Promoting Awareness of Autism Spectrum Disorders and Resources to Diverse Stakeholders in Rural Hawaii: a Community Based Approach

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Chapter One: Statement of the Problem, Project Aims and Objectives

Autism Spectrum Disorders (ASD) are a group of developmental brain disorders with a wide range of individual symptom and impairment expressions from mild to severely disabling. Data from 2010 indicated one in 68 children have an autism spectrum disorder (CDC 2014). An updated surveillance report confirms incidence rates have remained the same (Christensen, Baio, Braun, et al, 2016). Morrier, Hess, & Heflin (2008) found that Native Hawaiians and multi-racial children are under-identified with ASD 99% of the time. Many people associate ASD with severe repetitive behaviors such as hand flapping or significant communication problems and unfortunately disregard other subtle cues. Mandell, Ittenbach, Levy, and Pinto-Martin (2007) found a high prevalence of initial incorrect diagnosis in children with ASD prior to eventual correct diagnosis. Research has confirmed that diagnosis of children as young as two years old is reliable, valid, and stable, yet most children are not diagnosed until age four or older (Lord et al., 2006; CDC, 2015). Early intervention has been shown to be the most effective means of improving a child’s development and functional status, however intervention at any age is beneficial. Incorrect and under-diagnosis contributes to under use of intervention services that results in negative impact on IQ, functional ability, and adult productivity. Current research is focused on finding the earliest signs of autism as early intervention may prevent disabling ASD behavior expression (NIMH, 2012). However, this research may be ineffective without consistent early childhood screening and evidence-based (EB) interventions.

Background: Autism Spectrum Disorders
Autism has been referred to as a rainbow, umbrella, or spectrum syndrome as a means to explain the variable subtypes. “Spectrum” is the most widely accepted term. The five main categories of ASD include: Autistic disorder, Asperger’s disorder, Pervasive Developmental Disorder not otherwise specified (PDD-NOS), Rett’s disorder, and Childhood Disintegrative Disorder (CDD). Children with ASD do not follow typical developmental patterns with social and communication skills and tend to have repetitive, restrictive, and unusual behaviors (RRB’s). Occasionally symptoms will manifest in babies, while other children may appear to develop normally and then regress.

Communication in most children generally begins by the first birthday. Children with ASD are slow to respond to verbal cues such as their name and body gestures such as pointing. They have difficulty combining words into sentences but may repeat words or phrases they hear (echolalia) although they may not understand the meaning. These children often fail to make eye contact or respond to social input correctly. They have difficulty with non-verbal conversation, expressing their feelings, and understanding or following directions; and rarely seek out activities that involve the company of peers, such as group play (CDC, 2015). An inability to notice or interpret social cues such as voice tone, body language, and facial expressions contributes to social impairments. Poor language skills compound their inability to understand another’s point of view or actions. This may lead to aggressive behavior in attempts to fulfill their needs. Anxiety and depression is a common consequence in aging children as they become aware of their inability to communicate (CDC, 2015).

RRB’s can range from mild to extreme. RRB’s include unusual speech or behaviors, excessive adherence to routines, intense preoccupations, and highly fixated interests (CDC, 2015). The wide range of expression can vary from a preference and insistence for closed doors,
a unique way of walking (such as tiptoe) to severe hand flapping and rocking. Sometimes these repetitive behaviors are referred to as their stimulants (stims), as participation in the behaviors may serve to calm the child. The behaviors can change with time, for example, a six-month bout of teeth grinding could be replaced with high pitched squealing, or pulling out one’s hair (Trichotillomania). Additionally, changes in routine often result in meltdowns, emotional breakdown, and destructive or self-injurious behavior (NIMH, 2015).

While RRB’s and deficits in communication and social interaction are key defining characteristics of children with ASD, other symptom expressions are common (NIMH, 2015). Unusual sensory problems can range from dislike of touch or clothes on skin, over reaction to lights, sounds, tastes, or textures to no reaction from painful stimuli. Sleep problems are common. Poor sleep can make it hard for autistic children to pay attention and function during the day. Gastrointestinal disorders and co-occurring mental disorders are also common co-morbidities (CDC, 2015). Seizures caused by abnormal electrical activity in the brain can manifest as staring spells, convulsions, or short-term loss of consciousness. One in four children with ASD develop seizures in early childhood or teen years (NIMH, 2015). Intellectual abilities may vary widely. While children with ASD often have some form of intellectual disability, they may also have average or above average skills in other areas (CDC, 2014). Children with ASD often display behaviors similar to Attention Deficit Hyperactive Disorder (ADHD) therefore a diagnosis of ASD precludes a diagnosis of ADHD.

**Problem**

Hawaii state ASD rates have grown exponentially. The Hawaii Department of Education (DOE) reported 364 children age three to 21 received autism services in 1999-2000 through the Office of Special Education. Data from 2008-2009 indicate that 1,185 children in this age group
received services (Easter Seals, 2011). Although the more recent statistics indicate more diagnosed cases, it is unclear if this is due to better diagnosis or increasing prevalence. Hawaii state child population for this time period has been estimated at 285,243 (CDF, 2010); these 1,185 children equal 0.4% of the child population. Average national and international childhood rates of ASD are approximately 1.4% (CDC, 2014). Notably, this confirms disparities in diagnosis. It is likely that autistic children in Hawaii are misdiagnosed or undiagnosed. Identification and treatment of ASD in children is imperative as early intervention significantly affects life prognosis. Incorrect and under-diagnosis contributes to lack of appropriate interventions. Review of the literature reveals variables of poverty and parental isolation contributes to knowledge deficits regarding ASD and ASD treatments. Parental and provider knowledge deficits contribute to increased parental stress, poorer family functioning processes, and lack of therapeutic interventions. Rural environments and minority culture status exacerbates disparities in care. These complex and intertwining aspects are woven throughout the landscape of rural East Hawaii.

The Centers for Medicare & Medicaid Services contracted with L&M Policy Research (L&M, 2014) to address the increasing demand for accurate and thorough data on existing ASD services, supports, policies, and disparities in services in all 50 states. The resulting work was published in the *Autism Spectrum Disorders (ASD) State of the States of Services and Supports for People with ASD* (L&M, 2014). The report notes the principle site of ASD services in Hawaii is through the state Department of Health - Developmental Disabilities Division (DOH-DDD) that works with the DOE and community organizations. Apart from DOH-DDD, services for individuals with ASD are delivered in a fragmented manner (L&M, 2014). ASD providers have different sources of funding and cost sharing. The majority of specialty service providers
and support services in Hawaii are located on the island of Oahu. The high costs of obtaining EB specialty services outside of the DOE can be prohibitive. In addition, the state of Hawaii has not had insurance regulations specific to ASD. Legislators proposed laws requiring insurance coverage specific to ASD diagnosis and intervention, first in 2008 and in 2012, however these bills did not pass. Fortunately, Hawaii’s Governor Ige recently signed into law, Hawaii Act 235 (Luke’s Law) which requires insurance providers to cover the diagnosis and treatment of autism for children ages 13 and under effective January 1st, 2016.

Many efforts to improve coordination of ASD services concentrated on development of a funding source for provision of services. Families can apply for DOH-DDD sponsored services, however eligibility for services is dependent on the child meeting criteria in developmental or adaptive deficits. Therefore higher functioning autistic children may not meet guidelines to receive interventional care. Services outside of DOH-DDD and DOE are limited or unavailable in East Hawaii. Families with need may be unable to afford therapeutic services. Easter Seals is a primary referral agency for children one to three years old. Unfortunately children age out when they reach their third birthday. The DOE does provide some services for children age three and older. Processes to initiate special education services for older children requires parents or guardians request their child be evaluated at their neighborhood school. Results of the assessments are the basis for an Individual Education Plan (IEP). Both procedures, whether for a younger or older child, are lengthy and can be emotionally traumatic for the parents. Another reality for parents is the lack of babysitters and daycare providers that are willing or qualified to care for children with ASD. Economic hardship is often the result of limitations in time available for employment. At this time ASD resources are scarce in rural East Hawaii, Hawaii Island. Perhaps with improved funding and insurance coverage therapeutic care services will be
more readily available. Many healthcare providers are unaware of the scope of the problem; and those that are aware may not know all the available resources or the processes needed to refer clients.

**Problem statement.** There is a knowledge deficit regarding screening and EB intervention for ASD in East Hawaii causing disparities in diagnosis and care.

Data from 2010 and 2012 found childhood prevalence rates of ASD at approximately 1.4% (CDC, 2014; Christensen et al, 2016) although only 0.4% of children in Hawaii have been identified with ASD. The growing body of research confirms children have greater functional gains when diagnosed and connected to interventional services earlier. The *State of the States* report (L&M, 2014) noted Hawaii’s primary reliance on pediatricians for diagnosis, and provision of fragmented intervention services complicates early intervention goals. This results in negative impact to IQ, functional ability, and adult productivity for children affected by ASD as well as increased burden to the community.

The Doctor of Nursing Practice (DNP) essentials emphasize the translation of evidence-based research into clinical practice to improve and transform the health of populations. The University of Hawaii at Hilo’s DNP mission statement stresses management of care for rural populations through transcultural (culturally appropriate) interventions.

**Project Goal, Aims and Objectives**

The overarching project goal is to decrease disparities in diagnosis and treatment of ASD for multiethnic and Native Hawaiian children on Hawaii Island by increasing knowledge of ASD and ASD resources to the diverse stakeholders within rural East Hawaii.

**Aim 1: Determine stakeholder knowledge and needs.**

*Objective 1. Identify stakeholders within the community.*
Objective 2. Determine knowledge and needs through surveys with stakeholders.

Objective 3. Analyze survey data to identify stakeholder deficits in knowledge and needs.

Aim 2: Determine community resources.

Objective 1. Perform a literature search to determine EB knowledge and EB intervention recommendations for ASD.

Objective 2. Perform an assessment of community resources available for ASD that meet EB recommendations.

Aim 3: Increase knowledge of ASD and ASD services.

Objective 1. Develop tools to increase knowledge.

1a. Develop a comprehensive ASD website for East Hawaii based on EB recommendations and community assessment.

1b. Develop a brochure of the website with key ASD facts.

Objective 2. Evaluate the website.

This Practice Inquiry Project (PIP) is a tertiary prevention project based on Health People 2020 goals. The PIP encompasses the main Healthy People goals of: 1) increasing life expectancy and quality of life, and 2) eliminating health disparities among segments of the population. One focus area goal of Healthy People is to promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities. This project addresses the disparities in ASD diagnosis and treatment services in rural East Hawaii through collaborative input from diverse stakeholders through open-ended survey questions and the creation of a website with comprehensive ASD information specifically for East Hawaii, Hawaii island. The website identifies healthcare provider
information, screening and diagnosis processes, EB treatment options, support groups, and other identified concerns of stakeholders to promote the health of those affected by ASD.

Identification of community specific needs and provision of community specific resources through one easily accessed site can improve provider and caregiver knowledge, may decrease fragmentation of services, and improve use of available resources.

Chapter Two: Review of Literature and Theoretical Framework

A review of literature was performed to best understand the scope of the current knowledge regarding ASD, diagnostic variables, and EB intervention services. The major search engines employed include Proquest, and EBSCOhost. Additional reference sites contributing extensive current knowledge include: the Centers for Disease Control, the Interagency Autism Coordinating Committee, the National Institute of Health, and the National Institute of Mental Health. Specific knowledge was sought in autism spectrum disorders, disparities, social determinants of health, ASD screening tools, diagnostic variables, and socio-cultural characteristic of Hawaiians.

Screening and Diagnosis of Autism

The American Academy of Pediatrics (AAP) recommends periodic well-child developmental screenings at nine, 18, and 30 months old, and ASD specific screening at 18 and 24 months (Johnson & Myers, 2007). The CDC’s Learn the Sign’s, Act Early program (2015) provides information on developmental milestones from two months of age until five years old. The CDC program provides parental guidance and information for clinicians in detecting children who are not meeting normal developmental goals. The Ages and Stages Questionnaire (ASQ) is a common parent completed developmental screening tool with a sixth grade reading level. It has 19 age specific questionnaires from birth to age 21. The ASQ has been found to
have inconsistent sensitivity (-.75 – 0.89) although specificity (0.82 – 0.96) for identifying development concerns is good (Ringwalt, 2008). The Denver developmental test is a common assessment test administered by a clinician or trained paraprofessional. There are 125 parent reported or performance based items that are used to identify functional status in language skills, gross and fine motor ability, and personal-social development. The Denver is available in English and Spanish versions. Ringwalt (2008) notes the normative population sample used to evaluate the Denver overrepresented Hispanic children and children of Caucasian mothers with higher educational levels while under-representing African American children. Therefore, the Denver may not be an appropriate screening tool for diverse populations. Additionally, screening with the Denver has been shown to miss children with developmental disabilities (Ringwalt, 2008).

The American Psychiatric Association's (APA) Diagnostic and Statistical Manual, Fifth Edition (DSM-5) provides standardized criteria to help diagnose ASD. The DSM-5 replaces the numerous diagnostic options in the DSM-IV (fourth edition) with just one classification of ASD. Gradzinski, Huerta, & Lord (2013) summarized the revisions to the DSM-5 and reviewed the literature that supports the changes to improve identification of ASD subtypes. The main criteria are, Section A: persistent deficits in social communication and social interaction; and Section B: RRB’s and unusual interests or activities. The criterion noted in section A includes difficulty with social emotional reciprocity, non-verbal communication, and lack of reciprocal relationships. The criterion noted in section B includes repetitive speech or movements, unusual use of objects, adherence to routines and rituals, restricted and intense interests, and unusual sensory interests or reactions. Changes in the DSM-5 include removal of the DSM-IV clinical subtypes; and removal of the requirement of verbal delay as this is not a universal characteristic
and has been shown to be highly variable in individuals with ASD. The addition of unusual sensory responses has been noted as common in ASD and helps distinguish the disorder from other conditions. While symptoms of anxiety and insistence on sameness are qualitative characteristics that may help identify ASD subtypes (Gradzinski et al., 2013).

Diagnosis of ASD is often a two-stage process. Generally, diagnosis relies on pediatrician identification of ASD risk and referral for further diagnostics and intervention services. Children found to have some level of developmental delay during screening are often referred for additional evaluation. First stage screenings do not diagnose, they only indicate a possibility for additional diagnostic evaluations. However, first stage screenings are key to improving early diagnosis of ASD. Additional evaluations for children who screen at risk for ASD may include referral to child psychologists, neurologists, genetic specialists, and speech and hearing therapists. Other tests include IQ, speech, language, problem solving, brain imaging, and fine and gross motor development.

There are many screening tools used for assessing ASD risk. The NIMH (2015) has numerous autism screening tools for toddlers and older children listed on their web publications. These include: The Modified Checklist for Autism in Toddlers (M-CHAT), Screening Tool for Autism in Two-Year-Olds (STAT), Social Communication Questionnaire (SCQ), Communication and Symbolic Behavior Scales (CSBS) and the Childhood Asperger Syndrome Test (CAST). The CDC provides an ASD webpage (2016) that also lists the M-CHAT, the STAT, and the CSBS. For the purpose of this project, the ASD screening tools previously noted by the NIMH (2015) and the CDC (2016) will be discussed.

Neuropsychologists Diana Robins and Deborah Fein and clinical psychologist Marianne Barton developed the original M-CHAT. The M-CHAT-R/F is a newer revised version with a
follow-up questionnaire. It is a validated, quick, easy to complete and score, screening tool that requires little to no training. Screening requires parent participation for 20 short answer questions with a structured clinician follow-up for those children with a score of three - to - seven indicating medium risk for ASD. A score greater than eight indicates high risk; these children should be immediately referred or scheduled for additional evaluation. A score less than three indicates low risk and requires no further follow-up. The screening time is approximately 10 minutes. The revised screening tool includes simplified language to improve utilization. The rate of ASD detection is significantly higher for the M-CHAT-R/F compared with the original M-CHAT, including a reduction in the initial screen-positive rate without affecting sensitivity (Robins et al., 2014). Children who screen positive on M-CHAT-R/F at their 24-month check-up were 114 times more likely to receive an ASD diagnosis than children who screened negative (Robins et al., 2014). Children who scored ≥3 on initial screening or those that scored ≥2 after follow-up interview had a 47.5% risk of ASD (95% CI: 0.41–0.54) and a 94.6% risk of any developmental delay or concern (95% CI: 0.92–0.98) (Robins et al., 2014). The use of the MCHAT-R/F results in significantly earlier diagnosis of ASD than for children who are not specifically screened for autism. The M-CHAT (R/F) is the primary ASD screening tool used both nationally and globally (Robins et al., 2014). It is the recommended screening tool for children 18 and 24 months old per the AAP guidelines (Johnson & Myers, 2007). The MCHAT-R/F is free for clinical, research, and educational use. It is available online in more than 45 languages.

The STAT tool was developed for screening of toddlers from 24 to 36 months at the Vanderbilt Kennedy Center Treatment and Research Institute for Autism Spectrum Disorders. The STAT consists of 12 items and takes about 20 minutes to administer from trained
individuals. The STAT tool is for use with children who are suspected of having ASD or developmental disorders; therefore it may not be the best tool for standardized screening. The STAT tool has less specificity for children younger than 24 months (Vanderbilt Kennedy Center, 2015). Pediatricians, psychologists, speech-language pathologists, social workers, preschool teachers, and early intervention specialists are the primary providers who administer the STAT (Vanderbilt Kennedy Center, 2015). Use of the tool requires a nominal fee and training provided through Vanderbilt Kennedy Center. Many children do not receive a definitive diagnosis until they are three years or older. The narrow age window for screening and the required training may inhibit acceptance of this tool for many providers.

The SCQ is useful as a quick and easy screening tool for older children. It is available through Western Psychological Services for a nominal fee. The SCQ is a 40-item parent-participation screening tool for children age four and over with a mental age of at least age two. The SCQ takes about 10 minutes to complete by a trained psychologist, therapist, or educator and provides information about a child’s body movements, use of language or gestures, and style of interacting. The mean SCQ score of children with autism is 24.2, whereas the general population mean is 5.2. The threshold reflecting the need for diagnostic assessment is 15 (Rutter, LeCouteur, & Lord, 2003). McConachie et al. (2015) performed a systematic review of screening and diagnostics tools used to measure aspects of ASD; results indicated internal consistency and good discriminative validity between autism and other disorders, although the SCQ is poor at identifying variant sub-types of ASD. Garcia-Primo et al. (2014) report a higher false-negative result with the SCQ in children with higher intellectual ability compared to toddlers with intellectual disability. This suggests higher functioning children with ASD are more difficult to discern on the SCQ from their peers without ASD.
The CSBS assesses speech, social communication, and symbolic abilities of young children. It consists of three sections: a 24 item Infant–Toddler Checklist (ITC), a Caregiver Questionnaire, and a face-to-face Behavioral Evaluation with the child, parent, and clinician. The three measures are designed to assess social, speech, and symbolic skills. McConachie et al. (2015) report g coefficients ranging from 0.92 to 0.97 for the composites and total score indicating good validity of the tool. However, the small sample size of the study may represent a biased outcome. The CSBS ITC measures seven language predictors and developmental milestones for children from six to 24 months of age. Wetherby, Brosnan-Maddox, Peace, and Newton (2008) found inconclusive evidence to support use of the tool in six to eight month old infants, however, they found the CSBS ITC has positive and negative predictive values that support the validity of the ITC for children nine to 24 months of age.

The CAST tool is a 39-item parent participation questionnaire. Also known as the Childhood Autism Spectrum Test. This questionnaire was developed by the Autism Research Center at the University of Cambridge for assessing the severity of autism spectrum symptoms in children. Although designed to screen school-age children for Asperger syndrome, a higher functioning subtype of autism, it targets the complete spectrum of symptoms. The CAST is more sensitive to milder ASD symptoms with a high specificity (.98). However, it has a poor predictive value (.64) and is determined to have a high false positive rate (Fernandopulle, 2011). The CAST may be more appropriate for children determined to be high risk prior to screening than as an overall screening tool.

**Physiology of Autism**

Diagnosis of ASD is challenging due to a lack of identified biological and genetic markers, diverse symptom presentation, changing diagnostic criteria, and individual variance in
perceptions of symptoms. Currently, diagnosis is determined by the child’s behavioral symptoms. Researchers believe there are numerous causes that result in the varied phenotypes of ASD (CDC, 2015). Contributing factors include environmental, biological, and genetic events during the critical period of child development In-utero, and during or immediately after birth (Gardener, Spiegelman, & Buka, 2011). Children conceived with assisted reproductive technology (ART) are twice as likely to be diagnosed with ASD compared to children conceived without ART. This is likely due to higher risk pregnancies from multiple fetuses and delivery outcomes such as prematurity and low birth weight (Fountain et al., 2015; Kissin et al., 2015). Kissin et al. (2015) found increased incidence of ASD with ART when children were conceived using intracytoplasmic sperm injection as compared to traditional In-vitro fertilization. Schieve et al. (2014) found a 12 -13% increased risk for ASD in children born too small, too early, or by Cesarean delivery. There are strong genetic risk factors. Couples who have a child with ASD have a higher risk of ASD in siblings. Maternal twins have a higher risk than fraternal twins (CDC, 2015). Genetic and chromosomal conditions such as fragile X and tuberous sclerosis are also associated with higher risk for ASD (CDC, 2015). Valproic acid and thalidomide have been linked with a higher risk of ASD when taken during pregnancy (Christensen et al., 2013; Strömland, Nordin, Miller, Akerström, & Gillberg, 1994). Children of older parents are also at higher risk for developing ASD (Durkin et al., 2008).

Gender Differences

Autism is diagnosed in boys much more frequently than in girls, with a ratio of 4:1. Supekar and Menon (2015) explored sex differences in brain structural organization and sex differences in behaviors of ASD between 25 boys and 25 girls with ASD compared to typically developing peers (mean age 10.2 years). Results of the research revealed significant differences
in brain structure associated with sex. This includes the cortical and subcortical motor systems associated with RRB severity as well as sex differences in the brain systems associated with social communication. However, there were no differences in overall symptom severity associated with sex, suggesting girls and boys are similarly autistic (Supekar & Menon, 2015). There are distinct behavioral phenotypes in girls compared to boys. Boys express more obvious RRB’s compared to girls. RRB’s are often the most overt and socially inappropriate symptoms that flag children for diagnosis. The difference in female behavioral expression of ASD may account for differences in diagnostic rates (4 boys: 1 girl) and suggests possible under-diagnosis, delay of diagnosis, and misdiagnosis for girls (Supekar & Menon, 2015).

**Prevalence of Autism Spectrum Disorders**

The Autism and Developmental Disabilities Monitoring (ADDM) Network is a department of the CDC and functions as an active surveillance system that estimates the national prevalence of ASD (CDC, 2012). The ADDM Network monitors ASD data on children eight years old, determined to be the age of peak prevalence. The ADDM has four main goals: 1) obtain dependable statistics of the prevalence of childhood ASD in the monitoring sites, 2) compare population prevalence and determine if ASD rates fluctuate over time, 3) determine if ASD is more common in specific population groups, and 4) provide descriptive statistics of children with ASD. While not representative of all individual states, the selected sites provide comprehensive surveillance data. Surveillance was performed through analyzing diagnostic and developmental reports from therapeutic providers, including pediatricians, psychologists, and therapists. Approximately one in 42 boys and one in 189 girls were identified with ASD (CDC, 2014). Information on functional ability such as I.Q., schooling, race, and sex was collected. Seven sites with statistics on intellectual ability found 54% of children with ASD had borderline
or below average IQ scores while 46% had average or above average intellectual ability (CDC, 2014).

In 2000, the incidence of ASD was estimated at one in 150 children. Data found from 2008 found prevalence rates of 11.3 per 1000 (one in 88) while data from 2010 and 2014 indicate one in 68 (1.4%) children have an autism spectrum disorder (CDC, 2014; Christensen et al., 2016). Lack of specific data types from some surveillance sites has resulted in significant differences in prevalence statistics. For example, one county in Colorado with both health and education records revealed twice the prevalence compared to the other six Colorado counties that reviewed only health records (CDC, 2012). Florida and Alabama had large percentages of children's records missing, which likely under-represents ASD prevalence in these counties. The 2010 prevalence estimates of ASD in children eight years old varied among ADDM sites from 5.7 to 21.9 per 1,000 (CDC, 2014). Other studies of prevalence rates in Asia, Europe, and the US show similar results to ADDM tracking statistics (CDC, 2012). A British study that employed both parental questionnaires and screening revealed ASD rates at nearly 1% of the childhood population (Fombonne, 2010). However, a South Korean study that used screening with clinician assessment found a prevalence rate of 26.4 children per 1000 (2.6%) (Kim et al., 2011). This could indicate the use of direct screening combined with assessment from trained professionals is a better ASD risk indicator than parental reports. Analysis of the National Health Interview Survey revealed a fourfold increase in ASD rates between the 1997-1999 and 2006-2008 surveys, while the 2014 report confirmed a continued upward trend (CDC, 2014).

**Health Disparities**

Numerous definitions of *Health Disparities* exist. Internationally, health disparity is often defined as a difference or inequality that is unnecessary, avoidable, unfair, and often
associated with socioeconomic status (Braveman, et al., 2011). The United States' National Institute of Health (2012, p.12) defines health disparity as “a population that suffers disproportionately in the burden of illness and death...a significant difference in the rate of disease incidence, prevalence, morbidity, mortality, or survival rates in a population group compared to the health status of the general population...with racial and ethnic minorities, low socioeconomic status, and rural persons currently designated as health disparity populations.” Healthy People 2010 refers to disparities as differences that occur related to gender, race, economic status, sexual orientation, or rural status. Healthy People 2010 had a goal to eliminate health disparities. Healthy People 2020 expanded this goal to include the achievement of health equity and improve health of all groups, including those with disabilities. Healthy People 2020 defines health equity as the attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally, and requires societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and healthcare disparities (USDHHSOMH, 2015).

Braveman et al. (2012) succinctly define disparities as "worse health among socially disadvantaged groups" (p.153). Health disparities have been well documented since the 1940s. Minorities often receive unequal and poorer quality healthcare than whites (Alwin & Wray, 2005; Gee & Payne-Sturges, 2004). Inequalities persist even when variables of access, socioeconomic status, and healthcare insurance are controlled. Health disparities affect not only specific populations but also the entire US health system. Disparities are not just differences in health outcomes but are inequities as a result of social injustice (Braveman et al., 2012). The costs associated with health disparities affect individuals, families, communities, healthcare organizations, employers, health plans, and government agencies. LaVeist, Gaskin, & Richard
(2009) estimated the combined direct and indirect costs associated with health inequalities in the US from 2003-2006 exceeds $1.24 trillion. Buescher, Cidav, Knapp, and Mandell (2014) evaluated the direct, indirect, and societal costs associated with ASD. The current lifetime cost of support for a person with ASD and intellectual disability was found to be $2.4 million. Whereas the lifetime costs of support for a person with ASD without intellectual delay is 1.4 million. A significant portion of the cost is associated with loss of parental productivity and supportive living arrangements for adults with ASD. This reflects the increased need for societal support services. Early intervention and behavioral therapies that improve skill acquisition for activities of daily living can substantially reduce lifetime costs. Despite the social injustice associated with health disparities, there is no wonder to the growing governmental focus toward elimination of health disparities from various departments of the NIH, including the Office of Minority Health, the National Center for Minority Health, the Joint Center for Economic and Political Studies, the Department of Health and Human Services, and the National Center for Children's Health, as well as numerous state and private agencies. Dean and Fenton (2013) found collaborative partnerships and health communication improved awareness, promoted exchange of ideas, and encouraged new conversations that resulted in sharing of helpful EB practices. Strategic actions that address awareness and involve broader partnerships promote health equity and address social determinants of health.

Research on healthcare disparities in minority children tends to group children into just a few categories. Research on childhood disparities in health has focused primarily on specific measures such as obesity, oral care, and unmet care. Lau, Lin, and Flores (2012) performed a secondary data analysis of the 2003 National Survey of Children's Health to better understand racial and ethnic disparities among adolescents. The data analysis reviewed 48,742 interviews of
children 10-17 from the 2003 National Survey of Children's Health. Lau, et al. (2012) evaluated 40 health and healthcare categories. The children were divided into six identifying subsets; Caucasian, Latino, African American, Asian/Pacific Islander, American Indian/Alaska Native (AI/AN), and Multiracial. Results of the data indicate marked disparities in specific racial and multiracial groups with regard to suboptimal health, obesity, poor oral health, non-insurance, deficits in preventive care, lack of personal primary care providers, lack of medications, and difficulty obtaining specialty care. African American and Latino adolescents had the highest rates of behavioral problems and ADHD diagnosis. AI/ANs were more likely to have learning disabilities. African American's, multiracial, and AI/ANs had the highest rates of difficulty with emotions, concentration, behavior, or interpersonal relationships. Native Hawaiians were categorized with Asians and other Pacific Islanders. Approximately half of Asian/Pacific islanders and AI/ANs had trouble getting specialty care. Although assessing for ASD diagnosis was not a health measure in this study, it is significant that Asian/Pacific islanders had substantially higher rates of not receiving both mental health care and physician visits within the last year. Therefore they may not be diagnosed with mental or behavioral health disorders.

**Social Determinants of Health**

Social inequalities have long been and are still prevalent in society (Alwin & Wray, 2005). Research to identify, clarify, and document social determinants of health has shown that health disparities are multidimensional and are the result of the interaction of social, environmental, behavioral, and biological factors. There is a clear relationship between social and structural inequalities and health disparities. Morello-Frosch and Lopez (2006) cite numerous research studies that confirm contributors to health disparities include imbalanced industrial development, zoning policies, tax incentives, corporate opportunities, and
discrimination in private and governmental financing. These policies result in racial segregation and disproportionate negative environmental exposures to minority communities. Disadvantaged communities face greater likelihood of exposure to ambient hazards, while the stress from racism and poor life conditions amplify the effects of toxins (Gee & Payne-Sturges, 2004). Fossil-fueled power plants and industrial facilities such as chemical, cement, and manufacturing facilities are major sources of dangerous air pollutants, including mercury, arsenic, dioxins, acid gases, heavy metals, and smog. Many heavy metals, chemicals, and agricultural pesticides are known carcinogens that can attack and disrupt the functioning of organs such as the kidneys, liver, lungs, or brain. Mercury is a neurotoxin that can cause brain damage and mental retardation, especially in the developing brains of unborn babies and infants. Manufacturing facilities are also major sources of soot pollution and other particles formed through fossil fuel combustion. These particles can penetrate into the lungs and trigger asthma attacks, cause bronchitis, heart attacks, strokes, and even death (EPA, 2012).

Seith and Kalof (2011) examined health disparities of poor children in the US by race and ethnicity. They found poor African American children are more likely to live in single-parent families, live in households with income less than half of the federal poverty line, are more than twice as likely as poor Caucasian and poor Hispanic children to have significantly higher blood levels of lead, and are more likely to be diagnosed with asthma. Poor Hispanic children are more likely to live in households with food insecurity; they are most likely to have no health insurance and no place to go for health care when sick. Poor Caucasian children are more likely to live in households with smokers.

Hochberg, et al. (2011) reviewed 565 reports on epigenetic research and child health, which confirmed the relationship of environmental conditions with the developmental origins of
disease. Children marginalized by race and socioeconomic barriers have a high risk for poor health. Environmental influences during fetal and early childhood experiences can alter gene regulation and influence disease susceptibility later in life (Hochberg et al., 2011). Childhood health can predict adult health and adult productivity. Social inequalities affect the conditions of one's life course, risk exposures, and resources. Which in turn can determine the quality of one’s health and can even predict death trajectories. Dickerson et al. (2015) evaluated the association between ASD prevalence and exposure to environmental hazards. A higher prevalence of ASD was found (CI; 95%) in residential neighborhoods within closest distance to facilities that emit air pollutants, industrial waste, agricultural pesticides, and high roadway traffic than in neighborhoods at the furthest distance from environmental pollutants (Dickerson et al. 2015).

**Disparities in Diagnosis of Autism Spectrum Disorder**

In an effort to determine the number of minority children with ASD in the Netherlands, Begeer, Bouk, Boussaid, Terwog and Koot (2009) performed a two-fold study that compared 712 records of children referred to autism institutions with actual population proportions, and evaluated 82 pediatrician responses to case vignettes. The vignettes were written to describe typical pediatric encounters and provoke clinical judgments associated with ASD diagnosis. Begeer et al. (2009) found a significant under-representation (2.1% compared to the expected 4.4%) of minority Moroccan and Turkish children at ASD institutions; and pediatrician bias toward Dutch majority groups with spontaneous clinical judgments. However, when the pediatricians were instructed to evaluate for ASD the bias disappeared. These results suggest standardized screening and awareness of biases will improve ASD diagnosis.

Dosreis and Weiner (2006) evaluated factors that influence the use of developmental and autism-specific screening tools in pediatric practice, barriers involved in screening, and
pediatrician’s beliefs regarding ASD. Although 71% of the pediatricians believed that ASD prevalence has increased, only 8% reported routine screening for ASD. The pediatricians attributed a lack of familiarity with the tools (62%), referral to a specialist (47%), or not enough time (32%) as their reasons for not screening for ASD. Increasing awareness and familiarity with screening tools are actions recommended to improve ASD screening.

To determine whether children diagnosed with ASD are first diagnosed with other disorders, and if there is a racial or ethnic difference associated with misdiagnosis, Mandell, et al. (2007) evaluated 406 children's files that had received ASD services through the Philadelphia, Pennsylvania Medicaid program in 1999. Only 178 children received an autism diagnosis on their first mental health visit. Of the 228 children who received other diagnosis, ADHD was the most common diagnosis (21.4%), followed by conduct related disorders, adjustment disorders, and cognitive disorders. African American children were more likely to receive conduct disorders, while Caucasian children were more likely to receive adjustment disorders. Children from families that had been Medicaid eligible for longer than one year received a diagnosis other than autism 3.4 times more often, suggesting poverty may play a role in diagnostic disparities. Thomas et al. (2012) evaluated the association of socioeconomic status (SES) with ASD diagnosis. Children who live in families and neighborhoods with higher SES received more healthcare visits. The data indicated younger diagnostic age and higher prevalence rates for those with higher SES than in children of low SES. Availability of and equitable access to healthcare resources may improve diagnostic sensitivity.

Liptak et al. (2008) suggest different cultures have different opinions of the importance of ASD symptoms and may prefer to keep their problems within the family or may have difficulty accessing health services. Parents from minority cultures may interpret symptoms of ASD
different than parents from the dominant western cultures. Parents from collective cultures may identify social deficits before language delay, and tend to focus on the child’s unique qualities rather than his or her disabilities. Some families may experience gaps in insurance coverage that can result in delayed or missed age-specific health screenings. Parents are often in denial or unaware of their child’s “differences”. Some parents referred for assessments may believe their child is just a little slow and will catch up and therefore may not participate in early childhood screenings (NIMH, 2015). While other children may not clearly demonstrate ASD behaviors until their social demands exceed their coping strategies (APA, 2013).

Morrier, et al. (2008) reviewed numerous research works that found consistent evidence of ethnic disproportionality in ASD diagnosis and treatment. The researchers explored the relationship between students and teacher’s ethnic background and educational placement. The majority of schoolteachers are Caucasian as are the majority of diagnosed children with ASD. Their data confirmed a cultural mismatch contributed to under-diagnoses of ASD in minority children, with Caucasian children identified 54 times more often. Parents, teachers, and healthcare personnel may miss or dismiss early signs of ASD. Parental perspective combined with provider bias and cultural mismatch between teachers and students compounds inequities in diagnosis of ASD (Begeer, et al., 2009; Morrier et al., 2008). Recognition of the cultural implications in identification of ASD in minority children is imperative as early diagnosis and treatment significantly affects life prognosis.

Native Hawaiian Sociocultural Characteristics

Hawaiians are the original sea faring people who settled the Hawaiian Islands in 500 A.D. Hawaiian includes all persons of Hawaiian ancestry, regardless of blood percentage, while native Hawaiian refers to persons of 50% or more Hawaiian blood (Palakiko, 2008). Caucasian
persons without Hawaiian ancestry who are in the state of Hawaii are considered “kama`aina”, where as “locals” are also long time residents but of multi-racial or minority status. For the purpose of this work, all persons with Hawaiian ancestry regardless of blood quantum will be referred to as Hawaiian. Hawaiians frequently form interracial relationships. Although many Hawaiians are of mixed racial blood they prefer to self-identify as Hawaiian and value traditional Hawaiian cultural beliefs (McCubbin & Marsella, 2009). Hawaiians had the highest percent (55.9%) of persons reporting multiple races in the 2010 US census (Humes, Jones, & Ramirez, 2011). In 1993, President Clinton signed a formal apology for the role of the US in the overthrow of the Hawaiian kingdom. Unfortunately, Hawaiians continue to struggle both economically and socially. Hawaiians have larger family groups, lower income, and less education than other United States population groups (Humes, et al., 2011).

Hawaiians are present-oriented, although they tend to look to the past for guidance to present-day problems (Gutmanis, 2011). Hawaiians prefer direct eye contact and prefer soft tones and calm speech. They often use a “talk story” dialog that allows all individuals to engage in the conversation. They may use silence for agreement and employ indirect message conveyance with body cues. Hawaiians have a deep spiritual connection among God (akua), fellow man (kanak maoli), and the land (aina). Their spirituality is based on maintaining lokahi, (unity, balance, & harmony). Spiritual energy (mana) is considered the essence of all living things. Balance is maintained through prayers, proper self-care, care of family (ohana) and care of the land. Spirituality is the source of all healing and includes: prayer, massage, and “setting right” (ho`oponopono). Hawaiians have an extensive and well-documented arsenal of plant and prayer based traditional healing practices. The kahuna (experts, priests) developed a classification of illnesses and symptoms that were treatable without the need to examine the
patient (Gutmanis, 2011). The cultural context of the Hawaiian expression of health and illness is significantly different from the dominant western culture. It is probable that the absence or inability of western healthcare systems and providers to understand and employ culturally congruent care actions has contributed to health disparities in Hawaii.

**Hawaiian and Multiethnic Children**

There is limited research on Hawaiian children. Research on child disparities generally groups children into one of few categories, such as Caucasian, African American, or Hispanic. Occasionally Hawaiian children have been categorized with Asians and other Pacific Islanders. As noted previously, Asian/Pacific islanders were found to have substantially higher rates of not receiving both mental health care and physician visits within the last year, and therefore may not be diagnosed with mental or behavioral health disorders (Lau, et al., 2012). Although research has not established a clear cause of ASD, the social inequities experienced by Hawaiians and other minority groups have been clearly linked with health disparities and poorer life trajectories. The World Health Organization has recommended that governments incorporate the social determinants of health into public policy, including increasing awareness of social inequities and health disparities as well as investing in communities to improve public health. The multidimensional aspects of health disparities will require similar multidimensional interventions. Community collaboration to determine unique needs and preferences is an essential component of care for individuals and families affected by ASD. This requires improved community awareness of ASD for primary health care providers, pediatricians, nurses, teachers, DOE special education therapists, mental health providers, and culturally appropriate education for parents and community groups.

**ASD and Rural Environments**
Hoogsteen and Woodgate (2013) studied the lived experiences of parenting an autistic child in rural mid-western Canada. Twenty-six families (n=26) participated in semi-structured open-ended interviews that were audio-recorded. Parents felt that autism was invisible to the community because the child looks normal. To the untrained eye the child displaying typical ASD behaviors appeared bad. The community viewed this as bad parenting and in many times were hostile to the family. Most rural parents noted they received a diagnosis without any referral or follow-up services. Participating families expressed frustration that rural communities have less of everything: resources, services, and professionals trained in ASD. Lack of community and parental knowledge along with feelings of denial, shock, confusion, and anger are common experiences for parents. Parents noted that when their community became aware and knowledgeable about ASD they no longer felt isolated. Increasing public awareness of ASD may reduce stigma attached to ASD families, which in turn may decrease a family’s sense of isolation and increase community support. The limitations of the research included a primarily Caucasian female caregiver’s perspective. This is valuable insight and an important step in gaining knowledge of the rural experiences of autism.

Early intervention services have long been considered key to communication and behavioral improvements in children with ASD. Children who live in rural environments experience numerous challenges to acquiring early intervention including a lack of service providers within their community, large commute times, and increased costs to reach provider locations. Additionally, children in rural communities are more likely to live in poverty than children in urban communities and may not have resources for specialty intervention services. Meadan, Meyer, Snodgrass, and Halle (2013) evaluated the benefits of internet-based parent implemented strategies as a means of improving early intervention. The results indicate internet-
based strategies decrease barriers to early intervention in rural communities. Internet services may be a key in improving knowledge in rural Hawaii.

Miller and Ward (2013) developed academic and community partnerships in rural Alaskan communities to provide interdisciplinary services and care. The goal was to improve the health of children with ASD and other developmental disabilities and the health of their families. Alaska is similar to other rural and frontier states with difficulty providing healthcare services. Additionally, Alaska has highly diverse populations widely dispersed throughout the state. Isolation creates barriers to screening, diagnosis, and intervention services for children with ASD. Improving existing services, use of telehealth for service delivery, distance delivered education strategies, and developing capacity were core focus items for increasing community services and reducing disparities. Many of the providers that participated in the programs noted the success of the programs for their community members with ASD and developmental disabilities.

Beatson and Prelock (2002) developed a training project for educational providers to better serve students with ASD and their families. The goal of the project was to create a system change including strength-based and family-centered service models. The foundation of the project relied upon the understanding that families have unique strengths and expert knowledge of their children. Participant’s comments after participation in the project indicated an overall positive experience for the children and families. Parents described the training as empowering, being part of the team, everyone learning, and respectful.

Farmer and Reupert (2013, p. 20) note that “stress levels for parents of children with ASD are significantly higher than those reported by parents of children with almost any other type of disability or health problem”. Increased parental stress may be a result of the antisocial
and obsessive behaviors of the child. Rural parents experience even greater stress related to lack of service providers and support systems. Although parent education programs have been shown to be effective, there is a lack of programs in Australia for parents of children with ASD. Farmer and Reupert (2013) studied the effectiveness of an educational program for parents of children with ASD. Ten programs were delivered over six years to 98 parents of young children with ASD living in rural Australia. Results of statistical significance (P<0.001) were noted in parents having increased understanding of autism disorders and behaviors, understanding their own child, increased parental confidence, and decreased parental anxiety. Qualitative data found parents valued learning about autism and sensory processing, and reported feeling less alone.

**Implications of Inequalities in Diagnosis and Treatment for Hawaiian Children**

ASD affects all ethnic groups (Fombonne, 2007). Review of the literature reveals environmental and social inequities cause increased risk for ASD and developmental disorders. Paradoxically, minority children are under-represented in ASD diagnosis. Travers, Tincani, and Krezmien (2011) confirmed under-representation of minority children with ASD in special education services. The under-representation of Hawaiian and multiethnic children with ASD suggests multidimensional inequalities related to a high prevalence of children who live in rural and socioeconomically disadvantaged communities, lack of access to health care, a cultural mismatch between care providers and patients, lack of cultural assessment and appropriate interventions, educational deficits with limited information on ASD symptoms, and no routine assessment for ASD. Hawaiians preference for acceptance, trust, and balance may limit health-seeking behaviors. Elimination of diagnostic disparities would likely result in a higher than average percentage of Hawaiian children with ASD considering their social and economic disadvantage and history of disempowerment. Inequalities in diagnosis cause delays in
intervention and therapy. Early diagnosis and interventions for Hawaiian and multiethnic children with ASD could result in minimal symptom expression and reduction of disabilities with improvement in adaptive behavior, IQ, increased adult productivity, and a healthier community.

Figure 1. Health disparities concept map

Disparities Conceptual Representation Description

The Healthcare Disparities concept map identifies three major categories of variables linked with health disparities. These are derived from the literature review of health disparities...
and are noted as *Environment, Socioeconomic Status,* and *Culture.* The colors of the concept map are designed to provide a visual representation of the influencing factors resulting in disparities. These concepts are intentionally overlapping, as they are not exclusive to individual categories. The map identifies the major and minor contributing influences, however, it should be noted that numerous sub-categories and intertwining factors are also associated with disparities. For example, minorities (*culture*) are often segregated via racism, discrimination, poverty, and cultural security into marginalized communities (*environment*) that have decreased job opportunities, which result in increased poverty (*socioeconomic status*). Increased poverty contributes to food insecurity (*socioeconomic status*) as does limited neighborhood infrastructure (*environment*) contributes to decreased food options through limited transportation to shopping centers and lack of shopping options. Limited transportation and infrastructure is associated with poorer education, which consequently results in less job opportunities and inability of minorities to improve their neighborhood living environments. It is the interplay of these multidimensional factors that increase manifestations of disparities.

**Theoretical Framework**

Theoretical models are analytical tools useful to guide understanding, interpreting, and predicting an area of study. Theoretical models provide a framework to explain situations, behavior, and guide care actions. This project employs Pacquiao’s model (2008) *Culturally Competent Ethical Decision Making* to address the complexities of ASD screening and diagnosis for Hawaiian and multiethnic children, and direct project implementation. Pacquiao’s model is based on compassion as the driving force for ethical decision-making and the promotion of human. Four levels of cultural knowledge are required to apply the model. This includes: 1) cultural values and practices of the client/family, 2) organizational assumptions that affect the
situation, 3) dominant professional norms that influence practitioners, and 4) dominant societal norms/laws that impact decisions. Compassionate actions work through partnership, collaboration, and advocacy to understand the significance and influence of one’s culture in their lifeways; to respect, protect, and preserve cultural differences while minimizing any negative consequences that may be associated with one’s culture (Pacquiao, 2015).

Figure 2. *Culturally Competent Ethical Decision Making*, Dula F. Pacquiao (2008) (Used with Permission, Appendix S.)

Healthcare reflects the dominant cultural norms and may not be culturally congruent with minority populations’ lifeway’s and belief systems. Vulnerable groups are exposed to numerous risk factors and have an increased response to risk factors that result in health disparities. Pacquiao (2015) stresses cultural competence as a moral obligation to promote patient and group autonomy and human rights that results in ethical-decisions. Cultural competence starts with an awareness and sensitivity of cultural care differences and similarities within oneself and others (Leininger & McFarland, 2002). Culturally competent care actions provided through the three modes of either: cultural preservation, cultural accommodation, & cultural repatterning requires
partnership, collaboration, and advocacy to promote social justice and human rights (Leininger & McFarland, 2002; Pacquiao, 2015). Cultural preservation is considered the actions that promote retention of one’s meaningful values and lifeway’s (Leininger & McFarland, 2002). Cultural accommodation refers to actions that facilitate collaborative negotiations to promote positive goals (Leininger & McFarland, 2002). Cultural repatterning refers to modification of actions with new knowledge, behaviors, and adaptive strategies that promote positive health outcomes and attainment of goals (Leininger & McFarland, 2002; Pacquiao, 2015). Pacquiao (2015) notes that goals are not limited to medical outcomes, they include physical, social, cultural, spiritual, and psychological experiences of health. Cultural repatterning includes the practice of promoting healthy behaviors with clients as well as requiring healthcare providers to repattern their thoughts and actions to accommodate the needs of the clients. Ethical decision-making respects and protects the inherent values of people. Collaborative partnerships are necessary for incorporating culturally specific care values, beliefs, and respected practices into health services. Community outreach for stakeholder input is necessary to understand current knowledge and needs, and to direct culturally congruent project development for the promotion of social justice, and human rights.

This project employs Kleinman’s (1978) *Explanatory Model of Health Systems* (EM) to illicit collaborative stakeholder input. Arthur Kleinman is an anthropologist well known for his work in promoting understanding of the cultural context of human systems. He recognized healthcare as a unique cultural system that often has opposing views to patients’ cultural systems. Kleinman (1978) proposes that healthcare systems are both social and cultural systems with behaviors and norms attached to the social relationships and institutional settings. The three social contexts in which sickness is experienced are the popular, the folk, and the professional
arenas (Kleinman, 1978). The popular arena is the family context and includes social and community activities and networks. The folk arena includes the non-professional traditional healing specialists, while the professional arena includes western medicine and professionalized healing therapies (chiropractic, acupuncture, etc.). Individuals organize their beliefs and behaviors of sickness and care within these arenas. The EM employs questions that elucidate the meaning of health and illness from the patient. Kleinman (1978) defines his EM as the notions about an episode of sickness and treatments that are employed by all those engaged in the clinical process.

Identification and awareness of differences among populations regarding health determinants and health outcomes are essential first steps toward reducing health disparities (CDC, 2013). Cultural competent care requires stakeholder collaboration to determine the unique needs and preferences for individuals and families affected by ASD in East Hawaii. Compassionate care promotes social justice and health equity as a human right. East Hawaii needs improved community awareness of ASD and ASD resources. It will be impossible to achieve improvements in the health of children with ASD in East Hawaii without improving the current state of under-diagnosis and fragmented care. Inequalities in diagnosis cause delays in intervention and therapy. Early intervention for children with ASD can reduce or prevent disabilities, and may improve adaptive behavior and IQ. Lack of early intervention significantly impacts individual prognosis for adult functioning and creates substantial economic burden to society.

**Chapter Three: Project Design and Evaluation Plan**

This chapter addresses the specific actions employed to promote awareness of ASD and ASD resources in East Hawaii. The focus of the work was directed through collaborative input
from the various stakeholders to inform and guide the creation of a website designed to house ASD information and EB services specifically for East Hawaii. Identification of community specific needs and provision of community specific resources through one easily accessed site can improve provider and caregiver knowledge, may decrease fragmentation of services, and improve use of available resources.

**Project Goal, Aims, and Objectives**

**Problem.** There is a knowledge deficit regarding screening and intervention for ASD in East Hawaii causing disparities in diagnosis and care.

**Goal.** The overarching project goal is to decrease disparities in diagnosis and treatment of ASD for multiethnic and Hawaiian children on Hawaii Island by increasing knowledge of ASD and ASD resources to the diverse stakeholders within rural East Hawaii. The following aims and objectives directed achievement of the goal.

**Aim 1: Determine stakeholder knowledge and needs.**

**Objective 1. Identify stakeholders within the community.** The stakeholders are the population of interest. They are persons or groups that have a vested interest in the goals, decisions, and the evidence that supports the decisions. Each stakeholder has a unique and valuable perspective (AHRQ, 2015). Stakeholders were sought from various groups including pediatricians, primary care physicians, psychologists, nurse practitioners, public health nurses, community agencies, DOE autism specialists, elementary and special education teachers, Easter Seals, DOH-DDD case management branch, parents, and caregivers of children with ASD. Identification of stakeholders was completed through an Internet search for parent groups, community providers, kindergarten through grade 12 school administrators, teachers, and autism specialists, health insurers practice directories, and referrals from known sources.
Objective 2. Determine knowledge and needs through surveys with stakeholders.

Identified stakeholders were contacted and provided with the East Hawaii ASD Project Recruitment Flyer (Appendix C). The recruitment flyer was developed by the PIP director and includes key facts about ASD and the project. Contact was initiated through face-to-face encounters with known individuals, community groups, referrals, email, and letters. A paper or e-copy of the recruitment flyer with a hyperlink to the online Stakeholder Survey (Appendix E) was provided in all contacts. The survey consisted of one question to determine each stakeholder’s primary role, and eight questions regarding the participant’s experiences with ASD screening, diagnosis, and care services in East Hawaii. The survey was based on Kleinman’s EM with open-ended/free-text survey questions to elicit each participant’s unique perspective. The consent form (Appendix D) was imbedded in the online survey introduction. The survey was initially open for one month. However, additional requests were received from stakeholders to participate in the survey. Therefore the survey was extended to a total of 40 days. Participants were limited to one completed response. The participants had the option to exit the survey at any point. There was an option to provide a mailing address for delivery of a $10.00 gift card of choice to Starbucks or Jamba Juice in acknowledgement of their contribution.
Table 1. *Kleinman’s EM and Adapted Survey Questions*

<table>
<thead>
<tr>
<th><strong>Kleinman’s EM Questions</strong></th>
<th><strong>Modified Stakeholder Questions</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>What do you call the problem?</td>
<td>What problem(s) related to screening, diagnosis, or care services have you encountered with your child or client with autism spectrum disorder?</td>
</tr>
<tr>
<td>What do you think has caused the problem?</td>
<td>What do you think has caused the problem(s) related to screening, diagnosis, or care services for your child or client with autism spectrum disorder?</td>
</tr>
<tr>
<td>Why do you think it started when it did?</td>
<td>What do you think makes the problem(s) worse?</td>
</tr>
<tr>
<td>What do you think the sickness does? How does it work?</td>
<td>How do the problem(s) impact your professional or personal life?</td>
</tr>
<tr>
<td>How severe is the sickness? Will it have a long or a short course?</td>
<td>What do you think will help correct the problem(s) you encountered with screening diagnosis, or care services for your child or client with autism spectrum disorder?</td>
</tr>
<tr>
<td>What kind of treatment do you think the patient should receive?</td>
<td>What do you wish others knew about autism spectrum disorder?</td>
</tr>
<tr>
<td>What are the chief problems the sickness has caused?</td>
<td>What resources and services for autism spectrum disorder are you aware of in your community?</td>
</tr>
<tr>
<td>What do you fear most about the sickness?</td>
<td>What resources and services for autism spectrum disorder would be useful to you?</td>
</tr>
</tbody>
</table>

**Objective 3. Analyzed survey data to identify stakeholder deficits in knowledge and needs.** The online Stakeholder Survey was designed and completed using SurveyMonkey®. SurveyMonkey® is a provider of web-based survey options. SurveyMonkey® provides free and paid, easily customizable surveys with a variety of question formats and security features. Data can be analyzed and converted in numerous representations and linked to back-end programs such as DataCracker®, Microsoft Excel®, IBM SPSS Statistics, and other analysis programs. These tools work in partnership with SurveyMonkey® to provide ease in extracting numerical data, text based themes, and creating tables and charts of the results. The project proposal included a budget for DataCracker®. However, it was found that while the text analysis tool in DataCracker® was slightly more responsive than SurveyMonkey® analytics in creating word clouds, neither were appropriate to convert large text responses into tables or graphs. Therefore,
the purchase of textual analysis tools from DataCracker® was eliminated from the project. Text analysis was completed using a simple document table with verbatim survey responses collated and common themes extracted.

**Aim 2: Determine community resources.**

**Objective 1. Perform a literature search to determine EB practice interventions.** An intensive online search of the CDC, AAP, APA, HRSA, Agency for Healthcare Research and Quality (AHRQ), and the University of Hawaii Library was performed to identify peer reviewed EB practice for ASD interventions. Key words included autism, strategies, interventions, behavioral therapy, medications, support services, education, and evidence-based practices. The services that met EB guidelines were collected and disseminated on the website with hyperlinks provided when available.

**Objective 2. Perform a community assessment of resources available for ASD that meet EB recommendations.** The stakeholder survey included questions regarding the services the respondents were aware of and which services they would like. These responses helped identify some services available in the community as well as deficits in services. The majority of ASD resources appropriate for the website were obtained through a comprehensive online assessment of local, state, and national agencies. Target agencies included: the DOE, DOH-DDD, Hawaii Public Health Department, East Hawaii Child and Family Services, Hawaii Medical Services Association (HMSA), Kaiser Permanente, Easter Seals, the Autism Society, and numerous local organizations. Contact was initiated to the various agencies and individual providers via email, telephone, or in person; to determine services available, and to identify other providers of services within East Hawaii.

**Aim 3: Increase knowledge of ASD and ASD services.**
Objective 1. Develop tools to increase knowledge.

1a. Develop a comprehensive ASD website for East Hawaii. GoDaddy® is an affordable easy to use web hosting provider. It also manages domain names and provides tools for website creation and hosting services. The domain name “Kiannaslist.com” and website builder tools were purchased through GoDaddy®. Additional add-on tools acquired included email to the “webmaster.” This creates an extra level of privacy and allows for future collaboration or exchange of the website to others without disrupting the contact process. The second add-on tool purchased promotes search engine optimization (SEO). The extra cost of the tools is less than the planned cost for DataCracker® and improved the website without going over budget.

1b. Develop a brochure of the website with key ASD facts. The brochure (Appendix R) was designed as a referral tool for the website using Microsoft Office Word®. The brochure incorporates key ASD facts derived from the review of literature, the CDC, and the NIMH. The brochure defines the purpose of the website and lists the categories of resources available on the website. The brochure is presented on the website. Interested persons can submit requests for copies of the brochure via a form on the website. Kiannaslist.com brochures were provided to the DOH-DDD case managers department, Easter Seals Early Intervention Program, and East Hawaii Child and Family Services, and various pediatricians and nurses within East Hawaii.

Objective 2. Evaluate the website. The stakeholders represent the continuum of care for children with ASD. The survey participants were asked to provide an email if they were interested in receiving the results of the survey. The results of the Stakeholder survey were emailed to the original survey participants who provided an email address, along with the website link to Kiannaslist.com. Survey results were deleted from the website after the project evaluation was completed as a means to protect the data until publication of the PIP.
The Project Evaluation Tool (PET) is an anonymous six question seven-point Likert scale survey (Appendix F) developed by the director. The goal of the PET was to identify accomplishments or deficits of the website in addressing the identified needs found in the stakeholder survey. The PIP director emailed the participating stakeholders a request to evaluate the website, the website hyperlink, and the PET hyperlink to the survey on SurveyMonkey®. Adjustments and additions were made to the website based on the PET evaluations and comments. Future comments, evaluations, and suggestions can be submitted via the Contact Us webpage at Kiannaslist.com.

**Methods**

**Setting and population.** The entirety of Hawaii Island (Hawaii County, 2012) is designated *Rural*. Many communities lack basic infrastructure such as city water, sewage, paved or lighted roads, home postal delivery, none or limited bus service, and limited economic opportunity. Hawaii had the highest percent (77%) of minorities in the total state population (Humes et al., 2011). Hawaii ranks 43rd on the Household Income Inequality Measures for States, 2005 - 2009, compared to US average (Hoeffel, Rastogi, Kim, & Shahid, 2012). There are numerous agencies that provide community services, education, and healthcare services within East Hawaii. For the purpose of this project, stakeholders are defined as adults who care for children with autism in East Hawaii. The target population was approximately 400 stakeholders from the various groups noted previously.

**Instruments.** The Stakeholder Survey is comprised of one question to identify stakeholder role and eight modified open-ended questions (see Table 1.) based on Kleinman’s EM (1978). The questions were designed to elicit the views, needs, and experience of ASD in East Hawaii. The information derived from the Stakeholder Survey will minimize the conflicts
inherent between institutional and lay (popular and folk) healthcare and community resources. Listening to diverse perspectives promotes empathy, understanding, and compassion, the foundation of ethical care (Pacquiao, 2015). Incorporating the results of the survey questions into the website promotes culturally competent care. Collaborative partnerships allow for sharing of resources and services, which promotes human rights. The stakeholder survey also included one question requesting a mailing address for delivery of the gift card and a final question asking for an email address if the participants wished to receive the results of the survey and a link to the website.

The PET was an anonymous survey designed to take less than 5 minutes to complete, and was available online via SurveyMonkey®. The answer choices ranged from 1 (agree) to 4 (neutral) and 7 (disagree). Stakeholder evaluation of the website design, content, and usability is an essential component in promotion of culturally congruent care. The PET hyperlink was sent to the participants who provided email information in the survey.

**Data analysis and project evaluation.** Data analysis of stakeholder survey response themes and the project evaluation was completed with the assistance of SurveyMonkey® and Excel© data analysis tools. Analysis focused on subjective and objective results. Major themes were identified and comments categorized to appropriate theme. The survey data was easily converted to multiple tables and charts in Excel® and Apple Numbers©.

Results of the PET were analyzed to determine stakeholder reports of improved knowledge of ASD and ASD resources in East Hawaii, and to verify usability and appropriateness of the website for the East Hawaii community. SurveyMonkey® provided objective analysis of the PET scores. The project results and processes were presented in written and oral defense to the DNP chair and the DNP committee.
Protection of Human Subjects

Project approval from the Institutional Review Board (IRB) from University of Hawaii was acquired prior to commencement of the project. Informed consent was provided prior to survey participation. It was not anticipated that there would be any risks for stakeholders that are above ordinary risks of daily life for participation in the Stakeholder Survey and the PET. A possible risk included the potential for participants to feel upset when presented with the survey questions. Therefore, the ability to exit the survey at any point was embedded in the online survey format. Additionally, a 24-hour crisis access line number was provided for anyone who felt overwhelmed or needed mental health services. A loss of privacy is considered a possible risk. Confidentiality of participants was maintained through protected files. SurveyMonkey® provides HIPPA protection services in their survey tools. All data is protected. Participants are not directly or indirectly identified in any aspect of the website and the oral or written presentations of the project. No ethical concerns arose during the project.

Timeline and Budget

The project Timeline and Budget are located in the appendices (Appendix A and B).

Chapter Four: Results

The overarching project goal was to decrease disparities in diagnosis and treatment of autism for multiethnic and Native Hawaiian children on Hawaii Island by increasing knowledge of ASD and ASD resources to the diverse stakeholders within rural East Hawaii. This goal was derived from the problem statement that identified a knowledge deficit regarding screening and intervention services for ASD in East Hawaii causing disparities in diagnosis and care. The project aims and objectives are the processes used to achieve the overarching goal. The results of the aims and objectives are detailed in this chapter.

Framework Guidance
The project was based on Pacquiao’s model, *Culturally Competent Ethical Decision Making*. The model was the guiding framework for all activities and decisions. The fundamental concept is the requisite of compassion as the driving force to eliminate disparities in health through the promotion of social justice and protection of human rights. Core actions included partnership, collaboration, and advocacy. This is the basis of culturally competent care.

**Data Analysis**

**Aim 1: Determine stakeholder knowledge and needs.**

**Objective 1. Identify stakeholders within the community.** Numerous approaches were used to identify and contact stakeholders. Initial contact was to known stakeholders. Other avenues used to promote the survey within the community included attending a developmental disabilities support group, a parent ASD support groups, a Public Health nurses’ staff meeting, a busy pediatric office, meetings with the Director of East Hawaii East Seals, a DOH-DDD case manager, and personal visits to community support service agencies (Bayada and Child and Family Services: The Institute for Family Enrichment. Contact information for healthcare providers is available online and in published health insurer’s directories. Approximately 100 recruitment flyers were mailed to pediatricians, primary care providers, mental healthcare providers, psychologists, and advanced practice nurses (APRN’s) listed in the health insurer’s directories for Hawaii Island. The DOE provides contact information on their website for school staff and autism specialists. Email requests were sent to the school administrators and autism specialists at private and public elementary schools in East Hawaii. Recruitment flyers were posted on campus at the University of Hawaii at Hilo, the local library, and a community bulletin board on the town main street. Flyers were distributed at the local hospital and two provider clinics. Fortunately, John Robison was visiting the community to deliver a lecture to teachers,
parents, and DOE autism therapists. He is a well-known, high functioning autistic, multi-published autism author, and has collaborated with the NIH specifically for ASD. The project director was allowed to present the PIP and survey requests to Mr. Robison’s audience prior to his lecture. Approximately 30 lecture attendees accepted the recruitment flyer. The recruitment flyer was also posted on Facebook®. Stakeholders were requested to forward the survey to others when applicable.

**Objective 2. Determine knowledge and needs through surveys with stakeholders.** In total, 350 paper recruitment flyers and 100 emailed flyers and survey requests were distributed within the community. Results of the 450 recruitment flyers led to 105 surveys (23%) submitted to SurveyMonkey®. Eighteen incomplete or out-of-area responses were eliminated from the sample. Completed responses meeting the project objective was \( \eta = 87 \). The completed survey response rate \((\text{RR})\) of 19.3% was calculated by dividing \( \eta \) (87) by the total number of recruitment flyers \( \left(\frac{87}{450}\right) \). This RR calculation should be considered an approximation as it is unknown if all recruitment flyers met with eligible and willing participants, therefore it is not possible to calculate non-response error. The eight open-ended explanatory questions on the stakeholder survey provided extensive insight into the needs, concerns, and knowledge of the community. While some respondents answered with single statements, other respondents gave multiple answers with detailed examples. All responses were categorized to themes. The responses to each question ranged from 11-16 thematic variables with upwards of 140 - 160 comments per question. Therefore, response variables are noted as \((\chi)\) per question and are calculated as sample proportion \((\hat{p})\) instead of absolute frequency per participant. The results of the survey are discussed in detail with corresponding tables and charts following each question.
Figure 3. *Participant Role*

There were 10 primary roles and one “Other” category for respondents to self-identify. Of these roles the largest response rate ($\hat{p} = 29.89\%$) came from “Parents/Family.” The next highest category came from “Teachers/School Staff” ($\hat{p} = 19.54\%$). The “Other” option was for respondents who did not identify with any of the provided roles, and accounts for $\hat{p} = 14.94\%$ of the responses. Community providers composed $\hat{p} = 12.64\%$, while nurse practitioners ($\hat{p} = 8.05\%$), specialty providers ($\hat{p} = 5.75\%$) physicians ($\hat{p} = 4.6\%$) registered nurses ($\hat{p} = 3.45\%$) and one psychologist ($\hat{p} = 1.15\%$) trailed significantly.
**Objective 3. Analyze survey data to identify stakeholder deficits in knowledge and needs.**

*Question 1: What problem(s) related to screening, diagnosis, or care services have you encountered with your child or client with autism spectrum disorder?* Eleven themes were found within the responses. The major themes for this question included diagnostic problems ($\chi = 40, \beta = 26\%$), followed closely by services/providers unknown, limited, or not available ($\chi = 35, \beta = 22\%$) and lack of knowledge and training ($\chi = 30, \beta = 19\%$). Diagnostic problems included comments such as “screening and diagnosis came too late for my child,” “there was a long wait list for diagnosis,” “wrong diagnosis,” and “there is a lack of experts qualified to diagnose.” Many respondents noted the lack of providers in East Hawaii. While knowledge deficits associated with parents, school staff, healthcare, and service providers contributed to the problems experienced with screening, diagnosis, and care. Difficulty accessing or providing services was noted at $\chi = 18, \beta = 12\%$. Funding, whether by insurance providers or program administrators and government agencies was noted as contributing to difficulties with access and provision of services. Other response themes included child behaviors ($\beta = 5\%$), provider resistance ($\beta = 5\%$), no standard processes for diagnosis ($\beta = 3\%$), complicated and confusing processes ($\beta = 3\%$), lack of time ($\beta = 2\%$), no referrals or follow-up after diagnosis ($\beta = 2\%$), and lack of retention of staff and providers ($\beta = 2\%$).
### Table 2. Question 1: response variables.

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnostic problems</td>
<td>40</td>
</tr>
<tr>
<td>Services/Providers unknown, limited, or not available</td>
<td>35</td>
</tr>
<tr>
<td>Lack of Knowledge or Training</td>
<td>30</td>
</tr>
<tr>
<td>Financial Difficulties - accessing services or providing services</td>
<td>18</td>
</tr>
<tr>
<td>Child Behaviors</td>
<td>8</td>
</tr>
<tr>
<td>Resistance from Providers/DOE</td>
<td>8</td>
</tr>
<tr>
<td>No Standard Processes</td>
<td>4</td>
</tr>
<tr>
<td>Complicated/Confusion</td>
<td>4</td>
</tr>
<tr>
<td>Lack of Time</td>
<td>3</td>
</tr>
<tr>
<td>No Referrals or Follow-up</td>
<td>3</td>
</tr>
<tr>
<td>Lack of Retention</td>
<td>3</td>
</tr>
</tbody>
</table>

Figure 4. **Question 1: sample response graph.**

*Question 2: What do you think has caused the problem(s) related to screening, diagnosis, or care services for your child or client with autism spectrum disorder?*  
The major theme that
arose with question two was a lack of awareness, knowledge, and training ($\chi = 41, \hat{p} = 27\%$).

“Some parents and grandparents have no clue what autism disorder is and what they can look for in their child,” said one respondent. Other answers included “lack of education about autism,” “people don’t understand what autism is,” “lack of awareness and training in doctors, professionals, and providers” and “not much awareness from the county, state, and federal entities.” The second most common theme was service providers unknown, limited, or not available ($\chi = 32, \hat{p} = 21\%$). Replies categorized into this theme included “lack of specialists,” “services not available,” and “lack of service capacity.” One respondent noted “there is no cohesive approach to getting well known resources to families, teachers, and healthcare providers.” Additional themes reported for this question are noted in descending order of occurrence: financial difficulties with funding, accessing, or providing services ($\chi = 18, \hat{p} = 12\%$), diagnostic problems ($\chi = 16, \hat{p} = 11\%$), rural community location ($\hat{p} = 7\%$), lack of time to provide diagnosis or services ($\hat{p} = 5\%$), child behaviors complicate provision of services ($\hat{p} = 5\%$), providers resistant to queries from parents and teachers ($\hat{p} = 4\%$), parents did not receive referrals or follow-up after diagnosis ($\hat{p} = 3\%$), no standard processes ($\hat{p} = 3\%$), the processes are complicated and confusing ($\hat{p} = 2\%$), and a lack of staff retention ($\hat{p} = 1\%$).
Table 3. Question 2: response variables.

| Lack of awareness, knowledge, or training | 41 |
| Service providers unknown, limited, or not available | 32 |
| Financial difficulties/funding accessing/providing services | 18 |
| Diagnostic problems | 16 |
| Rural community, location | 10 |
| Lack of time | 8 |
| Child behaviors | 7 |
| Provider resistance | 6 |
| No referrals or follow-up | 5 |
| No standard processes | 4 |
| Complicated, Confusing | 3 |
| Lack of Retention | 1 |

Figure 5. Question 2: sample response graph.

**Question 3: What do you think makes the problem(s) worse?** One respondent stated, “Nearly every person I discuss autism with has no knowledge of it whatsoever, unless they are directly affected. If the entire community was more informed, and autism was more normalized
in our society, maybe people wouldn’t be so afraid to discuss it. I think the majority of the community doesn’t even see it, and if it’s not seen it is not addressed.” This was a common thread. The highest number of responses ($\chi = 51, \beta = 58\%$) within all roles except physicians noted a lack of awareness, knowledge, and training as the main contributor for making their problems worse ($\chi = 23, \beta = 40\%$ of specified themes). Three out of four physicians stated comments that fell into: service providers unknown, limited, or unavailable ($\chi = 19, \beta = 18\%$ of responses) and difficulty accessing and providing services ($\chi = 13, \beta = 15\%$ of responses). 

There is a disconnect between physicians and other respondents’ experiences. For example, parent responses to “what makes the problem worse?” included: “other doctors,” “not all pediatricians are well informed,” “professionals who approach the problem with prescription drugs,” “not enough doctors and those doctors do not help with the problem,” “my son’s pediatrician was too late in suspecting autism, he told me boys are slower, just wait,” “I kept saying something was wrong with my son…I needed the pediatrician to refer me to get a test but she never did until I pushed really hard…I relied on my son’s pediatrician, I thought she would know better than I do.” A community provider replied, “Practitioners refuse to believe because they are so sure they have the answer,” and another noted “I had one client who wasn’t identified until age 12.” Many teachers noted there is a general lack of awareness, education, and training for themselves, other school staff, and parents. Diagnostic problems continued as a significant theme at $\beta = 10\%$. While rural community location and complicated confusing processes were each found at $\beta = 5\%$. Lack of time ($\beta = 4\%$), no referrals or follow-up ($\beta = 2\%$), child behaviors ($\beta = 1\%$), lack of parental participation ($\beta = 1\%$), no standard processes ($\beta = 1\%$), and lack of provider retention ($\beta = 1\%$) were also noted.
Table 4. Question 3: response variables.

<table>
<thead>
<tr>
<th>Response Variables</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of awareness, knowledge, or training</td>
<td>51</td>
</tr>
<tr>
<td>Service providers unknown, limited, or not available</td>
<td>23</td>
</tr>
<tr>
<td>Financial difficulties/funding accessing/providing services</td>
<td>19</td>
</tr>
<tr>
<td>Diagnostic problems</td>
<td>13</td>
</tr>
<tr>
<td>Rural community, location</td>
<td>6</td>
</tr>
<tr>
<td>Complicated, Confusing</td>
<td>6</td>
</tr>
<tr>
<td>Lack of time</td>
<td>5</td>
</tr>
<tr>
<td>No referrals or follow-up</td>
<td>2</td>
</tr>
<tr>
<td>Child behaviors</td>
<td>1</td>
</tr>
<tr>
<td>Lack of parental participation</td>
<td>1</td>
</tr>
<tr>
<td>No standard processes</td>
<td>1</td>
</tr>
<tr>
<td>Lack of Retention</td>
<td>1</td>
</tr>
</tbody>
</table>

Figure 6. Question 3: sample response graph.
Question 4: How do the problem(s) impact your professional or personal life? The major theme found within all respondent roles except parents was categorized as confusing, difficult, and frustrating ($\chi = 43, \beta = 36\%$). These stakeholder expressed worry, concern, and feeling inadequate to help the child or family. The main themes for parents was feelings of stress, anxiety, depression, isolation, and health problems associated with the stress ($\chi = 18, \beta = 15\%$); and a disruption in their child’s learning due to service problems and staff turnover ($\chi = 17, \beta = 14\%$). Parents noted that raising a child with autism is time consuming ($\chi = 13, \beta = 11\%$). This affects their ability to complete life tasks such as care for their spouse, other children, and maintain employment. One respondent wrote, “I have no personal life. I had to quit my job and drop out of school. It’s impossible with the amount of stress I face as a single parent… I have so much anxiety if my son will ever be able to take care of himself or get a job. Who will take care of him if I die or am hospitalized? I feel so alone and depressed a lot. Will it ever get better?”

Table 5. Question 4: response variables.

<table>
<thead>
<tr>
<th>Response</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confusing, difficult, frustrating</td>
<td>43</td>
</tr>
<tr>
<td>Stress, anxiety, depression, isolation</td>
<td>18</td>
</tr>
<tr>
<td>service problems and staff turnover cause disruption in child’s learning</td>
<td>17</td>
</tr>
<tr>
<td>Time consuming, affects other life tasks, family, marriage, job</td>
<td>13</td>
</tr>
<tr>
<td>Sleep problems, tired, exhausting</td>
<td>6</td>
</tr>
<tr>
<td>Financial difficulties</td>
<td>6</td>
</tr>
<tr>
<td>Concerned, afraid for child’s future</td>
<td>6</td>
</tr>
<tr>
<td>Child behaviors</td>
<td>5</td>
</tr>
<tr>
<td>unknown, none, NA</td>
<td>4</td>
</tr>
<tr>
<td>desire to advocate</td>
<td>2</td>
</tr>
<tr>
<td>more cautious approach to child</td>
<td>1</td>
</tr>
</tbody>
</table>
Figure 7. Question 4: sample response graph.

Question 5: What do you think will help correct the problem(s) you encountered with screening diagnosis, or care services for your child or client with autism spectrum disorder?

The most significant theme (χ = 55, β = 35% of responses) was the need to improve awareness, education, and training. Comments included, “educate parents and caregivers to recognize autism in the prenatal period,” “provide evidence-based information, there is a lot of misinformation on the internet,” “training for doctors and other professionals,” “physicians and pediatricians need to be educated and knowledgeable in autism spectrum…they need to provide options about therapy, support, and help,” “we need more doctors educated on autism and qualified to handle autism patients here on the island,” and “there needs to be a better way for people to get information about ASD, diagnosis, screening, and services. The information is not readily available to the community, it is not openly discussed or advertised.” The next highest category (χ = 30, β = 19% of responses) is the need for available and accessible EB services.
Parent and community collaboration came in at $\chi = 21, \beta = 14\%$, while funding and fair wages continued as a theme ($\chi = 12, \beta = 8\%$). One parent wrote, “parents are constantly struggling and battling with the DOE to do what’s right for their child instead of what the budget dictates…they [DOE] are pitting the future of many children at risk, costing the state more money in the long run if these children are not as independent as they could have been with the proper assistance early on.” Comments included better funding for paraprofessional tutors, insurance providers acceptance of diagnosis and coverage of services, while others noted government investment and grants would help. Smaller ranked yet important suggestions for correcting the problems included: standard procedures for screening and diagnosis ($\beta = 6\%$), restructuring government systems to collaborate and provide an integrated system ($\beta = 5\%$), inclusion for autistic people in afterschool and community activities ($\beta = 4\%$), and provide information and referral options ($\beta = 3\%$). Suggestions for a dedicated ASD clinic with specialists trained in autism came up periodically ($\beta = 2\%$), along with a local directory of services ($\beta = 2\%$).

Table 6. Question 5: response variables.

<table>
<thead>
<tr>
<th>Response Variable</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased awareness, education, training</td>
<td>55</td>
</tr>
<tr>
<td>Availability and access to EBP services</td>
<td>30</td>
</tr>
<tr>
<td>Parent and community collaboration</td>
<td>21</td>
</tr>
<tr>
<td>Funding &amp; fair wages</td>
<td>12</td>
</tr>
<tr>
<td>Standard procedures for screening and diagnosis</td>
<td>10</td>
</tr>
<tr>
<td>Restructuring local, state, national systems</td>
<td>8</td>
</tr>
<tr>
<td>Inclusion in after-school and community activities</td>
<td>6</td>
</tr>
<tr>
<td>Information on referral options</td>
<td>4</td>
</tr>
<tr>
<td>Dedicated ASD clinic</td>
<td>3</td>
</tr>
<tr>
<td>Local directory of services</td>
<td>3</td>
</tr>
<tr>
<td>Unsure, none, NA</td>
<td>3</td>
</tr>
</tbody>
</table>
Figure 8. Question 5: sample response graph.

Question 6: What do you wish others knew about autism spectrum disorder? Increased awareness, education, and training claimed the top category of response themes again, with $\chi = 45$ comments for $\beta = 33\%$ of the responses. This included statements for improving provider, parent, educator, and community awareness and education. “Everything about them [autistic persons] is something the whole community needs to be educated on,” “there is a stigma associated with an adult-child with autism,” and a desire to improve community efforts for “appropriate responses to autistic child and adults.” One theme involved comments such as “a variety of services that can help,” and “interventions should be individualized as each person has a unique presentation of symptoms, strengths and weaknesses ($\chi = 21, \beta = 15\%$). Others expressed the desire that the community should understand autism is a difficult and lifetime commitment, with a desire for empathy and compassion to the family ($\chi = 20, \beta = 15\%$) and
many comments about understanding the uniqueness of each person, “it’s a spectrum,” “they are not dumb” or “Rainman,” and it [autism] doesn’t have a “look” ($\chi = 17, \beta = 12\%$). “They are just like everyone else, they have social needs, the need to be accepted, cared for, and loved” ($\chi = 14, \beta = 10\%$). Connecting families to services and “unknown” both came in with $\beta = 4\%$, while allowing children extra time and consistency in treatment and routines was noted in $\beta = 3\%$ of the responses. Understanding diagnostic and eligibility criteria, and understanding that ASD is not caused by vaccines both garnered $\beta = 2\%$ and $\beta = 1\%$ of the comments.

Table 7. Question 6: response variables.

<table>
<thead>
<tr>
<th>Increased awareness, education, training</th>
<th>45</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s a spectrum, all unique, not stupid, not broken, not bad, No “look”</td>
<td>21</td>
</tr>
<tr>
<td>A variety of and individualized treatments can help</td>
<td>20</td>
</tr>
<tr>
<td>It is a difficult and lifetime commitment, need for empathy &amp; compassion</td>
<td>17</td>
</tr>
<tr>
<td>They have the same needs for love, respects, and desire to contribute to society</td>
<td>14</td>
</tr>
<tr>
<td>How to connect families to appropriate services</td>
<td>6</td>
</tr>
<tr>
<td>None/unknown</td>
<td>5</td>
</tr>
<tr>
<td>Allow extra time and consistency in routines and treatments</td>
<td>4</td>
</tr>
<tr>
<td>Not caused by vaccines</td>
<td>3</td>
</tr>
<tr>
<td>Diagnostic and eligibility criteria</td>
<td>2</td>
</tr>
</tbody>
</table>
Question 7: What resources and services for autism spectrum disorder are you aware of in your community?  The major resources noted by the respondents were the same resources reported by the author as the primary service providers. The DOE ($\chi = 26, \hat{p} = 17\%$), Easter Seals ($\chi = 24, \hat{p} = 16\%$), DOH-DDD ($\chi = 22, \hat{p} = 14\%$), and activities of daily living (ADL) skills trainers (various agencies) ($\chi = 20, \hat{p} = 13\%$) received the bulk of comments. ADL skills trainers generally work through the DDD and DOE programs. Outside of the agencies noted above, there were not many other services the community was aware of. Sadly, 18 respondents ($\chi = 18, \hat{p} = 12\%$) had no knowledge of resources or services in East Hawaii. While $\hat{p} = 7\%$ of the responses referred to state or national Internet sites as their source of information. The remaining resources had small rates as follows: Special Olympics ($\hat{p} = 5\%$), Support groups and Learning Disability Association of Hawaii (LDAH) both came in with $\hat{p} = 4\%$, adult day
programs were noted four times ($\beta = 3\%$), and Full Life, Surfers Healing, and community events received $\beta = 3\%$ each.

Table 8. *Question 7: response variables.*

<table>
<thead>
<tr>
<th>Program</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Department of Education</td>
<td>26</td>
</tr>
<tr>
<td>Easter Seals</td>
<td>24</td>
</tr>
<tr>
<td>Department of Health</td>
<td>22</td>
</tr>
<tr>
<td>ABA, PAB, Skills Trainers</td>
<td>20</td>
</tr>
<tr>
<td>None</td>
<td>18</td>
</tr>
<tr>
<td>Internet sites</td>
<td>11</td>
</tr>
<tr>
<td>Special Olympics</td>
<td>7</td>
</tr>
<tr>
<td>Support Groups</td>
<td>6</td>
</tr>
<tr>
<td>Learning Disabilities Association</td>
<td>6</td>
</tr>
<tr>
<td>Adult day programs</td>
<td>4</td>
</tr>
<tr>
<td>Full life</td>
<td>3</td>
</tr>
<tr>
<td>Surfers Healing</td>
<td>3</td>
</tr>
<tr>
<td>Community Events</td>
<td>3</td>
</tr>
</tbody>
</table>

Figure 10. *Question 7: sample response graph.*
Question 8: What resources and services for autism spectrum disorder would be useful to you? Awareness, education and training again hit the highest stated need, and shares this spot with requests for a website, brochure, or lists of resources and information about online education and training ($\chi = 24$ comments each, $\beta = 17\%$ respectively). Twenty-one comments ($\chi = 21$, $\beta = 15\%$) of the total responses want community support and inclusion in afterschool activities, summer camps, and social groups for children and parents affected by autism. Many people noted the importance of a support group specifically for autism ($\chi = 14$, $\beta = 10\%$), as well as a PCP or provider that specialized in ASD ($\beta = 6\%$). A reported need for special education services through the DOE was a particular concern for higher functioning students as they may not meet the intellectual deficit criteria for services but may still have many social deficits that would benefit from behavioral interventions. While some teachers reported needing more access to the DOE autism specialists ($\beta = 6\%$). Eight respondents stated a need to know how to get help, any help, or more help ($\beta = 6\%$). Additional themes include: home therapy/skills training ($\beta = 6\%$), applied behavioral analysis ($\beta = 5\%$), and respite and babysitting care ($\beta = 5\%$). Other small yet important needs were noted for music therapy ($\beta = 1\%$), assistance dogs ($\beta = 1\%$), Special Olympics ($\beta = 1\%$), care for adults with ASD ($\beta = 1\%$), and a wander monitor ($\beta = 1\%$).
Table 9. Question 8: response variables.

| Information, Education, Training | 24 |
| Website, brochure, list of local resources, services | 24 |
| Community support center, activities, peer social groups | 21 |
| Family support group | 14 |
| Provider Specialized in ASD | 9 |
| DOE special education, autism specialist | 8 |
| any, more, dont know | 8 |
| Home therapy, skills training | 8 |
| Respite / childcare | 7 |
| ABA | 7 |
| OT/Speech therapy | 6 |
| wander monitor | 1 |
| music therapy | 1 |
| Assistance dog | 1 |
| Special Olympics | 1 |
| Adult ASD care | 1 |

Figure 11. Question 8: sample response graph.

Aim 2: Determine community resources.
Objective 1. Perform a literature search to determine evidence-based (EB) knowledge and intervention recommendations for ASD. Identification of community resources is essential to improve awareness and use of the available resources within East Hawaii. An intensive online search of the CDC, AAP, APA, HRSA, AHQR, and the University of Hawaii library, the National Autism Center (NAC), and numerous Google searches were completed. Some children will need extensive help with ADL’s while others may only need help with language or social skills. Interventions should be individualized and directed toward improving areas of deficits. Applied Behavioral Analysis (ABA) is a widely accepted and beneficial evidence-based treatment for autism behaviors. The state of Hawaii now requires health insurers to cover ABA services for children age 13 and younger. Information about Hawaii Act 235 requiring coverage of ABA and other ASD treatments was included on the website. The National Standards Project is helping to reduce the confusion of evidence-based care for autism. The National Standards Projects (NAC, 2015) provides guidelines, evidence-based standards, and information on treatments. A description of the National Standards Project and a hyperlink to the National Autism Center was added to Kiannaslist.com as additional information. The following interventions are approved EB practices for autism (NAC, 2015).

Table 10. Evidence-based practices for ASD.

<table>
<thead>
<tr>
<th>Behavioral Interventions</th>
<th>Cognitive Behavioral Intervention Package</th>
<th>Comprehensive Behavioral Treatment for Young Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language Training (Production)</td>
<td>Modeling</td>
<td>Natural Teaching Strategies</td>
</tr>
<tr>
<td>Parent Training</td>
<td>Peer Training Package</td>
<td>Pivotal Response Training</td>
</tr>
<tr>
<td>Schedules</td>
<td>Scripting</td>
<td>Self-Management</td>
</tr>
<tr>
<td>Social Skills Package</td>
<td>Story-based Intervention</td>
<td></td>
</tr>
</tbody>
</table>

Objective 2. Perform an assessment of community resources available for ASD that meet EB recommendations. Responses to question seven (discussed above) were analyzed.
Named resources were contacted via phone, email, or Internet to verify services for inclusion on the website. Many of the resources provided by the stakeholders are not located on Hawaii Island, however, some met the criteria for inclusion on the website either in the East Hawaii community page or the state and national resource webpage. The responses also provided a base knowledge of resources to contact. Agencies contacted include: The DOE, DOH-DDD, the autism society, the local telephone book, and the East Hawaii Child and Family services. Additional services were found through referrals from the agencies noted above and numerous online searches. Contact was initiated through multiple modalities including email, telephone, and in person. Appropriate services and contact information was included on the website.

**Aim 3: Increase knowledge of ASD and ASD services.**

**Objective 1. Develop tools to increase knowledge.**

1a. *Develop a comprehensive ASD website for East Hawaii based on EB recommendations and community assessment.* The domain name (Kiannaslist.com) was purchased through Godaddy®, along with web hosting services and easy to use tools to create a professional website. The stakeholder survey provided the foundation for the contents of the website.
The website currently has 9 webpages. This includes a Home page (Figure 12) that provides a brief overview of the site contents. About Us (Appendix H.) discusses the University of Hawaii at Hilo’s DNP program and the purpose of the project. The page devoted to Screening and Diagnostic Tools (Appendices I. & J.) provides background and hyperlinks to: six common child developmental screening tools, nine ASD screening tools, and six ASD diagnostic tools.
Provider information including tips for referrals, service codes for Medicaid coverage of ASD, and a link to Autism Case Training modules with free CME/CEU credits is included. The *East Hawaii Community Resources* page (Appendices K. & L.) contains brief descriptions and contact information for 35 community resources. Content includes tips for the *Newly Diagnosed* and *After Diagnosis – Now What?* Additional information on this page includes basic information on ASD, the Department of Human Services Memorandum on Treatment of ABA for ASD, Hawaii Act 235, and Title 42 – Code of Federal Regulations for Developmental Disabilities/Intellectual disabilities Home and Community Based Services Waiver to promote community living. The *Hawaii State and National Resources* (Appendices M. & N.) includes 34 state and national resources, 25 books and articles on ASD, 15 training modules, videos, or audio programs to learn about autism, and a hyperlink to the Institute for Behavioral Training with over 40 hours of applied behavioral training modules. The *Evidence-based Knowledge and Practice* (Appendix O.) explains these concepts and provides hyperlinks to peer reviewed articles at PubMed.gov and the National Standards Project (NAC, 2015). Additionally, 16 evidence-based articles with hyperlinks, six on current knowledge of ASD and nine on EB practices are provided. *Our Story* (Appendix P.) describes the inspiration for advocating for autism awareness through this project. The *Contact Us* (Appendix Q.) page encourages community collaboration to maintain current information and add resources as they become available. Comments and requests for copies of the referral brochure can be sent to the webmaster@Kiannaslist.com via a form on the *Contact Us* page. While, the *Referral Brochure* (Appendix R.) is viewable on it’s own page.

1b. *Develop a brochure of website with key ASD facts.* A referral brochure to the website was developed by the PIP director using a basic template from Microsoft Word®. The brochure includes basic information about ASD and ASD in East Hawaii. The purpose of the website is
explained in the brochure, as is EB knowledge and practices for ASD. The inside of the brochure lists all the categories of information available on the website as noted above. The cost of printing the brochure varies greatly depending on printer services available. The local office supply store charges $1.50 per two sided tri-folded, color brochure on glossy paper. The university graphics department offers a savings at $0.90 each, while Vista Print, an online service quotes $150.00 for 500 copies. This is a substantial saving at $0.30 each, however Vista Print requires more time for printing and shipping. Discussions with Key personnel at each of the following agencies received positive results for collaboration in sharing the website information with their clientele. Printed brochures were delivered to East Hawaii Child and Family Services, DOH-DDD case management department, and East Hawaii Easter Seals Early Intervention program, and a pediatric practice site. Additional brochures have been distributed at community events and project presentations. The brochure is also available in PDF for email promotion.

**Objective 2. Evaluate the website.** The Project Evaluation Tool (PET) is an anonymous six question seven-point Likert scale survey (Appendix F) developed by the PIP director. The goal of the PET was to identify accomplishments or deficits of the website in addressing the identified needs found in the stakeholder survey. Eighty-four participants had provided email information in the stakeholder survey. The PIP director emailed these stakeholders a request to evaluate the website with the website hyperlink, and PET hyperlink. The emailed survey request was opened by 68 stakeholders, with 21 recipients completing the survey ($\eta = 21$). It is possible the unopened and therefore unread emails were filtered out as spam. The same equation noted above was used to calculate the RR for the PET survey. Although online surveys have been noted to garner lower response rates than in-person surveys, the PET was sent to people who had
identified themselves as appropriate candidates per their prior participation. Therefore, the PET achieved a significantly higher RR of 35% ($\frac{21}{68}$) within 16 days.

The results of the evaluation are discussed below each question. The seven points on the Likert scale started at one = agree, four = neutral, to seven for disagree.

<table>
<thead>
<tr>
<th>AGREE</th>
<th>NEUTRAL</th>
<th>DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 13. Likert scale example.

*Question 1. The website is easy to use?* Twenty respondents ($\beta = 95.2\%$) agreed that the website is easy to use, however, one respondent chose somewhat disagree (#5). This resulted in a median score of 1., a mean score of 1.38, with a standard deviation of 0.90.

*Question 2. The website contains information to improve your knowledge of ASD or ASD resources?* Nineteen respondents ($\beta = 90\%$) indicated varying levels of agreement. One respondent chose neutral ($\beta = 4.8\%$) and one respondent somewhat disagreed ($\beta = 4.8\%$). The results indicate a median score of 1., with a mean score of 1.62, and a standard deviation of 1.09.

*Question 3. The website addresses the identified community needs?* Eighteen respondents ($\beta = 86\%$) chose varying levels of agreement, two chose neutral ($\beta = 9.5\%$) and one respondent somewhat disagreed ($\beta = 4.8$). This resulted in a median score of 1., a mean score of 1.71, with a standard deviation of 1.20.

*Question 4. You will use the website for ASD information and resources?* Nineteen respondents ($\beta = 90\%$) chose varying levels of agreement, while two ($\beta = 9.5\%$) indicated neutral. The results show the median response score is 1., with a mean of 1.52, and a standard deviation of 1.01.
Question 5. The pamphlets are useful to refer others to the website? Nineteen respondents (p = 90%) agreed, while two (p = 9.5%) were neutral. The median response score is 1., with a mean of 1.48, and a standard deviation of 0.91.

Question 6. You will refer others to the website? Twenty respondents (p = 95%) agreed and one (p = 4.8%) somewhat disagreed. The median response score is 1., the mean is 1.38, and standard deviation is 0.95.

Table 12. PET Results.

<table>
<thead>
<tr>
<th></th>
<th>Agree - 1</th>
<th>2 (2)</th>
<th>3 (3)</th>
<th>Neutral - 4</th>
<th>5 (5)</th>
<th>6 (6)</th>
<th>Disagree - 7</th>
<th>Weighted Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>The website is easy to use.</td>
<td>76.19%</td>
<td>19.05%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>4.76%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>1.38</td>
</tr>
<tr>
<td>The website contains information to improve your knowledge of autism or autism resources within East Hawaii, Hawaii Island.</td>
<td>66.67%</td>
<td>19.05%</td>
<td>4.76%</td>
<td>4.76%</td>
<td>4.76%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>1.62</td>
</tr>
<tr>
<td>The website addresses the identified community needs.</td>
<td>66.67%</td>
<td>14.29%</td>
<td>4.76%</td>
<td>9.52%</td>
<td>4.76%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>1.71</td>
</tr>
<tr>
<td>You will use the website for autism information and resources.</td>
<td>76.19%</td>
<td>4.76%</td>
<td>9.52%</td>
<td>9.52%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>1.52</td>
</tr>
<tr>
<td>The pamphlets are useful to refer others to the website.</td>
<td>71.43%</td>
<td>19.05%</td>
<td>0.00%</td>
<td>9.52%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>1.48</td>
</tr>
<tr>
<td>You will refer others to the website in the future.</td>
<td>80.95%</td>
<td>9.52%</td>
<td>4.76%</td>
<td>0.00%</td>
<td>4.76%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>1.38</td>
</tr>
</tbody>
</table>

A comments section was also added to the PET survey. Twelve participants (χ = 12, p = 57%) added comments. The majority of the comments were overwhelmingly positive; "What a great resource," "Very useful for anyone needing info about ASD," and "The web site is amazing. Easy to locate the information I needed." One respondent asked about specific services. Another asked for referral brochures. Two books were suggested as informative and
recommended readings. One additional diagnosing psychologist was identified for East Hawaii.

**Chapter Five: Recommendations and Conclusions**

Pacquiao’s (2015) model of Cultural Competence in Ethical Decision Making stresses the importance of defining the problem(s) and situation within the client’s perspective. Without this information, we cannot understand the emic variables of one’s lifeway’s and worldview nor begin to create solutions. Humans are holistic in nature. A significant problem or trouble cannot be separated from the whole of the organism, whether it is the individual, the family, or the community. When evaluating outcomes healthcare providers must understand that individuals express meanings to outcomes within many modalities. This may include biophysical, but also social, cultural, spiritual, and psychological (Pacquiao, 2015). Aim one focused on determining the stakeholders’ knowledge and needs. Efforts to achieve this aim relied on trust and partnership as the first step in promoting culturally competent care. Nursing has long been considered a trustful profession. The 2015 Gallop poll found American’s ranked Nursing as the top profession (at 85%) for honesty and ethics. Nurses have achieved the highest ranking for 16 of the last 17 years since they were added to the list in 1999 (Gallop, 2015). The positive public perception facilitated trust when approaching project stakeholders. The project director is also a caregiver to a child with ASD. This position as fellow stakeholder with emic knowledge on both professional and personal roles also contributed to trust within the various groups.

**Outcomes Evaluation**

The survey recruitment flyer and stakeholder survey consent specified the project purpose was specific to East Hawaii. Yet four surveys were received from respondents in other US states, and three surveys were from email addresses in the United Kingdom. It is probable that these respondents found the survey on Facebook. Thus, prospective projects for specific
populations may find broad recruiting efforts via *Facebook* or other online social media tools can hinder rather than help data collection.

A high RR has traditionally been considered a central component of quality research. Although RR’s are significantly lower in web-based surveys compared to telephone and mail surveys with identified populations; web-based surveys are inexpensive, easy to use, and useful when previous research is not available, as in this project (Kirkby, Wilson, Calvert, & Draper, 2011). Cook, Health, and Thompson (2000) performed a meta-analysis of RR in web-based surveys and found response representativeness is more important than the RR in survey research. However, a very low RR can result in biased responsiveness.

Substantial effort was made to recruit participation in the project by healthcare providers and psychologists. However, they had the lowest participating rate. Psychologists are often the specialists that primary care providers and pediatricians refer clients to who are deemed high risk for ASD. There is a lack of psychologists who provide ASD services on Hawaii Island. Interestingly, only one psychologist ($\chi = 1, \hat{\beta} = 1.15\%$) participated in the survey. This lone psychologist’s participation (although important) should not be generalized to all psychologists’ in East Hawaii. Caution should be used in interpreting responses from physicians and nurses due their low RR as well. However, when all participating healthcare providers are combined into one group their RR increases to $\hat{\beta} = 17\% \left( \frac{15}{87} \right)$. Therefore, this may represent an accurate perception of ASD within healthcare providers in East Hawaii.

The most significant recurring themes across all stakeholder groups was a lack of awareness; and need for improved awareness, education, and training in ASD. Parents topped the RR at approximately $\hat{\beta} = 30\%$, followed by teachers ($\hat{\beta} = 20\%$), and community providers ($\hat{\beta} = 13\%$). This suggests these responses are representative of the population. Hoogsteen and
Woodgate (2013) found parents in their study made every action of their lives a fight for autism awareness, thus improving visibility as a path to a better quality of life. Perhaps when one’s daily life is impacted by autism, the concerns are more pressing and life altering. Parent participants in this project may have viewed the survey as a vehicle to voice their concerns, frustration, and needs, which accounts for their substantial participation. As noted previously, the invisibility of autism in rural communities adds to parents’ sense of isolation and lack of community support. Participants noted limited community and afterschool events for persons with ASD in East Hawaii. Requests for services included: more inclusive community events and support groups for the children, families, and parents affected by autism. Disability rights include the right to equal access and the right to participate in all sections of society regardless of disability. Unfortunately, rural communities often do not uphold these rights due to deficient supports that may be needed by those with disabilities. For example, children have the right to participate in afterschool programs, however these programs may be staffed at a ration of one adult to 20 children. This is an unsafe supervision level for children with disabilities. Consequently, it is up to the parents to attempt enforcement of rights, often through judicial proceedings. Unfortunately, this is an additional burden on an already overburdened family. In an effort to respond to these needs, known community events and parent support groups were added to Kiannaslist.com. The website includes numerous publications regarding the rights of individuals with ASD and responsibilities of private and public entities to ensure promotion of social justice and human rights.

Many survey participants noted a lack of qualified providers, and a high turnover rate of providers. These variables may be contributing to the poor RR from healthcare providers. This should be interpreted as an important community concern and a “wake-up call” to healthcare
providers. Perhaps limited provider time related to lack of providers contributed to a low RR. The poor participation could also indicate provider obliviousness to concerns of the ASD community. However, some healthcare providers requested continuing medical and nursing education information in autism. The website has numerous resources and ASD training modules with hyperlinks for parents, teachers, and providers that can improve knowledge.

A principle theme identified by the stakeholders was diagnostic problems. The literature review confirms that many autistic children are misdiagnosed, diagnosed late, or not diagnosed at all (Mandell et al., 2007; Morrier et al., 2008; Liptak et al., 2008; Begeer et al., 2009). This was corroborated as true in East Hawaii by many parent reports. Interestingly, one nurse practitioner said she doesn’t have much problems with diagnosis or services for clients with ASD as she only treats people age 11 and over. Many children are not diagnosed until their coping mechanisms cannot keep up with their expected demands (APA, 2013). This may occur as the child ages. Recall the child who was not diagnosed until age 12 (question three discussion). Additionally, children with autism grow up to be adults with autism, who will seek care for many health related conditions throughout their lifespan. The comment from the APRN is an example of misinformation or unawareness that contributes to diagnostic problems. Doreis and Weiner (2006) reported that 62% of pediatricians in their study felt a lack of familiarity of screening tools was a barrier in diagnosis of ASD. Therefore, numerous developmental screening tools are discussed on the website with hyperlinks to additional information for use and scoring.

Of the 87 stakeholder respondents, 18 ($\chi = 18, p = 21\%$) had no knowledge of resources available to them while eight ($\chi = 8, v = 9\%$) asked for information on how to get help or access to any resources. The referral brochures were developed mainly for providers. This was to address the comments in the stakeholder survey that indicated a lack of referral information
after diagnosis. Nineteen (\(\hat{p} = 90\%\)) of the respondents found the brochures useful while two (\(\hat{p} = 9.5\%\)) were neutral. Use of the resources on the website by parents and caregivers of persons with autism may foster empowerment and consequently improve access, equality, and provision of additional resources to East Hawaii. While many respondents asked for information via a website, brochure, or Internet modules. This may be partly due to child behaviors that limit the caregivers’ ability to leave home for classes. Online parent training modules were included on the website as a means to improve parent and guardian ASD knowledge within their time constraints and while in the safety of the home. Internet based parent trainings were should to be effective in rural communities (Meadon et al., 2013).

It was found that many children are not receiving applied behavioral analysis (ABA) or other EB interventions outside of the DOE. Lack of funding to provide or access intervention services was a recurrent theme. Therefore, the PIP director included Medicaid insurance information and the hyperlink to Hawaii Act 235, which explains children’s rights and insurers obligations to provide ABA therapy. Perhaps with more coverage and increased awareness of insurers obligation, there will be more recruitment of professionals and certified ABA providers to East Hawaii. Additionally, a definition of EB practices and peer reviewed articles on EB services for autism was included on the website along with the community agencies that may provide ABA and other EB interventions. Hyperlinks to the National Standards Project, PubMed.gov and 16 peer reviewed articles on ASD are available as well as a hyperlink to the Institute for Behavioral Training with over 40 hours of parent and caregiver learning modules for ASD.

Additional community service information was provided on the website; although not specifically for autism, the resources address a variety of holistic concerns found in the
stakeholders’ comments. For example, many parents noted feelings of stress, isolation, depression, and financial difficulties. This is similar to results of high stress and isolation experienced by parents in rural communities found by Farmer and Reupert (2013). Therefore, including contact information for a 24-hour crisis line was imperative as well as information to apply for Medicaid or supplemental food assistance through the Department of Human Services. Information on service dogs and the Federal Aviation guidelines and rights for persons with disabilities were also added as resources. Additionally, educational and biographical books and articles were included in another section of the website.

The project director made adjustments and additions to the website based on the PET evaluation and comments. Two books and one additional diagnosing psychologist was added to the website resources. Interestingly, one respondent was responsible for all the poorest PET results. This included four “somewhat disagree” and two “neutral” replies (3% & 1% respectively) compared to the $\hat{p} = 92\%$ positive results regarding the use of the website and brochure. It appears the website did not meet the expectations or needs of this participant. Therefore, the PIP director evaluated this participant’s comments from the original stakeholder survey in an effort to determine possible improvements in the contents of the website. Evaluation indicated the participant as a teacher, who noted the primary problems encountered were identifying children with autism, and a lack of information, knowledge, and parental participation. The participant suggested more feedback from parents, other teachers, and nurses; and stated “any” resources would be beneficial. Perhaps the participant did not understand or read the survey results as a form of feedback, while the extensive lists of resources both local and national are meant to provide “any” resources as this participant requested.

The website (Kiannaslist.com) received substantial agreement from the stakeholders for
meeting the needs of the community as noted in the PET results. However, communities are fluid, and research steadily improves knowledge and treatment options. Change is constant. Therefore, a website contact form is necessary, as this allows for continual evaluation and adjustment of Kianaslist.com to continue meeting any evolving stakeholder needs.

**Facilitators and barriers.** The PIP director’s position as an ASD caregiver and “insider” with personal acquaintances of other stakeholders facilitated project implementation. Published insurance provider directories and DOE staff listings provided mailing addresses for potential participants. Requesting email addresses from participants of the original survey facilitated exposure of the finished website to respondents who self-identified as ASD caregivers, and facilitated the website evaluation process. Barriers included, not knowing all the people in the community who provide care for persons with autism, and not having personal knowledge of and access to the majority of healthcare providers in East Hawaii. Limited time for project completion can affect the ability to recruit additional stakeholders. Future projects may benefit with more face-to-face recruitment of healthcare providers.

**Strengths.** Solutions that promote health, social justice, and preserve human rights must be created in collaborative and culturally congruent partnerships (Pacquiao, 2015). The stakeholder survey provided insight into the needs and perspectives of the various stakeholder groups in East Hawaii. Parents and teachers comprised \( p = 50\% \) of the total survey respondents. One parent commented, “Wow, this website is AMAZING! … It will help many families, especially the ones with newly diagnosed children…we wish we had something like this before our kid(s) were diagnosed!” The strength of this project is the enlightenment into the reality, concerns, and daily experiences of those who care for children with ASD in East Hawaii, and the ability to share these experiences and collaborate on solutions.
Weaknesses. Hawaii is separated from the U.S. mainland by 2,390 miles of ocean. Hawaiians and multi-racial local residents have distinct life views that may differ from other population groups. Therefore, the results might not be applicable to other rural communities.

Project limitations. Community responses were evaluated and addressed as thoroughly as possible with the available resources. Lack of providers knowledgeable in ASD and lack of funding to provide and access intervention treatments was a recurrent theme. It is outside the scope of this project to correct the lack of providers or funding within the community. It is improbable that this project and Kiannaslist.com will correct all problems encountered by people caring for those with ASD. However, the solutions to every problem begins with awareness of the issues and collaborative actions to improve the lives of those affected.

Chapter Six: Implications for Practice

Implications for Practice

Contributions to practice. Improving use of societal support services may decrease the lifetime costs of ASD and has the capacity to improve adult life productivity. The goal of a DNP PIP is to improve the health of populations through the translation of evidenced based research. Healthy People 2020 emphasizes the importance of promoting the health of people with disabilities. This project and Kiannaslist.com strives to achieve these goals by improving community awareness and knowledge of ASD and resources for those affected by ASD.

A hit-tracker provides an accurate number of visits to Kiannaslist.com on a daily, monthly, and yearly basis. Objective visit-counts confirmed people are accessing the website. Within one month of launching, 696 visits were recorded to the website. This is far above the 68 original number of stakeholders that received and opened the PET request with website hyperlink. The visit-counts suggest the project goal of improved awareness of ASD and ASD
resources in East Hawaii is attainable through Kiannaslist.com.

East Hawaii Easter Seals Early Intervention Program, the DOH-DDD case management departments, and East Hawaii Child and Family Services all requested brochures to the website as a referral source for their clients with ASD. A community service case manager wrote, “I will be referring back to it [Kiannaslist.com] often and using it to help clients and prospective clients.” Providing autism resources to the community on a standard basis is improving autism awareness and knowledge. Increased awareness may improve coordination of care. Referral services will be facilitated through the accepted use of the brochure by community agencies. This is confirmation of successful accomplishment of the overarching project goal to increasing knowledge of ASD and ASD resources to the diverse stakeholders within rural East Hawaii. Improving awareness addresses the major stakeholder concern, and is an essential step toward decreasing disparities in diagnosis and treatment of autism for multiethnic and Native Hawaiian children on Hawaii Island.

**Suggestions for practice.** Statements from the stakeholders provided insight into the lived experiences of autism. A lack of and need for ASD awareness, education, and training was overwhelmingly noted as a major concern in 75% of the stakeholder survey questions. The responses confirmed the problem statement and overarching project goal.

The critical aspect that is often overlooked or underestimated is that repatterning is the responsibility of providers to change their approach and provision of care to meet the needs of the client and community. Pacquiao (2015) stresses culturally competent care includes repatterning behaviors. This is often incorrectly assumed as the client’s responsibility. It is within the professional duties of physicians, nurses and teachers to perform or recommend developmental evaluations of children who are struggling. The MCHAT-R/F is a simple tool
that can be used in healthcare and educational assessments. Begeer et al. (2009) and Dosreis and Weiner, (2006) found only 8% of pediatricians routinely screen for autism although it is recommended by the AAP at 18 and 24 months. An easy solution is to provide the questionnaire to the parent upon appointment arrival. Once the form is filled out, the nursing staff can score the results and have them available to the pediatrician or primary care provider during the appointment. This can substantially reduce primary care provider screening time and improve consistency with AAP guidelines for ASD screenings. Consistent screenings may also flag high-risk girls; who are likely under-diagnosed as found by Supekar and Menon (2015).

With incidence rates holding steady at one in 68 children (Christensen et al., 2016), it is imperative that communities are knowledgeable and ready for a deluge of adults with ASD. Medical and nursing schools should implement ASD specific training modules and requirement of clinical practice hours with autistic persons. One may argue that this would be difficult to coordinate in a healthcare facility, however, it is quite feasible to acquire practice experience within the greater community. The public school system is an appropriate agency to collaborate health clinics, while most communities have adult day programs for those with developmental disabilities such as autism. Teacher training programs should include autism specific information and professionally appropriate training ASD risk signs and screening tools.

**Future projects.** “This particularly poignant stakeholder comment inspires compassion and understanding, “ASD and typical kids are like MAC and Windows – they have two different operating systems. If you’re used to one, you may get frustrated with the other, but with a little patience you may grow to love the other. They are both great in their own way, they are just different from one another.”” This project improves awareness of the lived experiences of ASD within the diverse stakeholder groups in East Hawaii, and provides extensive resources to
improve care. The vision to continue improving awareness of ASD encompasses growth of the website statewide, with resource webpages specific to each of the seven main occupied Hawaiian Islands. Current collaboration with an ABA therapist residing on Maui is focused on expanding Kiannaslist.com by including a webpage specifically for Maui community resources. Outreach goals include contact with stakeholders in other Hawaiian communities. Achievement of the vision will require continued coordination and partnership with stakeholders statewide. Stakeholder surveys should be replicated in other communities as a means to shed insight into the unique experiences and needs of each population area. This will help guide culturally competent decisions and actions appropriate for each community.
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www.childrensdefense.org/child.../child-welfare-financing-hawaii-20

spectrum disorder among children aged 8 years — Autism and Developmental

Christensen, J., Grønborg, T. K., Sørensen, M. J., Schendel, D., Parner, E. T., Pedersen, L. H., &


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asd awareness


http://www.minorityhealth.hhs.gov/npa/templates/browse.aspx?&lvl=2&lvlid=34


## Appendices

### Appendix A. Project Timeline

<table>
<thead>
<tr>
<th>Item</th>
<th>Beginning Date</th>
<th>End Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Submit PIP chair selection</td>
<td>September 15\textsuperscript{th} 2014</td>
<td>September 30\textsuperscript{th} 2014</td>
</tr>
<tr>
<td>Finalize review of literature and draft of proposal with chair</td>
<td>August 1\textsuperscript{st} 2014</td>
<td>October 1\textsuperscript{st}, 2015</td>
</tr>
<tr>
<td>Identify additional committee members</td>
<td>January 1\textsuperscript{st} 2015</td>
<td>May 1\textsuperscript{st} 2015</td>
</tr>
<tr>
<td>Complete CITI training</td>
<td>January 2014</td>
<td>January 28\textsuperscript{th} 2014</td>
</tr>
<tr>
<td>Final Proposal to DSRC</td>
<td>October 20\textsuperscript{th} 2015</td>
<td>November 1\textsuperscript{st} 2015</td>
</tr>
<tr>
<td>Defend Proposal</td>
<td>October 20\textsuperscript{th} 2015</td>
<td>November 20\textsuperscript{th} 2015</td>
</tr>
<tr>
<td>IRB Approval</td>
<td>November 20\textsuperscript{th} 2015</td>
<td>January 22\textsuperscript{nd} 2016</td>
</tr>
<tr>
<td>Begin Project</td>
<td>January 22\textsuperscript{nd} 2016</td>
<td>ongoing</td>
</tr>
<tr>
<td>Contact Stakeholders</td>
<td>January 22\textsuperscript{nd}, 2016</td>
<td>February 29\textsuperscript{th} 2016</td>
</tr>
<tr>
<td>Analyze stakeholder responses, Develop website and brochures</td>
<td>February 29\textsuperscript{th} 2016</td>
<td>March 30\textsuperscript{th} 2016</td>
</tr>
<tr>
<td>Present website, brochures, &amp; PET to stakeholders</td>
<td>March 31\textsuperscript{st} 2016</td>
<td>April 8\textsuperscript{th} 2016</td>
</tr>
<tr>
<td>Evaluate PET results</td>
<td>April 15\textsuperscript{th} 2016</td>
<td>April 15\textsuperscript{th} 2016</td>
</tr>
<tr>
<td>Submit Manuscript Rough Draft to PIP Chair</td>
<td>April 16\textsuperscript{th} 2016</td>
<td>April 16\textsuperscript{th} 2016</td>
</tr>
<tr>
<td>Prepare &amp; Submit final project results to chair and committee</td>
<td>April 1\textsuperscript{st} 2016</td>
<td>April 30\textsuperscript{th} 2016</td>
</tr>
<tr>
<td>Complete Oral defense</td>
<td>April 22\textsuperscript{nd} - May 1\textsuperscript{st} 2016</td>
<td>April 22\textsuperscript{nd} 2016</td>
</tr>
<tr>
<td>Prepare and participate in DNP symposium</td>
<td>May 1\textsuperscript{st} 2016</td>
<td>May 12\textsuperscript{th} 2016</td>
</tr>
<tr>
<td>Submit Form 3</td>
<td>May 13\textsuperscript{th} 2016</td>
<td>May 13\textsuperscript{th} 2016</td>
</tr>
</tbody>
</table>
Appendix B. Project Budget

<table>
<thead>
<tr>
<th>Item</th>
<th>Estimated Cost/Quantity</th>
<th>Actual Final Cost/Quantity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stakeholder Survey recruitment flyer</td>
<td>$0.50 each/ $800</td>
<td>.57 x 320 = $190.75</td>
</tr>
<tr>
<td>Web-page GoDaddy®</td>
<td>$200.</td>
<td>3 years plus email privacy and search engine optimization = $359.00.</td>
</tr>
<tr>
<td>Gift Cards Jamba juice Starbucks</td>
<td>$10 each /x 200 = $2000</td>
<td>24 /$240. + 62 /$620. = $860.00</td>
</tr>
<tr>
<td>Mailing /postage</td>
<td>$0.49 / $300</td>
<td>$0.49 x 210 = $102.90</td>
</tr>
<tr>
<td>Survey Monkey® subscription</td>
<td>$300.</td>
<td>$300.</td>
</tr>
<tr>
<td>DataCracker® subscription</td>
<td>$228.</td>
<td>$0 - Not used</td>
</tr>
<tr>
<td>Website Brochures</td>
<td>$0</td>
<td>220 = $210.00</td>
</tr>
<tr>
<td>Total estimated costs</td>
<td>$3428.</td>
<td><strong>Actual costs</strong> = $1951.65</td>
</tr>
</tbody>
</table>
Appendix C. East Hawaii Autism Project Recruitment Flyer

**EAST HAWAII AUTISM PROJECT**

A DOCTOR OF NURSING PRACTICE PROJECT THROUGH THE UNIVERSITY OF HAWAI’I AT Hilo SCHOOL OF NURSING

**RESEARCH PROJECT**

PROMOTING AWARENESS OF AUTISM SPECTRUM DISORDERS AND RESOURCES

**FACTS:** One in 68 children have autism.
This is about 1.4% of children but only 0.4% of children in Hawaii are known to have autism.

Native Hawaiian and minority children are undiagnosed with autism 99% of the time.

Early diagnosis and care is the best way to improve a child’s skills and abilities.

Researchers have found that help for children and families with autism in Hawaii is often limited or disorganized.

This project is seeking community input to help understand autism in East Hawaii.

This project includes a short survey from people who care for children with autism. Your opinion is important.

The survey results will be used to develop a website for East Hawaii autism needs. The website will provide one easy access point for screening tools, care and services, and concerns found in the survey.

Participants will be compensated for their participation.
Only one response per person allowed.

**SEEKING SURVEY PARTICIPANTS**

**Until Feb 29**
Online at
https://www.surveymonkey.com/r/EastHawaiiAutism

Children with autism who learn to do self-care activities are more likely to be employed and need less help and services as adults.

For Questions please contact
Lisa Tostenson, 808-315-6212
Lisa@hawaii.edu

Alice Davis, Faculty Advisor,
aaldaiv@hawaii.edu
Appendix D. East Hawaii Autism Project Introduction

and Stakeholder Survey Informed Consent

**University of Hawaii Consent to Participate in a Research Project**

Promoting Awareness of Autism Spectrum Disorders and Resources to Diverse Stakeholders in Rural Hawaii: a Community Based Approach **East Hawaii Autism Project Stakeholder Survey**

My name is Lisa Tostenson. I am a doctoral student at the University of Hawaii at Hilo School of Nursing. I am doing a research project as part of the requirements for my degree. The purpose of my project is to promote awareness of autism and autism services in East Hawaii. The purpose of this survey to identify services and community needs for autism in East Hawaii. I am asking you to participate because you care for children with autism.

**Activities and Time Commitment:** There are eight questions about your experiences caring for children with autism in East Hawaii. The survey will include questions such as: Have you experienced any problem(s) with screening, diagnosis, or care services for your child or client(s) with autism? What do you think would help correct the problem(s)? What resources and services for autism would be helpful to you? The survey will take approximately 15 – 30 minutes. I hope to survey 200 people who provide various levels of care from parents to pediatricians, teachers, and community providers.

**Benefits and Risks:** There will be no direct benefit to you for participating in this survey. The results of the survey will be used to develop an autism website specific to East Hawaii. The purpose of the website is to provide one easy access point for autism information such as screening tools, support services, evidence-based practice recommendations, and address identified needs found in this survey. I do not anticipate that taking this survey will contain any risk or inconvenience to you. If you become stressed or uncomfortable answering the questions you may withdraw from the survey. The County of Hawaii, Child and Family Services offers a 24 hour crisis access line and mobile outreach services if you are feeling overwhelmed or need mental health services at (800) 753-6879.

**Privacy and Confidentiality:** All information collected will be used only for this project. All personal information will be kept confidential and secured in a password protected file. The survey program has embedded protection tools. Only my University of Hawaii advisor and I will have access to the information. Other agencies that have legal permission have the right to review research records. The University of Hawaii Human Studies Program has the right to review research records for this study. I will not use any personal information that can identify you. There will be no connection to you specifically in the results or in future publication of the results. I will use every means within the extent of the law to protect your privacy and confidentiality. Once the survey and project is finished I would like to share the results with you.

**Voluntary Participation:** Your participation in this survey is completely voluntary and you may withdraw your participation at any time without penalty.

You will receive a $10.00 gift card to Starbucks or Jamba Juice for your time and effort in participating in the research project. (Only one response per person is allowed)
Questions: If you have any questions about this study please contact me at (808) 315-6212 or Lisa8@hawaii.edu. You may also contact my adviser, Dr. Alice Davis at (734) 674-5160 or aedavis@hawaii.edu. If you have questions about your rights as a research participant you may contact the UH Human Studies Program at (808) 956-5007 or uhirb@hawaii.edu.

Your participation in this survey verifies that you have read the explanation of the survey, and that you agree to participate. Please answer the following questions as honestly as possible.
Appendix E. Stakeholder Survey

Please indicate the choice that most resembles your role

<table>
<thead>
<tr>
<th>Physician</th>
<th>Nurse Practitioner</th>
<th>Registered Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialty Provider, OT/PT/Speech</td>
<td>Teacher / School Staff</td>
<td>Parent / Guardian / Family</td>
</tr>
<tr>
<td>Psychologist</td>
<td>Community Provider</td>
<td>Other</td>
</tr>
</tbody>
</table>

1. What problem(s) related to screening, diagnosis, or care services have you encountered with your child or client with autism spectrum disorder?

2. What do you think has caused the problem(s) related to screening, diagnosis, or care services with your child or client with autism spectrum disorder?

3. What do you think makes the problem(s) worse?

4. How do the problem(s) impact your professional or personal life?

5. What do you think will help correct the problem(s) you encountered with screening diagnosis, or care services with your child or client with autism spectrum disorder?

6. What do you wish others knew about autism spectrum disorders?

7. What resources and services for autism spectrum disorders are you aware of in your community?

8. What resources and services for autism spectrum disorders would be useful to you?

9. Please include the mailing address where you would like to receive your gift card; please include an email contact address if you would like the results of the survey and website.
Appendix F. East Hawaii Autism Project Evaluation Survey

The website easy to use?

AGREE  NEUTRAL  DISAGREE

_1_________ 2_________ 3_________ 4_________ 5_________ 6_________ 7_____ 

The website contains information to improve your knowledge of ASD or ASD resources within the East Hawaii?

AGREE  NEUTRAL  DISAGREE

_1_________ 2_________ 3_________ 4_________ 5_________ 6_________ 7_____ 

The website addresses the identified community needs?

AGREE  NEUTRAL  DISAGREE

_1_________ 2_________ 3_________ 4_________ 5_________ 6_________ 7_____ 

You will use the website for ASD information and resources?

AGREE  NEUTRAL  DISAGREE

_1_________ 2_________ 3_________ 4_________ 5_________ 6_________ 7_____ 

The pamphlets are useful to refer others to the website?

AGREE  NEUTRAL  DISAGREE

_1_________ 2_________ 3_________ 4_________ 5_________ 6_________ 7_____ 

AGREE  NEUTRAL  DISAGREE

You will refer others to the website in the future?

_1_________ 2_________ 3_________ 4_________ 5_________ 6_________ 7_____ 

Comments
Appendix G. East Hawaii Autism Project Evaluation Survey Informed Consent

**University of Hawaii Consent to Participate in a Research Project** Promoting Awareness of Autism Spectrum Disorders and Resources to Diverse Stakeholders in Rural Hawaii: a Community Based Approach **East Hawaii Autism Project Evaluation Survey**

My name is Lisa Tostenson. I am a doctoral student at the University of Hawaii at Hilo School of Nursing. I am doing a research project as part of the requirements for my degree. The purpose of my project is to promote awareness of autism and autism services in East Hawaii. I am contacting you because you completed my first survey regarding your experiences of caring for children with autism in East Hawaii. Your input was helpful in creating the East Hawaii Autism website.

**Activities and Time Commitment:** There are six questions about your opinion of the East Hawaii Autism website. The survey will include questions such as: The website is easy to use? Answer choices range from agree to disagree. I expect the survey to take approximately 5 minutes. I am asking everyone who participated in the original project survey to review and evaluate the website in this short survey.

**Benefits and Risks:** There will be no direct benefit to you for participating in this survey. The results of the survey will help determine the usefulness of the website and identify areas for improvement. I do not anticipate that taking this survey will contain any risk or inconvenience to you. If you become stressed or uncomfortable answering the questions you may withdraw from the survey.

**Privacy and Confidentiality** All information collected will be used only for this project. No personal information will be collected. All information will be secured in a password protected file. The survey program has embedded protection tools. Only my University of Hawaii advisor and I will have access to the information. Other agencies that have legal permission have the right to review research records. The University of Hawaii Human Studies Program has the right to review research records for this study. There will be no connection to you in the results or in future publication of the results.

**Voluntary Participation:** Your participation in this survey is completely voluntary and you may withdraw your participation at any time without penalty.

**Questions:** If you have any questions about this study please contact me at (808) 315-6212 or Lisa8@hawaii.edu. You may also contact my adviser, Dr. Alice Davis at (734) 674-5160 or aedavis@hawaii.edu. If you have questions about your rights as a research participant you may contact the UH Human Studies Program at (808) 956-5007 or uhirb@hawaii.edu.

Your participation in this survey verifies that you have read the explanation of the survey, and that you agree to participate. Please answer the following questions as honestly as possible.

Do Not participate in this survey until you have reviewed the website.
The Hawaii Autism Project and Kiannaslist.com are the results of a Practice Inquiry Project (PIP) for the Degree of DNP through the University of Hawaii at Hilo's School of Nursing.

This PIP is a tertiary prevention project based on Healthy People 2020 goals of: 1) increasing life expectancy and quality of life and 2) eliminating health disparities among segments of the population. One focus area goal of Healthy People is to promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities. This project addresses the disparities in autism diagnosis and treatment services in rural East Hawaii through collaborative input from diverse stakeholders by the creation of a website designed to house ASD information specifically for East Hawaii, Hawaii Island.

It is hoped that identification of community specific needs and resources through one easily accessed site (Kiannaslist.com) can improve provider and caregiver knowledge, may decrease fragmentation of services, and improve use of available resources.
Appendix I. Kiannaslist.com: Screening and Diagnostic Tools

The American Academy of Pediatrics recommends well-child developmental screenings at 9, 18, and 30 months of age. For a full list of AAP recommended health screenings follow this link: https://www.aap.org/en-us/Documents/pediatrics_schedule_oral_health.pdf

Bright Futures is a national health promotion and prevention initiative led by the American Academy of Pediatrics. The Bright Futures Guidelines provide theory-based and evidence-driven guidelines for all preventive care screenings and well-child visits. Bright Futures content can be incorporated into health programs & clinics, schools, and family activities: https://brightfutures.aap.org/Pages/default.aspx

The CDC's Learn the Signs, Act Early Program provides information on developmental milestones from age 2 months to 5 years old. This program provides parental guidance and information for clinicians in detecting children who are not reaching normal developmental goals: http://www.cdc.gov/mchbd/dscrecy/

The Ages and Stages Questionnaire ASQ-3, and ASQ-SE (social-emotional) rely on parents to observe their child and to complete the simple questionnaires about their child’s abilities. Having parents complete the questionnaires is cost effective and enhances the accuracy of screening by tapping into parents’ in-depth knowledge about their children, however, it relies solely on parents' perception and not clinician observation. The healthcare provider scores the responses. There is an annual fee to use the ASQ tools. More information is available at http://agesandstages.com/

The American Academy of Pediatrics recommends Autism screenings at 18 and 24 months of age. Children found to have some level of developmental delay during a standard screening are often referred for additional evaluation. Screens do not diagnose, but rather indicate the need for additional diagnostic evaluations. First stage screenings are key to improving early diagnosis of ASD. There are a number of screening tools to assess for ASD to include:

- The MCHAT-RF is a quick, easy to fill out and score screening tool that requires little to no training and is available free from http://mchatscreen.com/
- The STAT tool is administered from training individuals and has a nominal fee. It is designed for toddlers from 24–36 months of age who are suspected of having ASD. http://stat.ueh.edu/sat/sat/littlenumber.html
- The SBAR is a brief screening tool that can be used with children who have a communication delay.
- The SCQ is a useful as a quick easy tool for older children. It has demonstrated good internal consistency and validity, however, there is a higher false negative with higher functioning children. Caregivers can rate the individual's 'lifetime' characteristics (which would be used to support a diagnosis or current behavior which may not meet the criteria for an autism spectrum disorder).

The American Psychiatric Association provides standardized criteria to help diagnose Autism Spectrum Disorders: http://www.australia.org/app/Content/australiahp-diseases.html

Diagnosis of ASD is challenging due to a lack of identified biological and genetic markers, a wide range of symptoms, changing diagnostic criteria, and individual perceptions of symptoms. Currently diagnosis is determined by the child's behavioral symptoms.

There are many tools to assess ASD but no single tool is used alone as the basis for diagnosis. Diagnostic tools usually rely on two main sources of information—parents' or caregivers' descriptions of their child's development and a professional's observation of the child's behavior. In some cases, the primary care provider might choose to refer the child and family to a specialist for further assessment and diagnosis. Such specialists include child neurologists, geneticists, child psychologists, and early intervention programs that provide assessment services such as Faster Screen (CDC, 2015).

Selected examples of diagnostic tools:

- Autism Diagnostic Interview Revised (ADI-R)
- Autism Diagnostic Observation Schedule (ADOS-2)
Appendix J. Kiannaslist.com: Screening and Diagnostic Tools continued
Appendix K. Kiannaslist.com: East Hawaii Community Resources

**East Hawaii** is an area on Hawaii Island. The southernmost and largest island in the Hawaiian chain.

Early intervention services have long been considered key to communication and behavioral improvements in children with autism disorders. Children who live in rural environments experience numerous challenges to acquiring early interventions including a lack of providers prepared to work with children with ASD, large commute times, and increased costs to reach provider locations.

A comprehensive assessment of community agencies that provide services for ASD in East Hawaii was carried out to determine services they provide and to identify other providers of services within East Hawaii.

The results of the community assessment of resources are noted below with web links provided when available.
Appendix L. Kiannaslist.com: East Hawaii Community Resources continued
Kianna's List

The Hawaii Autism Project: Hawaii State and National Resources

The state of Hawaii is an isolated group of islands in the Pacific Ocean, consisting of eight main islands: Oahu, Maui, Kauai, Molokai, Lanai, Kahoolawe, and Nihoa. The state of Hawaii is the only state that is completely surrounded by the ocean.

The Centers for Medicare and Medicaid services contracted with L&M Policy Research to address the increasing demand for on-duty mental health services among its clients. The report notes that it is the first state to develop an Aurora State and National Resources for Autism.

Learn about Autism

Let the research help you navigate the ways you can support your child. Don’t let the personal stories and experiences of others be the only guide for decisions.

- American Psychiatric Association: https://www.psychiatry.org/patients-families/families/families
- Association for Science in Autism Treatment (ASAT): An organization that provides information on autism interventions that are strongly supported by research.
- Assistance Dogs of Hawaii: https://assistancedogsahawaii.org/
- Autism Society of Hawaii: Offers periodic community events and sensory friendly events in Hilo.
- Autism Speaks: service@autismspeaks.org
- Early Signs of AED Video Tutorial: https://www.youtube.com/watch?v=xv55A5H4a4U

Hawaii State & National Resources

- Access Adult Mental Health Division 24 Hour Information and Crisis Line: 1-800-753-8679
- Aloha Independent Living, East Hawaii: 1020 Kinoe Street, Unit 202, Hilo, 808-339-7271
- The ABC, Autism Hawaii: http://autismhawaii.org/
- Hawaii State and National Resources for Autism: http://www.hawaiianautism.org/100-State

Recommended Books & Articles

- The Americans with Disabilities Act: http://www.adap.gov/
- ADA: Service Animals: http://www.adap.gov/service_animals
- Emergencies: labeled as autistic: a true story, Grenell, Tangle & Scarrano, Margaret (2005)
- Grand Central Publishing
- Individuals with Disabilities Education Act (IDEA) for Children with Special Needs provided by Center for Parent Information & Resources: http://www.parentcenterhub.org/parentaryidea
Appendix N. Kiannaslist.com: State and National Resources continued
Appendix O. Kiannaslist.com: Evidence-based Knowledge and Practice
Kianna was born in 2007. Through a series of events I took over as her legal guardian and assumed custodial care. Even though I have an extensive background in healthcare it was easy to rationalize away her differences. I had no other small children around to compare her to. She was just slow, not ready, preferred to be held, her needs were well anticipated so she did not have a reason to ask (talk), she didn’t play well with other children or really play at all, except for her intense fascination and preference for Hula, Hawaiian music, and instruments. In hindsight I now see these are typical signs of autism.

Other symptoms she has experienced include chronic constipation even with a diet high in vegetables, anxiety and meltdowns with changes in routine and exposure to high sensory environments such as stores, aversion to clothing on her skin but lack of pain response, and no sense of danger including fire, cars, or strangers. She insists on order and tidyness, everything must be in its place. She will shut any door that is open, at home or in public.

Kianna was eventually diagnosed with Autism. I found the ordeal of diagnosis excruciatingly long and painful. I thought after the diagnosis I was left (like many other parents) out of referrals or assistance. Her diagnosis at age four was past the age for early services from Easter Seal. I did not know what to do or where to turn, and it seemed, did anyone else I knew. Children with ASD do not look different from non-ASD children. Negative public comment from strangers in the community toward her typical ASD behaviors inferred I was a bad parent or she was a bad child. This led to stress and anxiety. I believe if more people are aware of ASD we will have a happier, healthier, kinder, and more inclusive society. Consequently, I developed a strong desire to improve knowledge of ASD and ASD resources. I hope you find benefit from this website.

Modification of an approach from focusing on what other kids can do and trying to teach her these “normal” skills to focusing on what she can do and enhancing her skills has been beneficial.

For example: switching out a tricycle with pedals (difficult concept) to a bike that moves with Kinetic energy and no pedals (easy concept) allows her to be successful and enjoy a bike.

She prefers to sort blocks by color rather than typical stacking and building play.

Exposure to Hula, musicals, and theater events has improved her social skills, appropriate public behaviors, as well as language and memorization of songs, rhythms, and the ability to verbalize recall of people and places. This is an example of using her preferred restricted behaviors to teach beneficial skills.

Kianna has taught me more about love, patience, and appreciation than I could ever have imagined. I dedicate this work to Kianna and all persons with autism who bring unique perspectives into our world.
Appendix Q. Kiannaslist.com: Contact Us

We want to hear about any new resources or information for people with Autism Spectrum Disorders that would be useful to people in Hawaii.

Perhaps you would like to list your services on our Resource pages.

Please contact: webmaster@kiannaslist.com or fill in the adjacent form.

For copies of the referral brochure please request via the adjacent form.

Mahalo for your kokua in maintaining this site's accuracy and usefulness.
Appendix R. Referral Brochure

Evidence-based knowledge is the result of research with strict guidelines and careful analysis. Research provides information about problems and solutions. Evidence-based practice is considered therapeutic healthcare treatments and services that have been shown to be helpful through scientific research.

Families, educators, and providers are constantly bombarded by a massive amount of confusing and often conflicting information about the treatments available. The National Standards Project is helping to reduce the resulting turmoil and uncertainty by addressing the need for evidence-based practice standards and providing guidelines for how to make choices about interventions.

Screening and Diagnostic Tools
Childhood Developmental Screening Tools
Autism Screening Tools
Autism Diagnostic Tools
For Providers
Medicaid Service Codes
Referral Guidelines
CHN opportunities
Evidence-Based Research
National Standards Project
Established Interventions for children, adolescents, and young adults
Evidence-based Knowledge
Evidence-based Practice

Kianna'slist.com
Promoting Awareness of Autism, Autism Information, & Resources for Families, Educators, & Providers in Hawaii

The Hawaii Autism Project

Kianna'slist.com
email: webmaster@kiannaslist.com

East Hawaii Community Resources
Newly Diagnosed with Autism
After Diagnosis - What now?
Hawaii Arc 235, Luka’s Law
Community Resources

Request copies of this brochure at Kianna'slist.com

East Hawaii Community Survey
Read the results of the East Hawaii Community ASD assessment on Screening, Diagnosis, and Care services.
Appendix S. Permission to Use Model

Permission to use my model

Dula Pacquiao

to me

Dear Lisa:

You may use my model, Culturally Competent Ethical Decision Making for your DNP capstone. I am here to support you.

Dula F. Pacquiao, EdD, RN, CTN-A, TNS
Diversity and Transcultural Nursing Consultant
Education, Research and Practice

208 Tingley Lane
Edison, NJ 08820

Click here to Reply or Forward
Appendix T. IRB Approval

UNIVERSITY OF HAWAII
MĀNOA

January 22, 2016

TO: Lisa Tostenson
    Alice Davis, Ph.D.
    Principal Investigators
    Nursing

FROM: Denise A. Lin-DeShetler, MPH, MA
    Director

SUBJECT: CHS #23616 - "Promoting Awareness of Autism Spectrum Disorders and Resources to Diverse Stakeholders in Rural Hawaii: A Community Based Approach"

This letter is your record of the Human Studies Program approval of this study as exempt.

On January 22, 2016, the University of Hawai‘i (UH) Human Studies Program approved this study as exempt from federal regulations pertaining to the protection of human research participants. The authority for the exemption applicable to your study is documented in the Code of Federal Regulations at 45 CFR 46.101(b) (Category 2).

Exempt studies are subject to the ethical principles articulated in The Belmont Report, found at http://www.hawaii.edu/irb/html/manual/appendices/A/belmont.html

Exempt studies do not require regular continuing review by the Human Studies Program. However, if you propose to modify your study, you must receive approval from the Human Studies Program prior to implementing any changes. You can submit your proposed changes via email at uhirb@hawaii.edu. (The subject line should read: Exempt Study Modification.) The Human Studies Program may review the exempt status at that time and request an application for approval as non-exempt research.

In order to protect the confidentiality of research participants, we encourage you to destroy private information which can be linked to the identities of individuals as soon as it is reasonable to do so. Signed consent forms, as applicable to your study, should be maintained for at least the duration of your project.

This approval does not expire. However, please notify the Human Studies Program when your study is complete. Upon notification, we will close our files pertaining to your study.

If you have any questions relating to the protection of human research participants, please contact the Human Studies Program at 956-5007 or uhirb@hawaii.edu. We wish you success in carrying out your research project.

Office of Research Compliance
Human Studies Program

1960 East-West Road
Biomedical Sciences Building 8104
 Honolulu, Hawaii 96822
 Telephone: (808) 956-5007
 Fax: (808) 956-8163
 An Equal Opportunity/Affirmative Action Institution