs, usage patterns and demographics, and delivered in a proactive and continuous manner (Abidi, 2001). This means that through understanding effectiveness and ineffectiveness of services, healthcare providers will be able to identify areas for improvement and/or capitalize on past successful methods, allowing them to adjust existing practices or define new plans for policy making (Abidi, 2001).

The literature on data-driven processes in healthcare suggests that quality data leads to the improvement and efficiency of programs. Such was the case for a hospital's emergency department, which was able to continually improve operational efficiency and decrease patient wait times after implementing a data-driven program in the emergency room setting (Stone-Griffith, Englebright, Cheung, Korwek & Perlin, 2012). Prior to the program, researchers observed that process improvement was hindered by a lack of data.

Population level data, in particular, can provide a big-picture view of a population's characteristics and needs. With the release of the first ever national/state population-based survey on children with special health care needs (CSHCN), the National Survey of CSHCN provided unique opportunities for states to participate with stakeholders in a discussion regarding the use of data gathered from this survey in helping to improve systems of care for this specific population (Fries, Sharp, Nudella & Peters, 2005). Data analyzed in this process included information about prevalence rates, met and unmet needs for child and family services, impacts on families, and core outcomes (Fries et al., 2005). Conclusions of this discussion suggest that new, population-based data can be used to prompt systems improvements through structured discussions and collaborative efforts.

A data-driven strategy to health care also has the potential to lower healthcare costs ("Data driven", 2011). Specifically, data regarding the prevalence of conditions within a population and their associated costs to health insurance companies can guide service providers in developing programs that minimize those expected costs ("Data driven", 2011). By using data in this way, agencies can manage costs by targeting specific needs of a population.

Data-driven decision making is the mantra of many recent education reform discussions. The recent push for more facts and information about the effects of different approaches was made in response to the lack of basic information necessary to build "logics" that support effective decision making (Loeb, 2012, p. 6). These logics are often developed from shared experiences presented in research (Loeb, 2012). By pulling from this data-driven decision making format in the education system, health care and service

providers can learn much from this new trend in education decisions made by the central government, particularly because special education and other school-based services are key to the academic success of many children on the autism spectrum (Loeb, 2012).

Research and scholarship can support decision making not only by collecting data but by hypothesizing and synthesizing knowledge (Loeb, 2012). In addition to providing information on needs and options, it provides frameworks for better understanding the population being served. This type of knowledge is key to providing services that meet the true needs of the population.

Good decision making regarding the provision of services, including type, amount, and duration, is dependent on the quality and relevance of the data available. The direct relationship between data and decision-making suggests the demand for standardized data collection and reporting strategies, which will assist health care providers in accessing information necessary to provide care that truly addresses the needs of the population. This need for quality data then poses the challenge of collecting and reporting data in a method that can easily be accessed and applied by health care and service providers.

#### **Barriers to obtaining and using quality data.**

Collecting and reporting accurate data is a time-consuming process (Ulmer, Bruno, & Burke, 2010). In addition, current national data systems are starting to become outdated and no longer provide the information necessary to address the appropriateness, costs, quality, outcomes, or changes in health care (Wunderlich, 1992). While there are numerous data sources, they are uncoordinated and duplicative (Wunderlich, 1992). Two

decades later, technology limitations in collecting data still remain. Furthermore, staffing requirements also pose challenges in collecting data (Stone-Griffith et al., 2012).

Abidi (2001) notes that while health care enterprises generate massive amounts of data and many opportunities to transform the data into empirical knowledge exist, healthcare data is rarely translated into a decision-support resource. This presents a major hindrance in the application of data in quality improvement efforts, such as in the case of numerous continuing care facilities and agencies that struggled to use the information they collected to support and initiate quality improvement strategies (Sales, Bostrom, Bucknall, Draper, Fraser, Schalm & Warren, 2012). In addition, the varying types and quality of data posed challenges in comparing across published reports (Sales, et. al, 2012). The findings of Sales and colleagues (2012) in their exploration of the use of data for process and quality improvement in long term care and home care highlights the need for similar types and qualities of data in improving the quality of care.

The above findings in the literature reveal significant implications for the development and implementation of the proposed project. Collected data must be organized and synthesized in a format that is accessible and leads organizations to form informed decisions about revising the allocation of funds for services, developing new services, or improving existing services.

### **Statement of Purpose**

There is an increased prevalence of ASD and a documented need for both additional and better services for this population. Various barriers, such as availability, accessibility, and financial barriers, prevent those who need services from obtaining them (Chiri & Warfield 2012; Ganz, 2007; MacFarlane & Kanaya, 2009). According to the literature, using data leads to improved services. Data can guide policy makers in forming informed decisions regarding the health status of our nation, as well as the effectiveness and efficiency of the delivery of care (Wunderlich, 1992). A data-driven strategy has the potential to lower costs of services, which could in turn reduce or eliminate one of the main barriers to receiving services (“Data driven”, 2011). Accessibility and availability of services, another barrier to receiving services, can also be resolved by using data, as good decision making regarding the type, amount, and duration of services offered is dependent on the available data.

The purpose of this project was to provide a data compilation containing relevant information and statistics on autism that will be useful to agencies that provide autism services, particularly the Marin Autism Collaborative (MAC), a collaboration of local autism service providers in Marin County, California that commissioned this data project. While MAC identifies the current services for individuals with ASD and gaps in services, gathering all necessary data presents a challenge, meaning that the available statistics are not being utilized fully. The data gathered in this data compilation was used to guide service providers in developing programs and supports for individuals with ASD and their families. By implementing a data-driven approach to program development, service-providers are able to use this data to gear services towards current and projected

needs, thus being able to more efficiently allocate resources where they are most requested.

## **Theoretical Framework**

A participatory occupational justice framework was used to guide the proposed project. This framework poses that individuals have the right to engage in meaningful occupations, regardless of ability or disability. It also claims that participation in daily life contributes to health, empowerment, and quality of life (Kronenberg & Pollard, 2005). The concept of occupational justice is grounded in the idea that humans are occupational beings, and therefore our health and well-being is largely determined by our participation in occupations (Townsend & Wilcock, 2004b). The justice portion refers to the vision of creating an “occupationally just world,” where individuals are able to do what they believe is meaningful and useful to themselves and their surrounding communities (Townsend & Wilcock, 2004a, p. 244).

The participatory occupational justice framework brings together three pillars of occupational therapy knowledge: occupation, enabling, and justice (Townsend & Wilcock, 2004a). Occupation describes a person’s participation in various aspects of daily life. Enabling describes interventions that utilize participatory, empowerment approaches in client-centered practice. Lastly, justice refers to factors and forms of occupational well-being and social inclusion that consider differences in people and contexts (Townsend & Wilcock, 2004a). The participatory occupational justice framework is best applied to situations in which individuals of certain ability/disability, age, and social class are excluded from opportunities to participate in meaningful occupations (Kronenberg & Pollard, 2005). Weaving these three concepts together, the participatory occupational justice framework promotes the inclusion of varying

populations in occupations that are both meaningful and therapeutic in order to promote health and well-being.

Occupational injustice often presents as unequal access or opportunity to participate in diverse, meaningful everyday activities (Kronenberg & Pollard, 2005; Townsend & Wilcock, 2004a). This outcome is unfortunately the case for many people with disabilities, who often have lower levels of income, education, employment, and access to health care, housing and transportation (Pollard & Sakellariou, 2012). Another outcome of occupational injustice is occupational deprivation, which is the inability of an individual to engage in meaningful and desired occupations due to factors outside of his or her control (Townsend & Wilcock, 2004a). Those on the autism spectrum experience such occupational injustices, partly due to the lack of information for themselves and their families about their needs and the possibilities for developing new physical and social skills (Pollard & Sakellariou, 2012). In addition, numerous barriers to receiving the services created to minimize these injustices and to support their occupational participation present even greater obstacles to occupational justice. An occupational justice framework is appropriate to this project, as it emphasizes the occupational inclusion of all populations in ordinary, daily life.

Because barriers to accessing services and gaps in services have large impacts on the ability of the ASD population to be meaningfully occupied in important activities of everyday life, occupational therapists need to advocate for the occupational inclusion of this population. One of the ways this is done is through the provision of support services for individuals with autism. Unfortunately, there are still unmet needs and service accessibility issues within this population, many of which are outlined in our literature

review. In order to bridge some of the gaps in services, a data-driven approach was used to guide intervention at the population level. A goal of this project was to support the participation of the ASD population in meaningful occupations. Steps to meeting this goal include (1) analyzing existing occupational injustices within this population, (2) evaluating client-specific resources and challenges, and finally, (3) planning, implementing, and evaluating client-specific services (Kronenberg & Pollard, 2005). The first step, analyzing existing occupational injustices within this population, required a search in the literature about the documented needs and gaps in current services. These issues have been documented as barriers to accessing services that individuals with ASD and their families experience. An analysis of these gaps in services provided a clearer perspective of what kinds of improvements in services and service accessibility are needed. The second step, evaluating client-specific resources and challenges stemmed from measuring the data needs of agencies that provide services to the ASD population. Through assessing the needs for information about the autism population, including diagnostic trends, satisfaction rates of services, barriers to accessing services, and gaps in services, the project developers were able to develop a project that truly speaks to factors that contribute to occupational injustice, or barriers to occupational participation. This was done in the form of needs assessments, which were conducted face-to-face or by phone with agency representatives. The third step, planning, implementing, and evaluating client-specific services, involved agencies that serve the ASD population. These agencies are supported in improving their services by the development and implementation of the data compilation.

As a profession that advocates for occupational participation on both an individual and population level, the concept of occupational justice is highly relevant to occupational therapy. In using the participatory occupational justice framework, this project seeks to prevent occupational deprivation of the ASD population by supporting the service development efforts of agencies that work to reduce gaps and barriers related to autism services, and ultimately improve the quality and accessibility of these programs. The presented data compilation synthesizes, organizes, and presents relevant autism statistics in a useful format where a data-driven approach to service development for the autism community is much needed in order to support participation and promote occupational justice.

## **Methodology**

### **Project Design**

This project was designed to provide a data compilation and visual representations of autism statistics (see Appendix A) as well as document gaps in autism data to organizations that serve individuals with ASD in Marin County. The data compilation is comprised of statistics related to the services used by individuals with ASD across all age groups as well as other needed statistics that the involved organizations have identified, such as demographics and trend data. These statistics will guide organizations as they help clients of various ages access the services they need. The goal of this project was to create a data compilation that contains all of the statistics that the involved organizations identified as necessary data in order to better develop and focus their services to meet the needs of the community.

### **Agency Description**

This project was developed for the Marin Autism Collaborative (MAC). MAC is an organization that is facilitated by Lifehouse, a non-profit agency that serves adults with learning challenges in Marin, Sonoma, and San Francisco Counties. MAC was created to identify the current services used by individuals with ASD in Marin County as well as the gaps in service delivery to families, professionals, and consumers with ASD (MAC, 2012).

A wide variety of agencies, organizations, providers, and families donate their time to MAC in order to ensure that individuals affected by ASD in Marin County receive the best services possible throughout their lifetime, including: parents, Marin County Office of Education, Marin SELPA, Golden Gate Regional Center, Matrix, Lifehouse, Area Board, Easter Seals, United Cerebral Palsy of the North Bay,

Opportunity for Independence, The Cedars, non-public private schools, residential and adult day centers, and consultants (MAC, 2012).

MAC meets on a monthly basis and has established an organizational structure with the intention of continuously looking at the gaps in services for individuals with ASD and helping to find solutions (MAC, 2012). This organizational structure includes a steering committee that decides which areas MAC should focus on, as well as overseeing MAC's two subcommittees, a youth subcommittee that addresses the needs of children and adolescents in Marin County with ASD and their families, and a transition years subcommittee that supports individuals with ASD as they experience transitional periods in their life, such as the transition from school to employment.

### **Target Population**

This project was developed for organizations in Marin County that assist individuals with ASD in finding services. The organizations that benefited from this project include The Cedars, Marin County Office of Education, Oak Hill School, Golden Gate Regional Center, Opportunity for Independence, and Lifehouse. The data compilation and visual representations will allow these organizations to provide better services to individuals with ASD as well as report current statistics when applying for grant funding.

### **Project Development**

During one of MAC's monthly meetings, its members determined that there was a need for recent autism data and statistics. Consequently, they contacted Dominican University of California, requesting that this issue be addressed by a thesis group. The project developers received contact information for the agencies that comprise MAC

from their thesis advisor. Meg Cadiz, the Director of Development of Lifehouse and the main contact for MAC, agreed to work with the project developers on this project (see Appendix B).

A needs assessment (see Appendix C) was sent to six agencies that comprise MAC. They were contacted via an email that contained a short description of the project and the needs assessment. The needs assessments were created by the project developers in order to determine the type of data and statistics that would be most beneficial to MAC, as well as the preferred format. Phone appointments were scheduled with Oak Hill School and Golden Gate Regional Center, and a face-to-face appointment was scheduled with Lifehouse.

The data gathered from the needs assessments concluded that the involved organizations needed recent data regarding education, housing, employment, services used, incidence and prevalence, trends, comorbidities (combinations of autism and other diagnoses), and area of residence within Marin County. The requests regarding the preferred product format included talking points, graphs, and narratives, with the final product being presented in both printed and PDF format.

These appointments directed the course of the project, as the data and statistics that were compiled were a result of the requests that were made during the appointments. The project developers received a reply from Opportunity for Independence, but the respondent reported that the organization did not have a need for autism data. Despite multiple follow-up emails, the project developers did not receive a response from The Cedars and Marin County Office of Education. One of the contacts from whom the project developers did not receive a response worked for Lifehouse, the same

organization that Meg Cadiz worked for, so the project developers were still able to learn the organization's needs.

Based on the involved organizations' needs, the project developers searched various sources in order to obtain data. Due to the nature of the requests, all data was found through the internet. The sources used are as followed:

- Autism Society of California
- California Department of Education
- Center for Disease Control and Prevention
- Easter Seals
- Golden Gate Regional Center
- Lucille Packard Foundation for Children's Health/Kidsdata.org
- Pacific Autism Center for Education
- U.S. Department of Education

### **Project Implementation**

After the involved organizations identified their needs, the project developers obtained the requested data and organized it (see Appendix D). The compilation was broken into chapters of national-level, state-level, and county-level data. Each chapter was further organized by data type, such as housing, education, employment, and trend data. The data compilation included visual representations, such as charts and graphs, as well as written representations of the data. The data was accompanied by short narratives that describe what the data means, along with from where the data was obtained.

The majority of recognized and reputable sources' data and statistics were from 2008 or earlier. Many of these sites also referred only to the CDC, meaning that

numerous sources presented identical statistics. The project developers consequently had to deviate from these sources to locate data from less obvious locations. The project developers had originally thought that the national-level data would be the easiest to find and the most plentiful, resulting in it being disproportionate to the other data, particularly the county-level data. The project developers found, however, that the national-level data chapter had the least amount of information.

The data compilation was made available to MAC to allow them to develop and focus their services to meet the current and projected community needs. The data may be used for various purposes, including in presentations or when applying for funding. The compilation was made to be searchable in order to find specific data points.

### **Project Evaluation**

The project developers created an evaluation form that was used to determine if the data compilation was useful, comprehensive, and beneficial to MAC (see Appendix E). Questions one through five used a five-point Likert scale, with responses ranging from strongly disagree to strongly agree. The questions included information regarding whether the data compilation: included all of the data needed to make informed decisions about service development and improvement, was well organized and presented in a professional format, was useful, would assist the respondents with grant writing, and would assist respondents when creating presentations about autism and autism services. Space was allotted after each Likert scale question to allow respondents to write additional comments. Questions six and seven were optional, open-ended questions in which the agency could elaborate on whether the compilation was missing any information or if there were any further suggestions for the project developers. The

project developers sent an email containing the completed data compilation and a link to the survey to nine members of MAC on September 3<sup>rd</sup>, 2013. The project developers utilized the Survey Monkey website, allowing the responses to be available in one central location. Eight participants completed the survey.

Sixty-two and a half percent of respondents agreed, 25 percent strongly agreed, and 12.5 percent disagreed that the data compilation included all of the data needed to make informed decisions about service development and improvement. Respondent one left the comment, “Wonderful work on compilation. I know it was not easy to attain this data from the many sources.” Fifty percent strongly agreed that the compilation was well organized and had been presented in a professional and useful format, while the other 50 percent agreed. Respondent one reported that, “This data is very easy to read and well presented!” Sixty-two and a half percent strongly agreed, 25 percent agreed, and 12.5 percent neither agreed nor disagreed, that the data compilation was useful to them. Respondent one wrote that, “This data will be used in many ways by many agencies.” Regarding whether the data compilation would assist the respondents with grant writing, 62.5 percent strongly agreed, 25 percent agreed, and 12.5 percent neither agreed nor disagreed. Respondent one expressed that, “This data did not exist and will be a tremendous help in grant writing.” The final Likert scale question asked if the data compilation would assist respondents when creating presentations about autism and autism services. Sixty-two and a half percent strongly agreed that it would, while 25 percent agreed and 12.5 percent neither agreed nor disagreed. Respondent one expressed that, “This will be an incredible tool for autism services and trends,” and respondent seven wrote, “Looks great easy to read.”

The final two questions were optional. Question six asked what information the data compilation was missing. Respondent four wondered who serves individuals with ASD before they age out of the school district and what percentage of them attend public schools, special day classes for students with autism, and special day classes for students with multiple non-ASD diagnoses. This respondent also wanted to know what percentage of classes offered to students with ASD were full inclusion or special day classes and whether they were public or private.

Question seven inquired about whether the respondents had any additional suggestions for the project developers. Respondent four reported, “Not at this time. I am very pleased to have this document. It will be very helpful for our strategic planning as well as grant writing for my non-public school.” Respondent seven commented, “Indicate the three counties served by the GGRC.” Respondent eight wrote, “Would like to see the school info clarified more. The CDE data is eligibility NOT disability...and there are more kids with ASD NOT counted in this data as their eligibility could be listed as something else or they may not be eligible for special ed...so to say these are the kids in the schools with ASD is very misleading. This is data on kids with ASD whose eligibility is ‘Autistic Like’. This does not include kids with ASD not eligible or eligible under another category,” on question seven.

The project developers had sent a draft of the compilation to MAC in April of 2013 to ensure that the format and content was approved. Following the distribution of this draft, the project developers received feedback similar to the feedback given by respondent eight on the final evaluation. The project developers searched the California Department of Education website to attempt to verify and understand the feedback;

however, no information regarding this topic was found, and the developers settled on reporting that statistics from the California Department of Education's DataQuest site were based on the Individuals with Disabilities Act Part B criteria.

After receiving the same feedback again on the evaluation, the project developers attempted to confirm this information once more. The respondent asserted that the data included children whose eligibility was autistic-like, and that disability was not how the students were categorized. The California Code of Education section 56846 reports that, "a 'pupil with autism' is a pupil who exhibits autistic-like behaviors," which was the only information found regarding the term "autistic-like" (California Code of Education, 1976). The project developers obtained the data in question, however, from the California Department of Education's DataQuest website. The data was found under the special education topic. The only specification that DataQuest provided was that the particular topic included data on "special education enrollment by age, grade, ethnic designation, and disability."

Having students create a data compilation can be a limitation in and of itself, as students do not always have access to the same resources as professionals do, particularly regarding the way the California Department of Education collects and presents its information. Because the project developers could access only the information available to the general public, some of the information in the data compilation may not be as thorough as possible. The feedback itself was also not as understandable as it could have been, causing the project developers to be unsure of what the respondent was attempting to express.

### **Ethical and Legal Considerations**

Throughout the duration of this project, the involved students made it a priority to uphold the Occupational Therapy Code of Ethics. There were three principles that were taken into consideration during this project. These principles were fidelity, veracity, and social justice (American Occupational Therapy Association, 2008). The principle of fidelity states that all colleagues and other professionals must be treated with respect, fairness, discretion, and integrity. Fidelity was an important principle to uphold during this project because the students worked with multiple professionals. The principle of fidelity was upheld by treating each professional with respect and avoiding conflict. The principle of veracity states that individuals must provide comprehensive, accurate, and objective information when representing the profession of occupational therapy. Veracity was significant in this project because the involved organizations expected the students to present their findings honestly. This principle was upheld by presenting all findings and ourselves honestly to each organization as well as disclosing all details regarding the reported information. The final principle was social justice. The principle of social justice states that individuals must conduct all work in a fair and equitable manner. This principle was important to consider during this project because the students collected and reported data on a vulnerable population. Social justice was upheld by obtaining and reporting non-biased data that accurately represented the population with ASD.

## **Conclusion**

### **Discussion**

As described earlier, the project developers were introduced to Meg Cadiz and Barry Benda, representatives of MAC and the main collaborators for this project, and agreed to develop a data compilation of current and relevant autism statistics that would help MAC better suit the needs of the ASD population through the improvement of its services. Through needs assessments and database and website research, the project developers gained information about the data needs of specific organizations and MAC as a whole, their challenges with accessing data, as well as the gaps in autism data.

While conducting the needs assessments, the project developers were astounded to find that organizations used data that was outdated, often by more than five years, in the grant writing process and in their presentations to other service providers. Representatives from the organizations also expressed that they were not sure where they could access the data they needed for their reports and requests for funding. These facts further illustrated the need for autism data to be readily available and accessible in one document for these service providers.

In researching for autism data on various websites and databases, it was challenging to locate sources for recent autism statistics. The data was scattered, demonstrating that in order to obtain necessary information about the ASD population, various locations must be searched. In addition, the project developers discovered many gaps in the data. Among the gaps discovered were data lacking in the categories of housing, education, adults with ASD, and comorbidities. Although data in each of these

categories was highly requested during the needs assessments, limited data could be found in these categories.

Furthermore, for local service providers for the autism community within Marin County, it is imperative that data specifically describing and quantifying the needs of the autism population of Marin County be available for service providers to utilize.

Although data was reported by the Golden Gate Regional Center, which provides services and supports to individuals with developmental disabilities in the Marin, San Francisco, and San Mateo counties, that data was not reported separately by county. Thus, little information specific to the ASD population in Marin county was publicly available.

The difficulty the project developers encountered in acquiring recent data (within the last two to three years) affirmed the results of the needs assessments, in which representatives from each organization reported that they were unable to readily access data about the ASD population. Published reports often required much time to filter through and required a critical eye in evaluating how and when the data was collected. According to the needs assessments, many service providers are not able to engage in such a time-consuming process in order to gain data for presentations, reports, and grant proposals. This affirms the usefulness of this project in providing current and relevant data about the ASD population in one central document that is organized by level of data and category. It also provides a template for future data compilers to report data in a format that meets the data needs of the organizations that provide services to the ASD population.

## **Future Recommendations**

Based on the results of the needs assessment and the process undertaken to create the data compilation for this project, the project developers propose the following recommendations for further and future research surrounding the ASD population. It is recommended that more frequent and widespread data collection about the ASD population be conducted to encourage a better understanding of the client population around which service providers design their supports. The data should also be made more readily available on accessible websites.

The gaps in autism data imply key recommendations for those involved with the research of and intervention for the ASD population, especially in Marin County. Relative to the needs assessments and the gaps identified in autism data, more data collection is needed in the categories of housing, employment, adults with ASD, and comorbidity data. There is also a need for more non-survey-based data that is collected at the county, state, and national levels. The rates of autism in the data compilation also suggest a need for transition services for individuals with ASD who are transitioning out of high school. In addition, the data shows an increased need for services catering to students who are around age ten, which is estimated to be the new age of the peak cohort for the ASD population in California as of 2013, according to numbers reported in 2010 by the Pacific Autism Center for Education (PACE).

Furthermore, organizations such as the Golden Gate Regional Center that collect data about the individuals they serve have the potential to compile this individual data to gain a population view of the clients they serve. According to the needs assessments, many organizations obtain their information from regional center websites. Having these types of data reports available online would ease the process of obtaining needed data for

various purposes. Lastly, because of the benefits data provides in tailoring services to a target population, organizations that provide services to the autism community are urged to utilize current and relevant data in order to better meet the needs of the population they serve.

### **Limitations**

Although the project developers initiated contact with and intended to conduct needs assessments with representatives of all organizations that comprise MAC, some organizations did not participate in the needs assessment process and were therefore unable to express the current and projected use of data within their organizations, request specific types of data, or provide input regarding the format of the data compilation. The lack of contribution from these service providers into the data compilation process presents a limitation of this project in that the final data compilation caters mostly to the data needs of the organizations with whom the project developers collaborated.

The data compilation is also limited by the gaps in available data. Although originally requested from the organizations, very little data on housing, employment, and adults with autism was available. In addition, the only comorbidity data provided in this data compilation was gathered from a survey. Thus, the data compilation is limited because of the lack of available data concerning these aspects of life for the ASD population. The lack of raw numbers in reports about the ASD population also limited the project developers' ability to reinterpret the data and to possibly represent it visually through graphs or charts in various ways.

The project may have benefited from more background information about how the research behind published reports was conducted. Such characteristics of the research, such as population size, locations in which data was collected, as well as

collection methods, would be helpful to consider in analyzing the quality and accuracy of the data. However, it was difficult to obtain these types of details from various organizations and government agencies that collect data and/or report it.

### **Summary**

With rapidly rising prevalence rates for individuals with ASD, there is an increasing demand for local support services for the autism community. In addition, poor quality of services and barriers to accessing and obtaining these services result in decreased occupational participation among the ASD population. Therefore, improvements in service provision and service access are necessary to support the participation of individuals with ASD by gearing support services towards the population's unmet needs.

The literature suggests that quality data that is organized in a useful format can help to improve services by targeting specific current and projected needs, both met and unmet, of a population (Abidi, 2001; Fries, et. al, 2005). Unfortunately, data needed to make informed decisions regarding the development and improvement of services for the ASD population was either missing from the literature, was not easily accessible, or was not organized in a central place, according to the responses in our needs assessments.

To address this problem, requested autism data was gathered from published reports, synthesized, and repackaged in a useful format for use by MAC, which is comprised of several agencies that serve individuals with autism and their families in Marin County, California. The data compilation features written and visual representations of relevant autism statistics meant to aid service providers in developing new programs or improving existing support services to more accurately meet the needs

of the growing ASD population. In order to more adequately support the autism community, resources will need to be allocated in efficient and effective ways. The presented data about incidence and prevalence of autism, education, housing, and employment will help service providers determine accurate approaches to service provision for the ASD population. It will also assist service providers in predicting the future needs of the population and thus, plan for the revision or expansion of services.

This project follows the shift towards data-driven health care systems and data-driven decision making in the area of service provision and development. It also embodies occupational therapy's role in preventing occupational deprivation of the ASD population and in advocating for their participation in diverse, meaningful activities of daily life. Furthermore, it illustrates the potential for occupational therapists to collaborate with agencies that provide supports for the autism community.

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## Appendix A: Thesis Proposal Form

### Thesis Project Proposal Form

Name (s): Sarah Jane Calub, Nicole Hofeditz, and Caitlin McIntyre

E-mail address(es): sarah.calub@students.dominican.edu

nicole.hofeditz@students.dominican.edu

caitlin.mcintyre@students.dominican.edu

Phone Contact(s): Sarah Jane Calub: (415) 794-6529

Nicole Hofeditz: (415) 328-2181

Caitlin McIntyre: (916) 207-6161

#### **Thesis advisor information:**

Name: Stacy Frauwirth

Campus Phone: (415) 257-1380

E-mail address: stacy.frauwirth@dominican.edu

#### **Project Information:**

**Proposed title of project:** Statistically Speaking: Developing a Data Compilation for the Marin Autism Collaborative

**Contact Person at Agency/Setting:** Meg Cadiz

**Phone Number of Contact & e-mail:** (415) 472-2373; mcadiz@lifehouseagency.org

**Duration of Project:** One year

#### **What problem will be addressed with this project:**

There is a documented need for better services for the autism spectrum disorder (ASD) population. Various barriers to receiving services present obstacles, such as availability, accessibility, and financial barriers. According to the literature, using data leads to improved services. Data can guide policy makers in forming informed decisions regarding the health status of our nation, as well as the effectiveness and efficiency of the delivery of care. A data-driven strategy has the potential to lower costs of services, which could in turn reduce or eliminate one of the main barriers to receiving services. Accessibility and availability of services, another barrier to receiving services, can also be resolved by using data, as good decision making regarding the type, amount, and duration of services offered is dependent on the available data.

The purpose of this project is to provide a database containing relevant information and statistics on autism that will be useful to agencies that provide autism services, particularly the Marin Autism Collaborative (MAC). The data gathered in this database will guide service-providers in developing programs and supports for individuals with ASD and their families. By implementing a data-driven approach to program development, service-providers will be able to gear services towards current documented needs (based on the data), thus being able to more efficiently allocate resources where they are most requested.

### **What are current approaches to this problem.**

MAC identifies the current services for individuals with ASD and gaps in services. However, gathering all necessary data presents a challenge, so all of the currently available statistics are not being utilized fully.

### **Description of participants and agency/setting.**

This project is being developed for the Marin Autism Collaborative (MAC). MAC is an organization that is facilitated by Lifehouse, a non-profit agency that serves adults with learning challenges in Marin, Sonoma, and San Francisco Counties. MAC was created to identify the current services used by individuals with ASD in Marin County as well as the gaps in service delivery to families, professionals, and consumers with ASD (MAC, 2012).

A wide variety of agencies, organizations, providers, and families donate their time to MAC in order to ensure that individuals affected by ASD in Marin County receive the best services possible throughout their lifetime, including: parents, Marin County Office of Education, Marin SELPA, Golden Gate Regional Center, Matrix, Lifehouse, Area Board, Easter Seals, United Cerebral Palsy of the North Bay, Opportunity for Independence, The Cedars, non-public private schools, residential and adult day centers, and consultants (MAC, 2012).

MAC meets on a monthly basis and has established an organizational structure with the intention of continuously looking at the gaps in services for individuals with ASD and helping to find solutions (MAC, 2012). This organizational structure includes a steering committee that decides what area MAC should focus on as well as overseeing MAC's two subcommittees, a youth subcommittee that addresses the needs of children and adolescents in Marin County with ASD as well as their families, and a transition years subcommittee that supports individuals with ASD as they experience transitional periods in their life, such as the transition from school to work.

### **Recruitment Procedure.**

The involved agencies will be contacted via email with a copy of the project's needs assessment (see Appendix C). The students will then meet with each agency's contact

person face-to-face to discuss the results of the needs assessments and any concerns related to the project.

### **Setting/Participant Consent Process:**

Consent forms will not be used, as this project does not include working with individuals.

### **Procedures.**

A needs assessment (see Appendix C) will be emailed to each of the involved agencies. Once each of the organizations have identified their needs, the project developers will obtain the requested data and organize it into a data compilation. The data will be made available to MAC to allow them to develop and focus their services to meet the community needs. An evaluation form (see Appendix E) will be provided to each agency in order to receive feedback of the effectiveness of the project and identify areas for improvement.

### **Potential Risk to Participants.**

The involved agencies could potentially face a monetary risk regarding the reallocating of funds for the development of new services based on the provided data.

### **Minimization of Potential Risk.**

The students will provide accurate, nonbiased representation of the data to the agencies.

### **Potential Benefits to Participants.**

The agencies will better understand the current and increasing service needs of the ASD population and trends in service use patterns. This will assist them in making more informed decisions regarding the development or improvement of services.

### **Intended Outcomes of the Project.**

The data compilation will guide service providers in developing programs and supports for the autism community. By implementing a data-driven approach to program development, service-providers will be able to gear services towards current documented needs (based on the data), thus being able to more efficiently allocate resources where they are most requested.

### **What are the Project Deliverables.**

The exact format of the project will be determined by the agencies upon completion and analysis of the needs assessments. The data compilation will include visual and written representations of autism statistics.

**Costs to Participants.**

Throughout the duration of the project, the agencies will spend time completing the needs assessment and maintaining face-to-face and virtual communication with the students. Upon completion of the project, the agencies will expend funds and time implementing and maintaining the project in order to preserve the relevancy of autism data to changing community needs.

**Reimbursement or Compensation to Participants:**

No reimbursement is necessary because the long-term benefits of the project outweigh the costs.

**Confidentiality of Records:****Check which of the following applies:**

Data will be anonymous

Population-level data will be obtained from published reports and public records.

Data will not be anonymous

**Signatures:**

I acknowledge that all procedures will meet relevant local, state, and federal regulations related to the setting and participants. I am familiar with and agree to adhere to the ethical principles set forth by AOTA.

\_\_\_\_\_  
Signature of Applicant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Applicant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Applicant

\_\_\_\_\_  
Date

## Appendix B: Site Verification Form

### Dominican University of California Department of Occupational Therapy Site Selection Verification Form

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**Student Name:**

Sarah Jane Calub, Nicole Hofeditz, & Caitlin McIntyre

**Title of thesis project or research:**

Developing a Data Compilation for the Marin Autism Collaborative

**Description of thesis project or research:**

This thesis project will entail the creation of a data compilation and visual representations of autism statistics for organizations that serve individuals with autism. The data used in this project will be determined based on the needs of the participating organizations. The goal of this project is to create a data compilation that contains statistics and other autism-related information that the involved organizations identified as necessary data in order to better develop and focus their services to meet the needs of the growing community.

**Name of Proposed Site:**

Marin Autism Collaborative

**Type of facility:**

Non-profit

**Address:**

899 Northgate Drive, Suite 500  
San Rafael, CA 94903

**Phone #:**

(415) 472-2373

**Contact Person related to approval at the site:**

Meg Cadiz

**Title:**

Director of Development

**Has initial contact been made? Yes No**

**If “yes”, describe:**

Initial contact has been made through email, and an appointment has been scheduled to meet in person.

**If “no”, state specifically when contact will be made (a site approval is necessary for the thesis proposal to receive approval):**

N/A

**What agreements have been made regarding project implementation (for example, collect data, prepare a manual, or develop an intervention)?**

Project developers will conduct an in-person needs assessment that will help determine the data needs of the organization. We will then compile existing relevant autism data in order to create a data compilation for MAC. This data compilation will provide useful information for developing new or improving existing autism support services to support the current and projected needs of the autism community in Marin County.

**Dates for proposed intervention(s), due date for manual, or dates planned for data collection:**

The data compilation will be sent to MAC by October, 2013.

**Potential problems, plans for addressing problems (pro-active planning for alternatives)**

A potential problem with implementing this project may be that a wide range of data is requested by the various participating organizations. While the goal of this project is to meet the data needs of each organization, the students may be unable to include all of the requested data in the compilation. In order to address this problem, the students will work with each organization to prioritize their data needs. A second potential problem may be that some of the requested data does not exist. In order to address this problem, the students will document the gaps in the data and suggest that future research projects focus their efforts on gathering data in order to fill the gaps.

**Agency Signature** \_\_\_\_\_

**Date** \_\_\_\_\_

**Print Name & Title of Agency person**

\_\_\_\_\_

**Faculty advisor  
signature** \_\_\_\_\_

## Appendix C: Needs Assessment

To whom this may concern:

We appreciate your willingness to participate in this project development process with us. Here is a brief description of our project and what we hope to achieve.

The purpose of this project is to provide a data compilation containing relevant information and statistics on autism that will be useful to agencies that provide autism services. The data gathered in this data compilation will guide service-providers in developing programs and supports for the autism community in Marin County. This data will allow service-providers to gear services towards current and projected needs, thus being able to more efficiently allocate resources where they are most requested.

Please reflect on the following questions and prepare notes for our face-to-face meeting, where we will discuss the data needs of your agency:

1. What do you currently use autism data for?
2. What would you like to use autism data for in the future?
3. What kinds of autism data have you used in the past and from what resources did you obtain this data?
4. Describe your past and present challenges with accessing data?
5. How have you organized data in the past?
6. What specific categories would you like data on?
7. Please describe any recent or past projects you have done that required autism statistics? What kind of data was needed to support the development of these projects?
8. How would you like the final data compilation to be formatted? What would be the most beneficial for your needs?

We appreciate your time and assistance with this project.

Sincerely,

Sarah Jane Calub, Nicole Hofeditz & Caitlin McIntyre

## **Appendix D: Data Compilation**

The Marin Autism Population, Statistically Speaking: A Data Compilation of Statistics at  
the Marin County, State of California, and National Levels

This document, created for the Marin Autism Collaborative, reports some of the most recent statistics and trends regarding the ASD population at the county, state, and national levels. Data was compiled from sources such as the California Department of Education, the Pacific Autism Center for Education, and Golden Gate Regional Center, among others, and are represented in this document in brief talking points and visual aids.

|   |    |
|---|----|
| Bay Area/County Level Data              | 4  |
| State Level Data                        | 11 |
| National Level Data                     | 15 |
| Limitations and Service Recommendations | 16 |
| Reference List                          | 17 |

## County/Bay Area Level Data

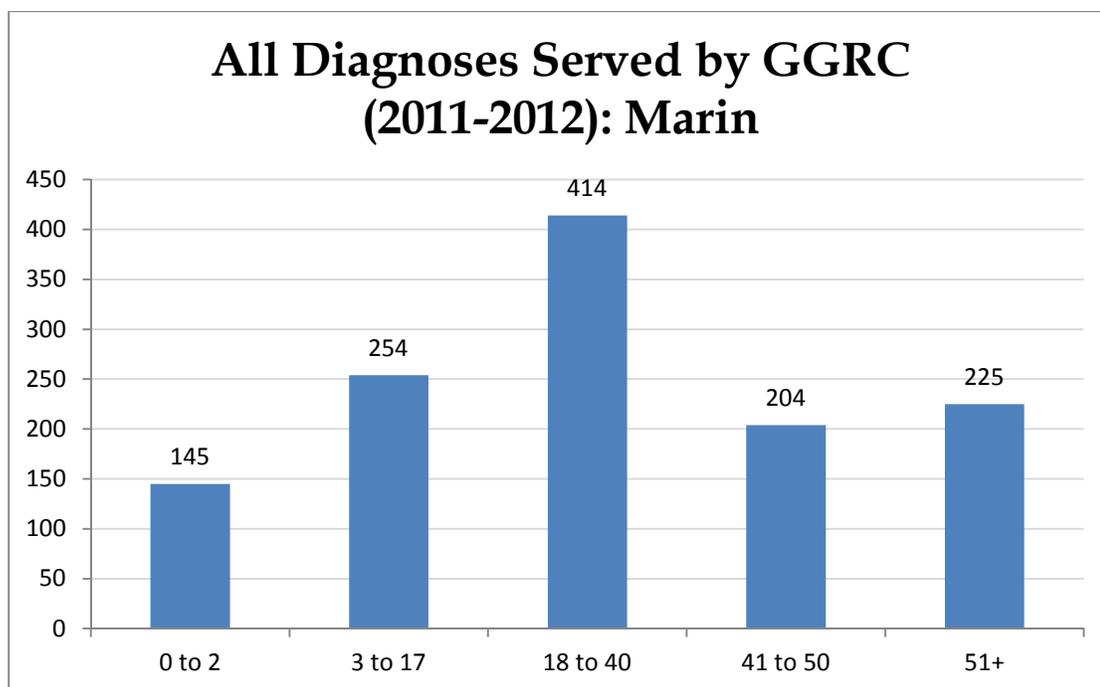
### Talking points:

- From 2001 to 2009, the average growth rate for autism ranged from 12% to 19% across 6 bay area counties (San Mateo, Santa Clara, Alameda, Santa Cruz, San Francisco, and Marin) (PACE)
- Marin autism ratios (PACE):
  - 2001: 1:378
  - 2009: 1:155
  - Average annual growth rate: 12% (lower than the other five counties mentioned)
- Bay Area growth rate numbers are slightly lower than the California average, at an annual growth rate of 16% compared to 18% for California from 2001-2009 (PACE)

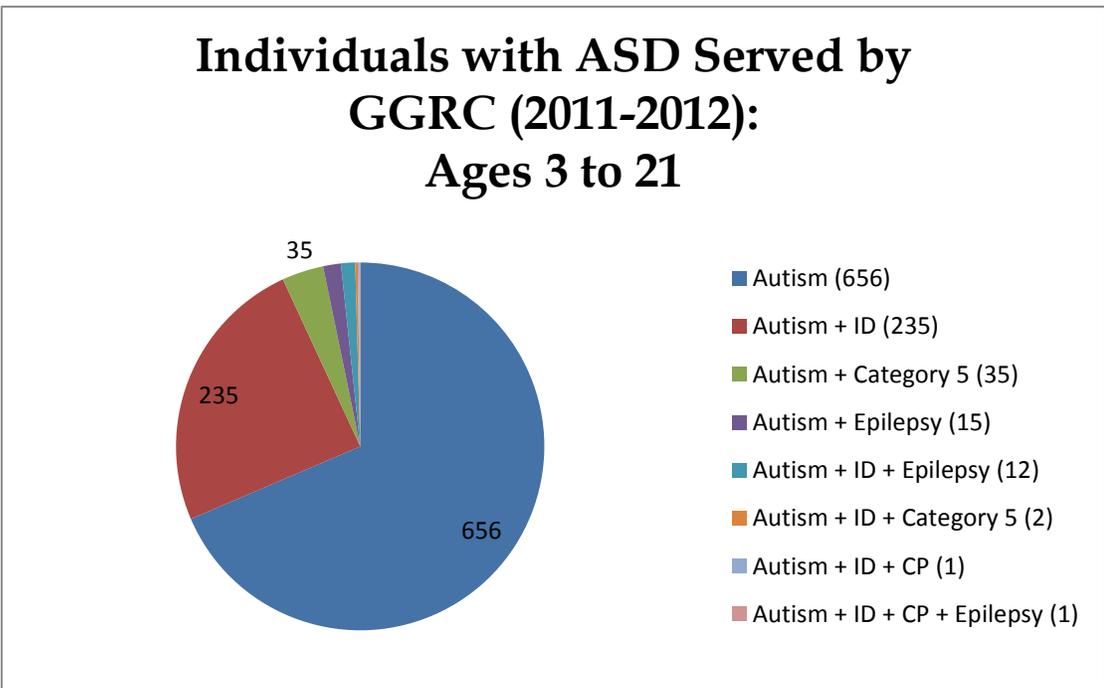
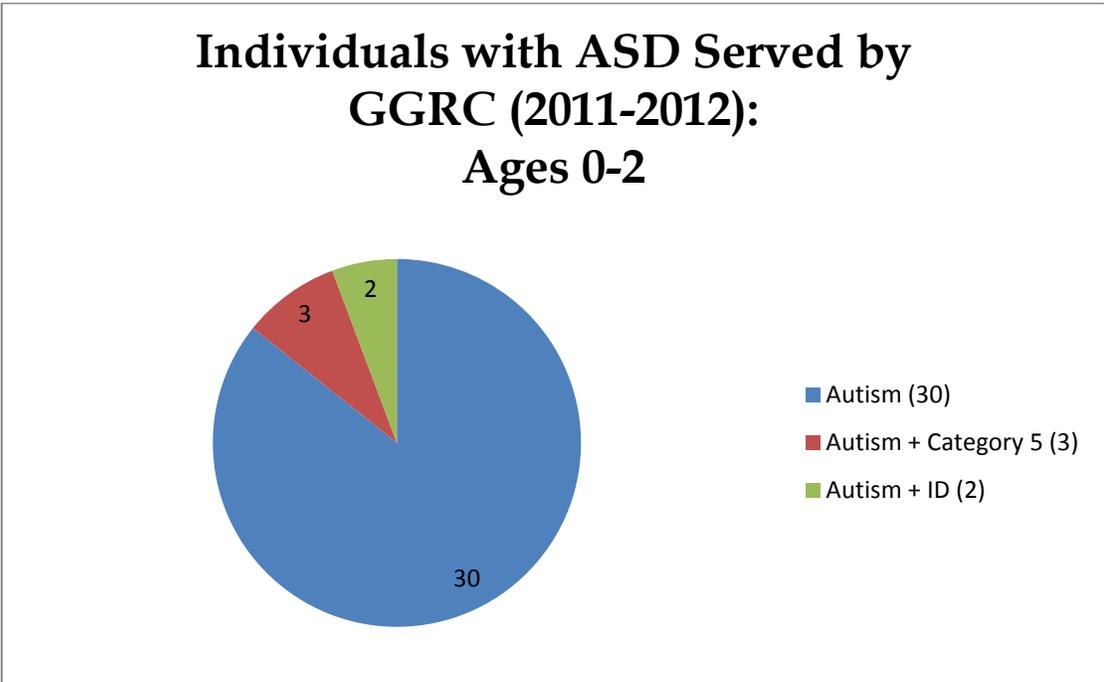
### Golden Gate Regional Center Data:

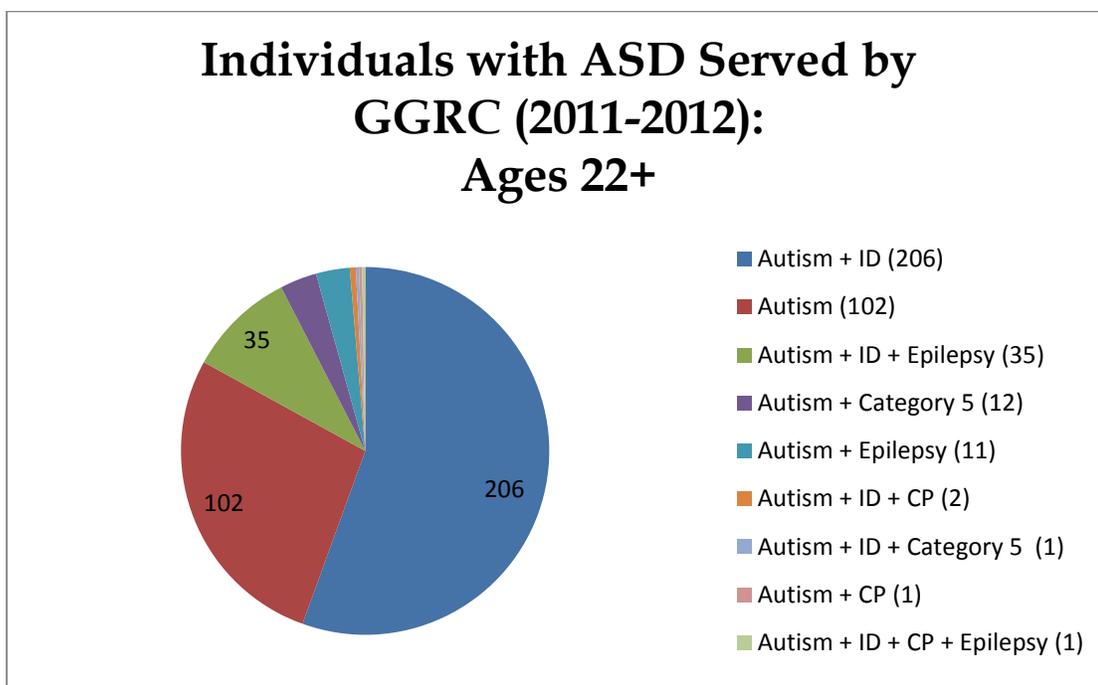
The data presented in the following graph is from [GGRC's website](#). It lists the consumers of GGRC's services by age group in Marin. However, the information describing Marin's demographics are not autism-specific.

The total number of people GGRC served in Marin for the fiscal year 2011-2012 was 1,242.



GGRC's website lists the total number of individuals with autism, or autism with additional diagnoses, served during the fiscal year 2011-2012. These numbers are divided into age groups as per their website and displayed in the following graphs. These numbers are not Marin-specific, but rather all individuals with autism served by GGRC.





*The total numbers of people with autism GGRC serves (all ages) are as follows: 788 with autism; 443 with autism and an intellectual disability (ID); 50 with autism and category 5; 47 with autism, ID, and epilepsy, 26 with autism and epilepsy, 3 with autism, ID, and cerebral palsy (CP); 3 with autism, ID, and category 5; 2 with autism, ID, CP, and epilepsy, and 1 with autism and CP.*

#### Education Data:

#### Talking points:

- 6.9% of children enrolled in special education have a diagnosis of autism (2012) (Kidsdata.org, Lucille Packard Foundation for Children's Health)

#### Trends:

- In the past eight years, the number of students with autism in Santa Clara County has more than tripled from 1 in 348 to 1 in 104 (PACE)
- In 2009 alone, Bay Area schools recorded a 13% growth rate – down from 19% in 2001. But the total number of students with autism continued to climb to 6,218 individuals in 2009 (PACE)
- Marin County special education enrollment: 257 children with autism (2012), up from 179 (2008) (Kidsdata.org, Lucille Packard)

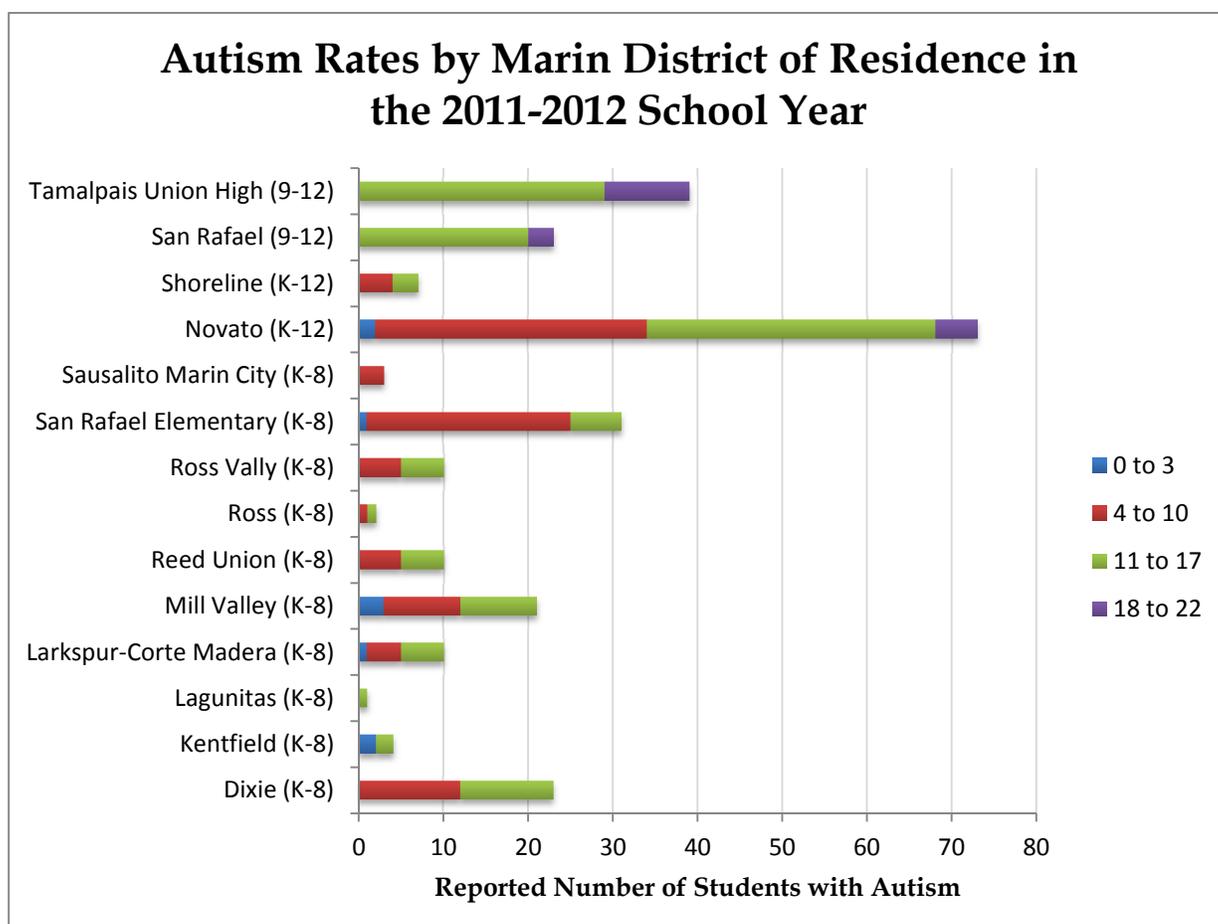
The following chart is comprised of data obtained by PACE (Pacific Autism Center for Education). This table shows the ratio of students with a diagnosis of ASD in six different bay area counties.

| County        | 2009 Autism Ratio | 2001 Autism Ratio | Average Annual Growth Rate |
|---------------|-------------------|-------------------|----------------------------|
| San Mateo     | 1:97              | 1:386             | 19%                        |
| Santa Clara   | 1:104             | 1:348             | 17%                        |
| Alameda       | 1:115             | 1:367             | 15%                        |
| Santa Cruz    | 1:144             | 1:570             | 18%                        |
| San Francisco | 1:124             | 1:372             | 14%                        |
| Marin         | 1:155             | 1:378             | 12%                        |
| Bay Area      | 1:111             | 1:371             | 16%                        |
| California    | 1:118             | 1:431             | 18%                        |

Additional data:

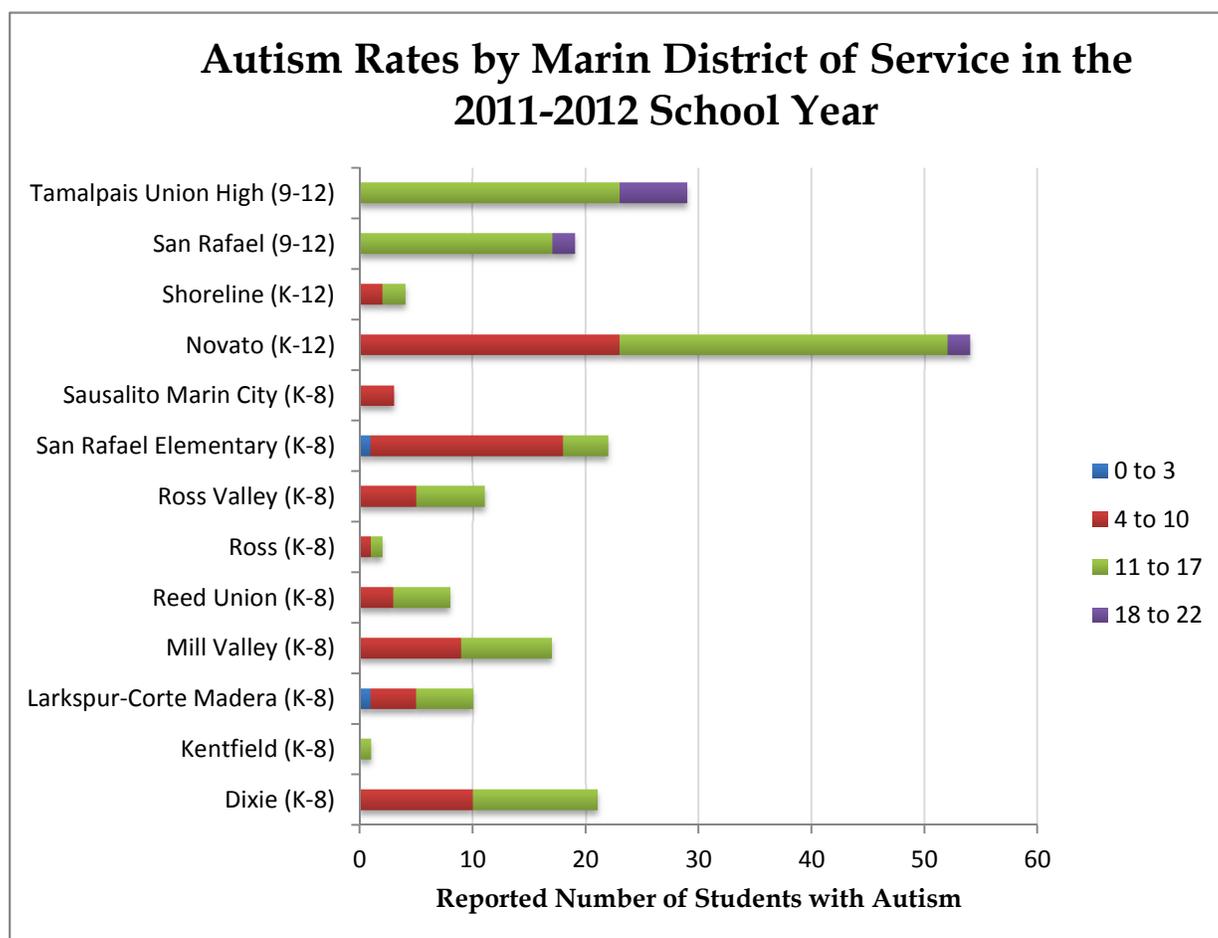
- In 2009 alone, the number of students with autism in six Bay Area counties increased to 707 – this is almost 4 new students added every day of the regular academic year (PACE)
- Autism is the least prevalent in Marin County, where the rate of students with autism is 5.2 per 1,000 (2007) (Kidsdata.org, Lucille Packard)

The data presented in the following graph represents the district that children with an ASD diagnosis resided in during the 2011-2012 school year in Marin County. The information was gathered from the California Department of Education's [DataQuest](#). Statistics are determined by IDEA Part B criteria.



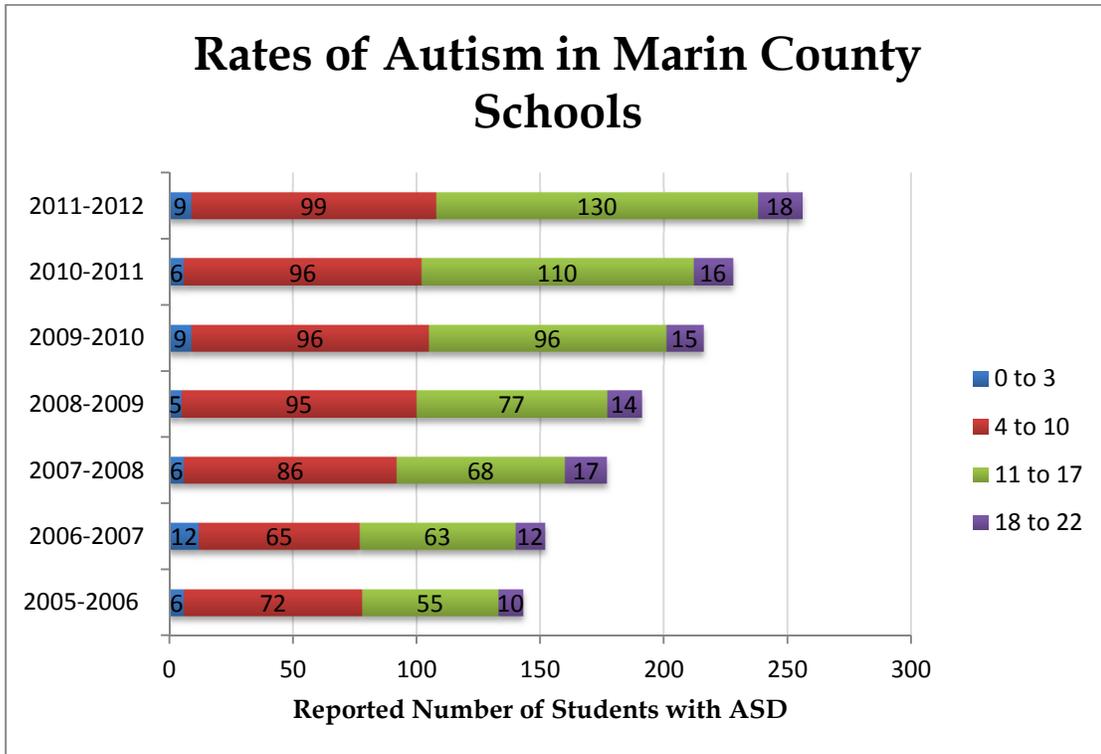
Districts of residence not included in this graph due to no reports of children on the spectrum: Bolinas-Stinson Union (K-8), Laguna Joint (K-6), Lincoln (K-6), Nicasio (K-8), and Union (K-12).

The following graph represents the district that children with an ASD diagnosis received services in during the 2011-2012 school year in Marin County. The information was gathered from the California Department of Education's [DataQuest](#).



Districts of service not included in this graph due to no reports of children on the spectrum: Bolinas-Stinson Union (K-8), Lagunitas (K-8). There was no data available for the following districts: Laguna Joint (K-6), Lincoln (K-6), and Union (K-12).

The following graph represents the number of students with autism in Marin County Schools by school year. The information was gathered from the California Department of Education's [DataQuest](#). DataQuest's statistics are determined by IDEA Part B criteria.



It is not reported whether this data includes students with diagnoses of Asperger's and PDD-NOS.

## State Level Data

### Talking points:

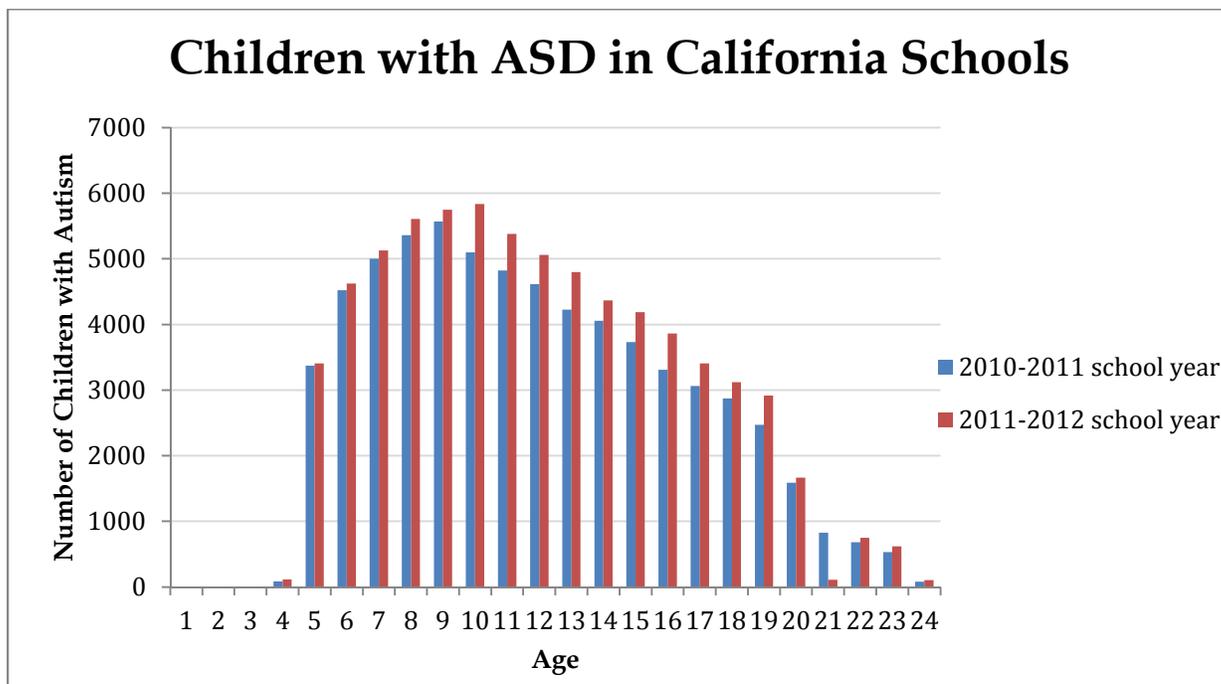
- Autism is the fastest growing diagnosis in the California Special Education System (PACE).
- Trend data shows more children are being supported during the early intervention years (ages 3-5) (PACE).
- From 2001-2009 the number of California students affected by Autism grew by 40,000 individuals (PACE)
- In 2001, individuals with autism made up 2% of the California special education system. In 2009, that percentage increased to 8% (PACE).
- As of 2008, the peak autism cohort in California schools is around five years of age (PACE).
  - This means that the peak cohort in 2013 would be around ten years of age. These students will be transitioning out of school in the next 8 to 10 years.

*The above data was collected from a [2010 report](#) by the Pacific Autism Center for Education (PACE) on the growth of autism rates in California schools.*

### Education Data:

- In 2000, 13,979 (2.17%) of children ages 3-21 who received special education services in California had autism (Easter Seals).
- In 2009, the California Department of Education reported that 53,183 students were receiving services related to an autism diagnosis (PACE).
- In 2010-2011, 65,735 (9.78%) of children with disabilities ages 3-21 who received special education services have autism (Easter Seals).
- In a survey conducted by the Autism Society of California (2012), 77% of children with autism were enrolled in special education.

The following graph is comprised of data collected by the [California Department of Education](#). This graph displays the age and number of children with ASD in California Schools (it is unknown whether this data only represents public schools in California or if it also includes private schools). The total number of students with ASD in California is 71,825 (2011-2012 school year).



#### Regional Center Data:

*Note: in 2009, the Regional Center served 15,941 fewer students than the California Department of Education. This may be because individuals with Asperger's and PDD-NOS are not eligible for services through the Regional Center.*

- In 2010, individuals with autism accounted for 23% of all cases in the regional centers (does not include individuals in the 0-3 age range) (PACE).
- From 2009-2010, individuals with autism accounted for 50% of all new cases in the regional centers (does not include individuals in the 0-3 age range) (PACE).
- Of the 48,888 Regional Center clients with Autism in 2010, 84% are 21 years or younger, 75% are 17 and younger (does not include individuals in the 0-3 age range) (PACE).
- In 2009, the Regional Center reported that 37,242 individuals between the ages of 3 and 21 were receiving services related to an autism diagnosis (PACE).

Housing Data:

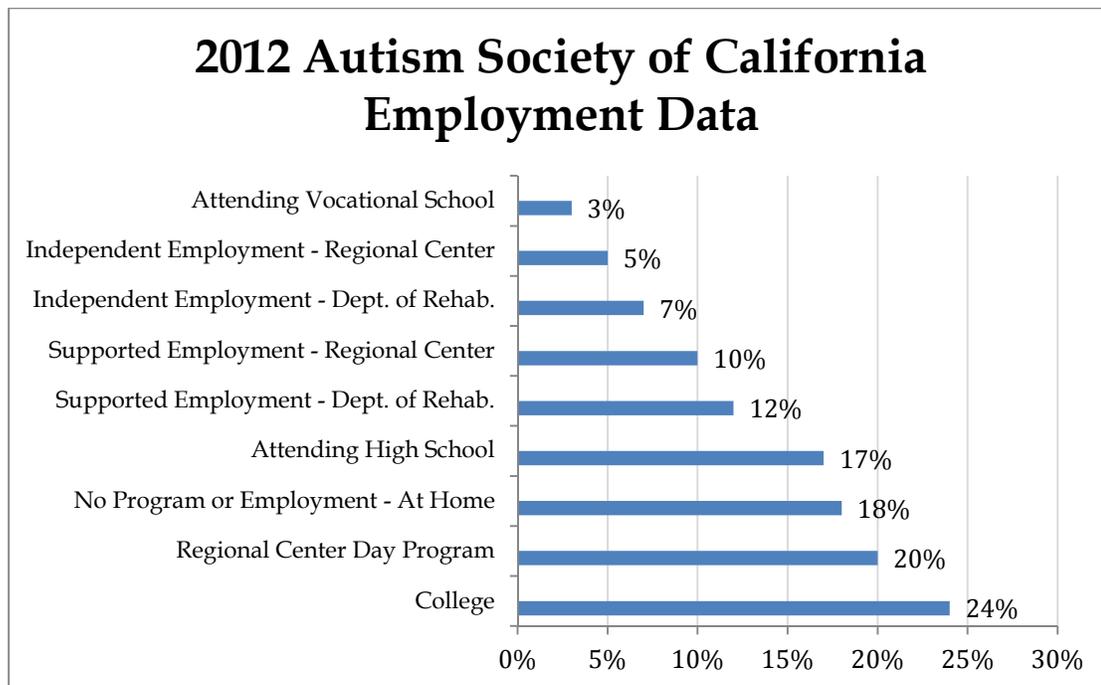
The following housing data was reported by the Golden Gate Regional Center (GGRC) and compares the [living arrangements](#) of adults and children served by regional centers at the local Golden Gate Regional Center and regional centers throughout California (2011). These numbers were estimated from a line graph and are not autism-specific.

Percentage of Adults and Children in Various Living Arrangements: A Comparison Between Local and State Levels (GGRC vs. California)

| Type of Living Arrangement             | GGRC    | State (California) |
|--|---------|--------------------|
| Adults living in home settings         | 71%     | 75%                |
| Adults living in 7+ bed facilities     | ~4.5%   | ~3.5%              |
| Adults living in developmental centers | 2%      | ~.75%              |
| Children living with families          | ~98.75% | ~98.75%            |
| Children living in 7+ bed facilities   | 0%      | ~.75%              |

Employment Data:

The following graph is comprised of data that was collected from a [survey](#) of over 1400 individuals with ASD and reported by the Autism Society of California in 2012.

Diagnostic breakdown of adults with ASD:

A 2012 [survey](#) by the Autism Society of California polled adults regarding the diagnostic labels they had received.

68% were diagnosed with autism.

14% were diagnosed with Asperger's.

14% were diagnosed with PDD-NOS.

4% did not receive a formal diagnosis.

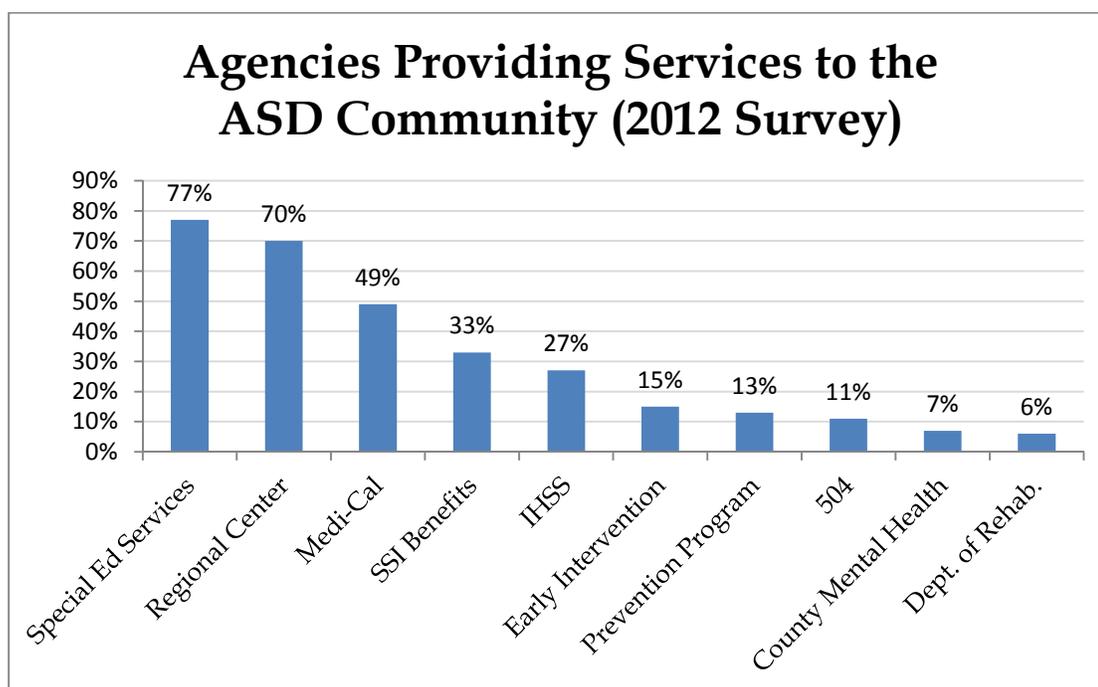
### Comorbidity Data:

87% of individuals with ASD who completed a [survey](#) for the Autism Society of California (over 1400 responses) in 2012 reported the following co-morbid conditions. More than 10% of families reported the following comorbidities. This list does not include all reported comorbid conditions.

| Comorbid condition      | Percentage of Children with condition | Percentage of Adults with condition |
|-------------------------|---------------------------------------|-------------------------------------|
| Anxiety                 | 47%                                   | 55%                                 |
| Sensory processing      | 43%                                   | 36%                                 |
| Feeding issues          | 43%                                   | 30%                                 |
| ADD or ADHD             | 37%                                   | 36%                                 |
| Allergies               | 37%                                   | 40%                                 |
| OCD                     | 29%                                   | 38%                                 |
| GI Issues               | 25%                                   | 29%                                 |
| Intellectual Disability | 23%                                   | 31%                                 |
| Executive functioning   | 21%                                   | Not reported                        |
| Learning Disability     | 19%                                   | Not reported                        |
| Sleep disorder          | 19%                                   | 24%                                 |
| Depression              | 15%                                   | 28%                                 |
| Seizures                | 11%                                   | 18%                                 |
| Bipolar disorder        | 6%                                    | 11%                                 |

### Agencies Providing Services to the ASD Community:

The following graph is comprised of data gathered in a 2012 [survey](#) conducted by the Autism Society of California. The data collected reflects the agencies in California from which individuals with ASD are currently receiving services, as well as what percentage of the sample receives services from each agency.



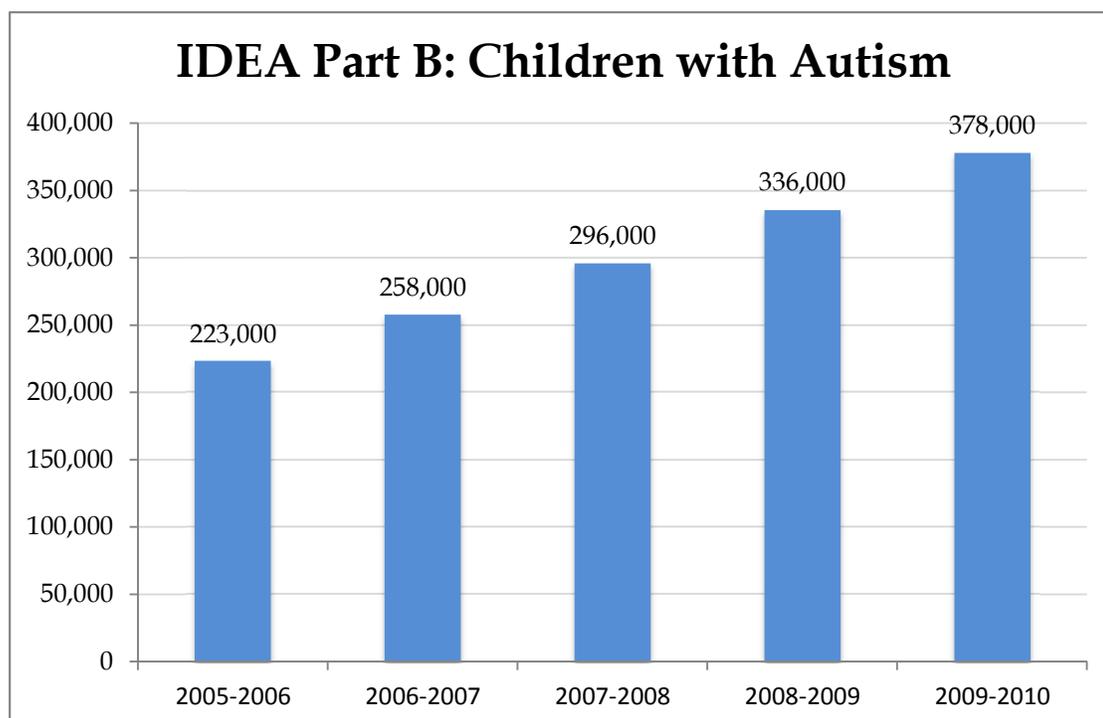
## National Level Data

Talking points:

- ASDs are almost 5 times more common among boys (1 in 54) than among girls (1 in 252). (CDC)
- About 1 in 88 children has been identified with an ASD. This marks a 23% increase since the CDC's last report in 2009 and a 78% increase since their first report in 2007. (CDC)
- ASD commonly co-occurs with other developmental, psychiatric, neurologic, chromosomal, and genetic diagnoses. The co-occurrence of one or more non-ASD developmental diagnoses is 83%. The co-occurrence of one or more psychiatric diagnoses is 10% (2010). (CDC)
- 1 in 50 school-aged children have autism, according to a survey (2012) (CDC, \*[national survey](#) of 65,556 parents of children with ASD between the ages of 6-17)

## Education Data

The following graph is comprised of data obtained by the [U.S. Department of Education](#). This graph displays the number of children between the ages of three and twenty-one with a diagnosis of ASD who received services under IDEA Part B.



**Limitations/Gaps in Available Data Include:**

1. Limited data regarding **housing, employment, and adults with autism**
2. The only **comorbidity data** available was gathered from a national survey
3. Lack of raw numbers in reports about the ASD population (data usually represented in graphs without exact numbers)

**Service Recommendations:**

1. Increased need for transition services for students transitioning out of high school
2. Increased need for services catering to ASD students around age 10, which is estimated to be the new age of the peak cohort in California as of 2013 (*See page 11*)
3. It is recommended that local websites maintain updated resources for relevant autism statistics.

## References

Autism Society of California (<https://autismsocietyca.org>)

California Department of Education (<http://www.cde.ca.gov>)

Center for Disease Control and Prevention (<http://www.cdc.gov>)

Easter Seals

([http://bayarea.easterseals.com/site/PageServer?pagename=CABY\\_homepage](http://bayarea.easterseals.com/site/PageServer?pagename=CABY_homepage))

Golden Gate Regional Center (<http://www.ggrc.org>)

Lucille Packard Foundation for Children's Health (<http://www.kidsdata.org>)

Pacific Autism Center for Education (<http://pacificaautism.org>)

U.S. Department of Education (<http://www.ed.gov>)



**The data compilation will assist you in creating presentations about autism and autism services.**

1

2

3

4

5

Strongly disagree

Strongly agree

Comments:

**If the data compilation does not include all of the information you need, what is missing?**

**Do you have any additional suggestions for us?**