Primary Provider Education Regarding Adults with Autism Spectrum Disorder

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CHAPTER 1: INTRODUCTION

Background and Significance

In the Institute of Medicine Report: The Future of Disability in America (2007) the challenge of transitioning from pediatric to the adult care system for the disabled was identified as an issue that needs to be addressed (Perrin & Hicks, 2008). According to Johnson and Carter (2011), a goal of *Healthy People 2020* is to eliminate health disparities. Many of the challenges in accessing healthcare for adults with autism are directly related to the symptoms of Autism Spectrum Disorder (ASD). These symptoms include impairments in spoken as well as nonverbal communication, difficulty in understanding emotions and altered sensory perception (Johnson & Carter, 2011). As an example, sensory impairment can impact feeding issues due to touch, taste or smell of certain foods. This can lead to a diet that is limited in variety and nutritional value (Tyler, et al., 2011). In a study by Tyler, et al. (2011), the investigators compared two groups of young adults; one cohort had autism and the other did not. In the cohort with autism rates of chronic disease were 34.9% for obesity compared to 30.3% for the control group, 31.5% for hyperlipidemia compared to 18.9% for the control group, 22.2% for constipation compared to 7.3% for the control group, and 22.2% for epilepsy compared to 2.9% for the control group (Tyler, et al., 2011). Without early intervention, adults with autism are likely to have chronic health conditions like diabetes, heart disease, heart failure, arthritis, and cancer. Nicolaidis, Kripke, and Raymaker, (2014), also found autistic adults have high rates of epilepsy, gastrointestinal disorders, feeding and nutritional problems, metabolic syndrome, anxiety, depression, and sleep disturbances. The literature reports that healthcare providers are unable to accommodate to the needs of this population.

Adults with autism report that visits with their health care providers are impaired due to providers who were unable to accommodate communication, sensory integration, and executive functioning resulting in poor outcomes (Nicolaidis, Kripke, & Raymaker, 2014). Adult primary providers have confusion about who should be responsible for managing the care and assume the mental health provider or community disability team will do so (Webb & Stanton, 2009). Additionally, adults with ASD have noted that their providers make assumptions about the autistic adult's ability to understand what is being said and to follow through with care because they are often able to speak at a higher level than their ability to process what they are being told and to follow through with a plan of care. Nicolaidis et al. (2015) broke down the challenges that impact healthcare for those with autism. Autism-related factors include verbal communication challenges, sensory sensitivities, challenges with body awareness, the need for consistency, slow processing speed, atypical nonverbal communication and challenges with organization.

An option that is gathering interest is the medical home model. Rogers and Zeni (2015) discussed how this model has been successful in meeting the needs of children with chronic health needs. The medical home model is designed as a system where healthcare services are easily available and meet the needs of the client and their family. The care in a medical home is coordinated and comprehensive (American Academy of Pediatrics [AAP], 1992). The complexity of autism as a lifelong challenge lends itself well to this model. Noted barriers to establishing a medical home include providers who do not spend enough time with their clients and the providers who also lack adequate information about ASD (Rogers & Zeni, 2015). Khulthau, Warfield, Hurson, Delahave and Crossman (2015) found that even pediatric providers considered to be experts in ASD had done little to create a smooth transition to adult care for their patients. According to this study, only 21.1% of youth with ASD receive any transition planning services. It was also noted that those with disabilities receive routine preventative care less often than the neurotypical population.

In 2005, the United States Department of Health and Human Services reported that in women with disabilities over the age of 40, only 65% received a mammogram compared to 75% of women without disabilities. In children and adults with disabilities, 37% reported to have annual dental visits compared to 46% of those without disabilities (Bruder, Kerins, Mazzarella, Sims, & Stein, 2012). There are many reasons for this disparity in access to healthcare with physician training, comfort level and reimbursement as the main factors (Bruder, et al., 2012).

Research has been done that looks at the experiences of primary care providers to better understand this issue. Bruder, et al. (2012) reported that over half of the physicians that they surveyed were interested in having more training in the form of workshops or conferences. Providers lack knowledge about ASD. Because of this knowledge deficit they incorrectly assume that they have the necessary skills or needs to work with this population. Providers have an unwillingness to communicate in writing and may not open to considering accommodations and incorporating supporters. Lost revenue is one reason that providers do not want to take on more complex patients like those with ASD (Warfield, Crossman, Delahaye, Der Weerd, & Kuhlthau, 2015). This is an issue that needs to be addressed at the state and national policy level to incentivize providers to care for these adults. Warfield, et al. (2015) reported that challenges at the practice and provider level include scheduling issues, family involvement, physical environment, and communication challenges. Survey respondents reported that they had virtually no education or experience in caring for this population.

Problem Statement

Autism Spectrum Disorder (ASD) is “a developmental disability that is caused by differences in how the brain functions. People with ASD may communicate, interact, behave, and learn in different ways” (Autism and Developmental Disabilities Monitoring Network [ADDM Netword], 2016, p. 1). According to the Centers for Disease Control (CDC), in 2012 the incidence of children with autism was 1.47% of the total population (CDC, 2016). This is an increase from the year 2000 when the incidence of autism was 0.67%. It is estimated that 1% of adults currently meet the criteria for ASD (Nicolaidis, Kripke, & Raymaker, 2014). Among children identified with ASD, about a third also had an intellectual disability. In Arizona, the CDC reports the diagnosis rate is even higher with 1.56% of children diagnosed with autism (ADDM Network, 2016). Due to this increase in diagnosis, there is a larger cohort of children who have or will soon be reaching adulthood (Kuhlthau, Warfield, Hurson, Delahave, & Crossman, 2015; Nicolaidis, Kripke, & Raymaker, 2014).

May barriers exist for adult with ASD including: adult primary care providers who do not have adequate training in caring for adults with autism, nor do they have an interest in receiving such training due to cost issues and extended length of appointments Bruder, Kerins, Mazzarella, Sims, and Stein (2012). Adults with autism identify the waiting room and waiting time as barriers to care (Saqr, Y., Braun, E., Porter, K., Barnette, D., and Hanks, C., 2018). Autistic adults report healthcare providers make incorrect assumptions about their abilities and needs and are unwilling to accommodate written communication. According to Sarris (2016), in a survey of adult care providers performed by Kaiser Permanente, 79% rate their knowledge and skills with autism as fair to poor. Nicolaidis, et al. (2014) found that in general adults with autism did not receive adequate health care, tend to use the emergency room as a source of primary care, do not use preventive care services, are generally dissatisfied with healthcare, do not perform self-care activities, and face significant challenges in accessing healthcare.

It was reported by a parent in the Phoenix area how difficult it is to find an adult primary care provider for her son with autism as he was turning eighteen. When searching for a provider using her healthcare insurance company, the only listed providers with an understanding of autism were pediatricians (G.C., personal communication, 04/12/18). The author interviewed pediatric and adult primary care physicians in the Phoenix area who are familiar with ASD and they have confirmed the shortage of adult primary care providers who are ready to care for adults (G. C., personal communication, 04/12/18). A review of the literature found that most of the articles are focused on the pediatric autism population. In searching the literature, there was confirmation that this is indeed a national issue that needs to be addressed as the incidence of autism has continued to rise. The lack of adult primary care providers for adults with autism impacts the health of this population.

Compounding the problem of a lack of adult primary care providers is the fact that those with autism are prone to certain health problems due to poor self-care. Those with disabilities are more likely to use drugs and alcohol, are less likely to receive routine oral care, engage in physical exercise and to be overweight or obese (Johnson & Carter, 2011). Autism is associated with a reduced life expectancy of about 2-3 times higher than matched peers in the general population (Nicolaidis, Kripke, & Raymaker, 2014).

This practice gap impacts the healthcare system at different levels. Adults with ASD often do not have access to a primary care provider who is comfortable in caring for adults with autism or understand the specific healthcare needs of this population. Without a primary care provider, many adults in this population will not seek any preventative/wellness care and are likely to use the emergency department as their primary source of healthcare (Liu, Pearl, Kong, Leslie, & Murray, 2017).

This problem affects adults with autism and young adults who are aging out of pediatric care. It impacts pediatric and adult health providers. It also impacts family members and caregivers of adults with autism. A lack of primary care providers also directly impacts the health and wellness of these individuals. It affects the costs both directly and indirectly to all who pay taxes and pay health insurance premiums as adults with autism are more apt to use the emergency department as their primary source for receiving healthcare. Additionally, it affects people with autism by a decreased quality of life, an increase in risk for chronic health conditions and also an increased chance of a shortened lifespan (Nicolaidis, et al., 2014).

PICOT Question

The background and significance outlined in this inquiry has led to the clinically relevant PICOT question, "Among primary care providers (P) how does education on autism spectrum disorders in adults (I) compared to no education (C) affect knowledge, attitudes and beliefs in providing care to this population (O)?

Literature Review

Databases searched for the literature review included Cumulative Index of Nursing and My Allied Health Literature (CINAHL), PubMed and PsycINFO. Key words included; *adult*, *autism spectrum disorder, autism spectrum disorders, autistic disorder, healthcare, nurse practitioners, primary care*, *provider*, and *physicians*. The initial search of *autism, adult*, and *healthcare* yielded 40 results in CINAHL (Appendix A), 13 results in PsycINFO (Appendix B), and 12 results in PubMed (Appendix C).

Exclusion criteria included work published before 2012, studies not available in English, and unpublished works. After appraising 41 articles, ten have been selected to be included in this examination of evidence. Studies that were discarded were informational but did not provide any research data or the data was not conclusive. Those studies that were included involved older adolescents and adults, autism and other developmental disabilities. The selected papers evaluated the relationship between healthcare provider experience and understanding of autism in providing care to this population.

Ten studies were selected for this review including one non-randomized control study, one systematic review, two exploratory retrospective reviews, two cross-sectional data surveys, one intervention/longitudinal study and three qualitative studies. Levels of evidence range from three to six according to the *Rating System for the Hierarchy of Evidence for Intervention/Treatment Questions* (Appendix D). The Picot question being studied is focused on patient and provider experiences and has not generated randomized control trials (RCT's). The age ranges of the participants included adults with autism 18 years and older. One study looked at transitional planning for adult primary care on focused on 12-21-year-old participants. Most studies relied on self-identification or chart review for diagnosis of ASD and did not confirm through evaluation. The majority of studies were set in primary outpatient care and the rest looked at acute care facilities (Appendix E).

The studies looked at both adults with autism and healthcare providers and as a result, the demographic data is mixed. For studies with providers not all of them included demographic information. In the study by Bordini, et al. (2015) 68% were female, the mean age was 46 years, and the mean age since graduation was 20.7 years. For those studies focused on adults with autism the ages looked at were 18 and over with a majority being male.

Primary interventions focused on identification of barriers to primary care for adults with ASD. Most studies focused on the lack of providers willing and able to care for this population. There was an additional focus on the need for more training for providers and staff to better care for adults with ASD. Several studies looked at the general health of adults with ASD and identified disparities when compared to the non-ASD population such as seizures, gastrointestinal diseases, diabetes, obesity, depression and anxiety (Croen, Zerbo, Qian, Massolo, Rich, Sidney, & Kripke, 2015).

Outcomes focused on the need for more training for healthcare professionals. Autistic adults are more likely to have other medical and psychiatric conditions and to develop complications which stresses the need for primary care with this population. They are also more likely to access the Emergency Department (ED) for primary care. The studies addressed this problem from both the adults with autism and adult primary care providers.

The three qualitative studies used multiple evaluators to review the data to assure that the data was being coded consistently and themes were identified. Nicolaidis et al. (2016) used three heterogeneous surveys (Appendix D). Changes in outcomes were significant for identified barriers to healthcare ($p = <0.0001$), healthcare self-efficacy ($p = 0.016$), and patient-provider communication ($p = 0.027$). Heterogeneity in the studies was tested by chi-square, Wilcoxson, Cronbach’s alpha, and Fisher’s exact tests. The effects between studies did vary, but all did show that there is a need for training in autism for healthcare providers (Appendix F).

Purpose Statement

This topic was selected because adults with ASD are a forgotten population. ASD is thought of as a pediatric issue however autism is not something that a person “grows” out of. Once teenagers and young adults with ASD age-out of healthcare as a pediatric patient, options are limited for finding an adult health care provider who is comfortable and confident in caring for them. The goal for this problem is to improve the overall health of adults with autism by increasing access to adult primary health care providers through provider education.

CHAPTER 2; APPLIED CLINICAL PROJECT: METHODS AND RESULTS

Evidence Based Practice Model and Conceptual/Theoretical Model

The Star Model of Knowledge Transformation addresses the challenges of large amounts of research, the disconnection between knowledge and practice, and the value of integrating provider expertise and patient preference into best practice (Melnyk & Fineout-Overholt, 2015). The Star Model has five points (Appendix G).

Sociocultural learning theory (SCT) is thought to have been initially developed by Lev Vygotsky. In his theory, Vygotsky believed that learning involves self-instruction, assisted learning and the zone of proximal development (ZPD) which focuses on what the learner can do without help and with help (Vygotsky, 1986/1962). SCT emphasizes that in order for learning to occur, the participants need to be actively involved (Andersson & Andersson, 2005). This theory was selected because the evidence in the literature shows that providers have a desire to learn more about this patient population and learners need to be engaged and motivated for learning to occur.

Project Methods

Protection of Human Subjects

The Institutional Review Board (IRB) at Arizona State University granted approval for this project (See Appendix H). An approval letter was also obtained from the participating institution, Mountain Park Health Center (MPHC) (See Appendix I) where the project was to be implemented. There were five clinics within the MPHC system. Four clinics ultimately participated. Participants were adult primary care providers at the clinics. All providers were invited to participate. Participation in the project was voluntary, and anonymous and presented no anticipated risk of harm.

Data was collected anonymously. All potential participants were provided with a letter outlining the project (Appendix J). Completing surveys and attending the education summit was taken as consent to participate in the project. Each survey was coded with the participant's first three letter of their parent's first name and the last three digits of the participant's phone number. All surveys were then able to be matched up while protecting the anonymity of each participant.

Setting, Organizational Culture, and Participants

The project took place in a large metropolitan city in the Southwestern United States. A multi-site primary care clinic with five adult care campuses was selected as the site. The organization focuses on providing affordable health care using a multidisciplinary Care Team model. The education program will target adult primary care providers and may include physicians, nurse practitioners and physician assistants. According to the website there were 45 providers that met the criteria of being a primary care provider who sees adult clients in the organization.

Procedure

The lead provider for each clinic was approached to ask for participation from their clinic. Four agreed to participate while one clinic did not feel that they could be a part of this project. Arrangements were made to attend a provider meeting to present the education program. The week before the education session, a pre- education session survey was sent electronically to each lead provider to distribute to their team. It was estimated that each survey would take about 15 minutes to complete. The education sessions were all part of weekly provider meetings and took about 30 minutes. After the education session, each participant was asked to complete an immediate post-test survey. Arrangements were made to send an electronic 1 month post-test survey out to each lead one month after the education session. The leads were asked to distribute at their next team meeting to the providers to fill out. The final surveys were then picked up.

Learning Objectives

1. Discuss the prevalence of autism and diagnostic criteria
2. Identify at least four comorbidities associated with Autism Spectrum Disorder (ASD).
3. Determine at least four changes that can be implemented into your practice that would improve the experience for clients with ASD.
4. Identify one local and one national resource that can assist you to improve the health of your ASD patients.

The face to face education session was presented to all participants. The current prevalence of ASD compared historical diagnosis rates was presented. Commonly used medications and the current diagnostic criteria according to Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) were highlighted. The risks and benefits of adult diagnosis of ASD were discussed. Associated co-morbidities were presented as well as an understanding of the experiences of adults with ASD in accessing healthcare. Nicolaidis (2014) outlined the factors that make up a successful healthcare experience as operating at a system-level, patient-level and provider-level. Multiple resources were presented including the Autism Healthcare Accommodations Toolkit (AHAT). Specific needs that must be addressed include sensory accommodations, the need for consistency, atypical non-verbal communication, slow processing speeds, typical body awareness, and difficulty with planning, organizing and sequencing. The PowerPoint slides were made available as handouts.

Outcome Measures and Data Collection

A pre-module demographic survey (Appendix L) was developed including questions about gender, age, race/ethnicity, type of provider, area of practice, years of experience, any previous autism education, frequency of seeing ASD clients in their practice, and their clinic location. One additional question was asked on the follow-up survey asked if the provider had seen an adult with ASD in their practice.

A 26-question pre- and immediate post-test was designed to measure provider participant's knowledge, attitudes and behaviors before and after the education session regarding adults with ASD (Appendix K). The 1-month post-test survey asked for additional questions. Validity and reliability of an instrument is important in determining the actual performance of the tool (Billings & Halstead, 2016). Validity assures that the tool is evaluating what it was designed to measure. Reliability is the "extent to which an instrument is dependable, precise, predictable, and consistent (Billings & Halstead, p. 392, 2016).

The content of the questions was designed to measure the learning objectives of the education session. The tool was created by modifying tools that had been used in previous research and the addition new questions. Knowledge questions were adapted from a tool developed by Bordini, Lowenthal, Gadelha, de Araujo Filho, de J. Mari, and Paula (2015). Permission was obtained from the principal author and the tool was translated from Portuguese to English. Each question was evaluated to assure the all answer choices were plausible and there was only one correct answer. Attitudes and behaviors statements were modified from Nicolaidis, et al. (2016). Dr. Nicolaidis reviewed the developed tool as an expert and provided feedback. No formal specific test for reliability were performed prior to beginning the project. It should be noted that participants were asked the same questions on all three surveys. Participants were then aware of the questions on subsequent surveys which could have potentially impacted scores on the post-test and follow-up surveys.

The Modified Knowledge/Attitudes/Beliefs (KAB)questionnaire consisted of two sections. The first section had 19 statements that participants answered based on a seven point Likert scale ranging from *one – Strongly Disagree to seven- Strongly Agree*. These statements measured attitudes and behaviors regarding adults with ASD. The second section contained 7 multiple choice questions with four responses to measure knowledge about ASD. Question 21was discarded because a typographical error was found on some of the surveys which resulted in no correct answer being available for participants to select.

The Modified Knowledge/Attitudes/Belief instrument used in this project was a blend of several different tools. The Likert scale attitudes and beliefs statements were developed based on a tool created by Dr. Christina Nicolaidis and her team. The knowledge questions were adapted from a translation from Portuguese to English of a survey developed by Dr. Bordini and her team. Dr. Nicolaidis, as a research expert in autism in adults reviewed the tool and provided suggestions. There are no reliability and validity results for this tool developed by the author.

Project Budget

This project did not require a formal budget. The main resource was the author’s time in developing, implementing and evaluating this project. Project participants were all employees of MPHC. Participation was voluntary and no compensation was provided. Costs incurred by the author were for duplication of presentation handouts and surveys as well as mileage for driving to the clinics to present and pick up surveys.

Project Results

This is a pilot project is based on current evidence in practice. The question asked was the basis of the evaluation.

1. How did adult primary care provider’s knowledge, attitudes and beliefs about ASD change over time?

Data Collection

Survey data were collected manually using paper questionnaires. A total of 30 (66.7%) providers out of 45 participated in some aspect of the project. Twenty-eight participants (66.2%) completed the pre-survey demographics, the KAB pre-test and the education session and immediate post-test. Of those 28 participants, 17 (37.8%) completed 1 month post-test survey.

Demographics of the Sample

All adult primary care providers at MPHC were invited to attend. One clinic declined to participate. Of the seventeen participants who completed the demographics pre-survey, the education session and all three KAB surveys, slightly more were males than females. The average age of the participants was 35.7 with a range from 29-50 years of age. Two participants did not respond to this item. The average number of years in practice was 5.6 years with a range from less than one year to 40 years in practice.

The majority of providers identified as non-Hispanic White with three other ethnic groups making up the rest of the sample. Provider types represented were Physicians, Nurse Practitioners, and Physician Assistants. Clinic sites represented in the sample were Gateway, Tempe and Maryvale.

Prior to this educational program, participants that had received education about ASD (*n*=13, 76.5%) were fewer than those who had never received education (*n*=4, 23.5%). The frequency with which providers see ASD patients ranged from weekly, monthly, every 2-3 months, every 4-6 months, yearly to never. A summary of all demographic information can be found in Appendix M.

Data Analysis and Findings

SPSS statistics software (version 23, IBM Corp., 2015) was used to manage and store all data. Descriptive statistics were used to describe the sample and outcome variables. Friedman's ANOVA is a nonparametric test was used to analyze the outcome variables. It can determine if the medians of measures that are being compared are different. Criteria met for using Friedman's ANOVA include the same group being measured three times, the group is random, and the dependent variable is measured at the ordinal level (Kellar & Kelvin, 2013). A p value of <0.05 was used to determine statistical significance.

A non-parametric Friedman test of differences among repeated measures was conducted and rendered a Chi-square value of 130.483 which was significant (p<0.001).

Results

Change in Knowledge, Attitudes and Beliefs Change Over Time

To evaluate for change in all areas, the scores were compared. Pre-test knowledge scores ranged from 1 to 5 with a mean of 3.59. Immediate post-test knowledge scores ranged from 4 to 6 with a mean of 4.94. One-month post-test knowledge scores ranged from 1-6 with a mean of 4.12. Pre-test attitudes scores ranged from 36-72 with a mean of 57.49. Immediate post-test attitudes scores ranged from 65-83 with a mean of 74.31. One-month post-test attitudes scores ranged from 70-105 with a mean of 87.32.

Pre-test beliefs scores ranged from 7-38 with a mean of 25.77. Immediate post-test beliefs scores ranged from 8-36 with a mean of 26.71. One-month post-test beliefs scores ranged from 14-45 with a mean of 33.67 (Appendix N).

A chi-square goodness of fit test was calculated comparing total scores for knowledge, attitudes and beliefs on the pre-test, post-test and follow-up surveys. The null hypothesis stated that there would be no significant difference in scores after the education intervention. Significant deviation from the hypothesized values was found ($X^2(8)=130.48$, $p<0.001$). The null hypothesis is rejected. There was statistically significant improvement over time in knowledge, attitudes and beliefs (Appendix N).

Conclusions/Discussion

The project focused on determining if an education program for adult care providers about ASD would increase knowledge, attitudes and beliefs. Based on the results of this project, there was a significant change in knowledge, attitudes and beliefs. The great majority of providers (76.5%) had never had any education about ASD prior to this session. The evidence suggests that additional education sessions like the one from this project would be beneficial to adult care providers. Adult primary care providers will certainly be seeing more adults with ASD coming to their practices. Attitudes and beliefs may have increased over time due to further learning about ASD or possibly having the opportunity to practice what was learned with ASD clients in the clinic.

The risks of comorbidities in adults with ASD as identified in literature are significant and speaks to the need for better health care. Schools of medicine, nurse practitioner and physician assistant programs should add similar content to their curriculum in theory and practice based on the provider reports that they had not had any prior to this education session. It would also be beneficial for current adult practice providers to have more in depth education and practice in seeing adult patients with ASD in either a clinical setting or a simulated clinical setting.

Strengths of this project were that participation was voluntary and included multiple types of providers. Limitations were the location of the project to one geographic location and one health care clinic system. Results may have been different if there had a been a broader cross-section of providers either in the area or from different parts of the country. The length of the education session was short. Further changes in practice may be more likely with more in-depth education and opportunities to reflect and develop changes to the current practice setting.

Future areas of study would be to replicate the project in a different geographic location. Including all members of the clinic team such as nursing and reception staff would help to develop greater awareness throughout the clinic and hopefully create a better patient experience for adults with ASD. Working with the whole patient care team to design a more welcoming environment for adults with ASD would also be a good project to deliver.

Summary

Access to healthcare by providers who have an understanding of autism and how to work with this population will make a significant improvement in health outcomes. More than half of adults with ASD have additional psychiatric conditions (Croen, Zerbo, Qian, Massolo, Rich, Sidney, and Kripke, 2015). Primary care providers need to support and encourage mental health care as part of the overall health of the individual. Many common chronic health problems are seen with greater frequency in adults with ASD. Those conditions include dyslipidemia, hypertension, diabetes, obesity and thyroid disease (Croen et al., 2015). The incidence of these conditions could be decreased if adults with ASD are working with a primary care provider.

Goals would be to have a decrease in use of the ED for primary healthcare and an increase in adult primary care providers who indicate that they are comfortable in caring for adults with ASD. Connecting adults with ASD to a primary care provider rather than seeking primary care in the ED will help to reduce overall health care costs.

There is a great amount of progress that needs to be made to assure that adults with autism are afforded the same opportunity to receive adequate healthcare. Primary care providers who are committed to addressing the needs of this identified group will need to become the coordinator of care between disciplines to achieve better health care outcomes and a more welcoming physical environment. Imagine a clinic where adults with ASD are welcomed and supported and the environment addresses their special sensory needs. Living a healthier life has the potential to decrease healthcare costs and increase life expectancy. Being healthier will improve quality of life and peace of mind for themselves and their families.

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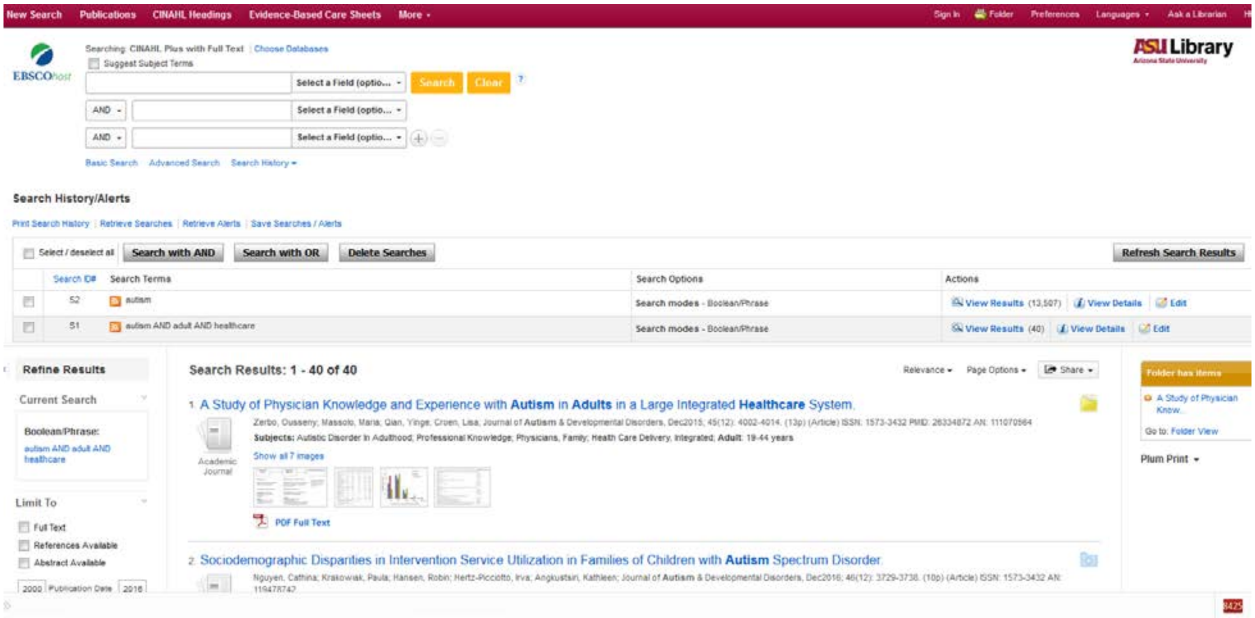
Appendix A

CINAHL



Searching: CINAHL Plus with Full Text | Choose Databases

Search History/Alerts

	Search ID#	Search Terms	Search Options	Actions
☐	S2	autism	Search modes - Boolean/Phrase	View Results (13,507) | View Details | Edit
☐	S1	autism AND adult AND healthcare	Search modes - Boolean/Phrase	View Results (40) | View Details | Edit

Boolean/Phrase:
autism AND adult AND healthcare

☐ Full Text
☐ References Available
☐ Abstract Available
2000 Publication Date 2016

Search Results: 1 - 40 of 40

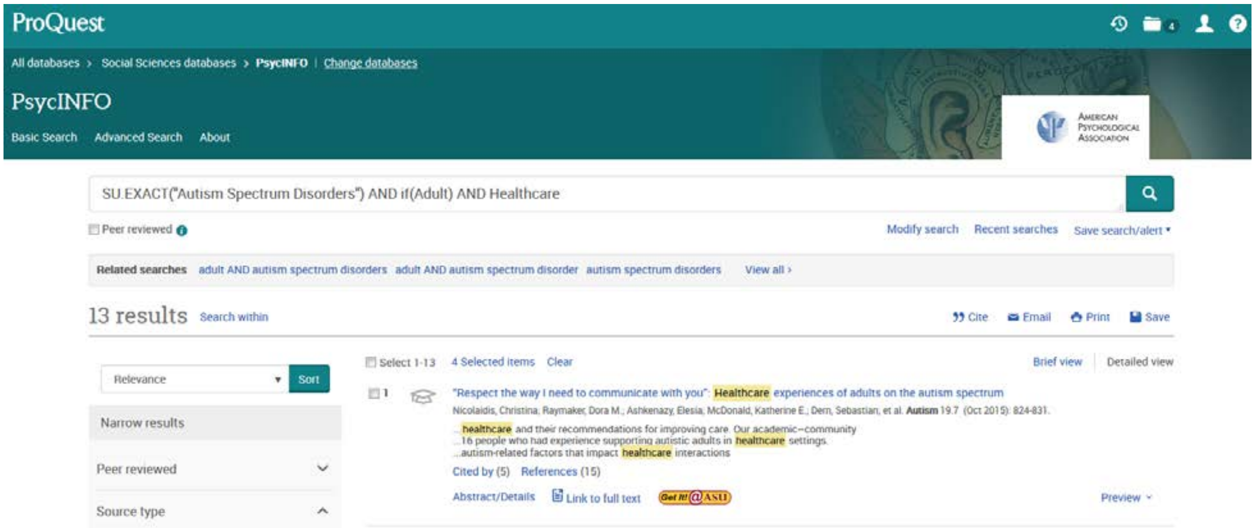
1. A Study of Physician Knowledge and Experience with **Autism** in **Adults** in a Large Integrated **Healthcare** System.
Zerbo, Ousseny; Massolo, Maria; Qian, Yinge; Croen, Lisa; Journal of **Autism** & Developmental Disorders, Dec2015; 45(12): 4002-4014. (13p) (Article) ISSN: 1573-3432 PMID: 26334872 AN: 111070564
Subjects: Autistic Disorder in Adulthood; Professional Knowledge; Physicians, Family; Health Care Delivery, Integrated; **Adult**: 19-44 years

2. Sociodemographic Disparities in Intervention Service Utilization in Families of Children with **Autism** Spectrum Disorder.
Nguyen, Cathina; Krakowiak, Paula; Hansen, Robin; Hertz-Picciotto, Irva; Angkustsiri, Kathleen; Journal of **Autism** & Developmental Disorders, Dec2016; 46(12): 3729-3738. (10p) (Article) ISSN: 1573-3432 AN: 119478742

Folder has items
A Study of Physician Know...

Appendix B

PsycINFO



SU.EXACT("Autism Spectrum Disorders") AND if(Adult) AND Healthcare

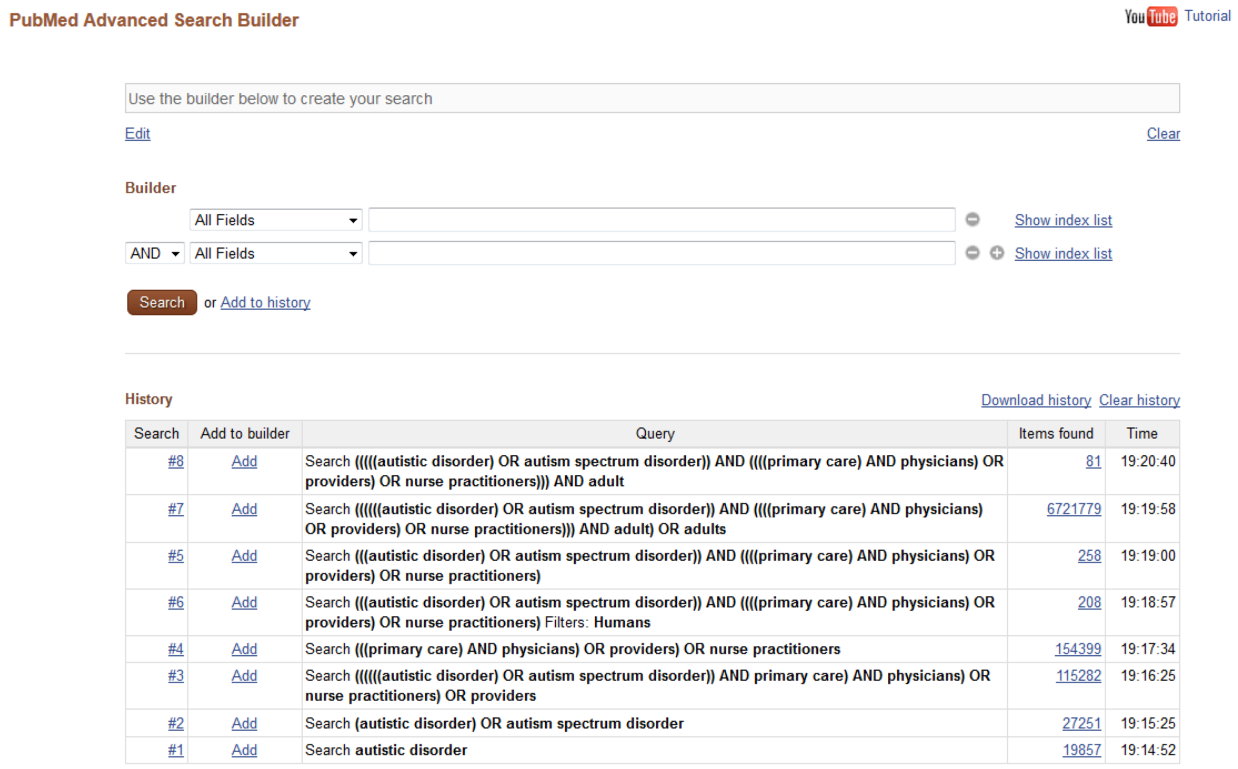
☐ 1 "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum

Nicolaidis, Christina; Raymaker, Dora M.; Ashkenazy, Elesia; McDonald, Katherine E.; Dern, Sebastian, et al. **Autism** 19.7 (Oct 2015): 824-831.

...healthcare and their recommendations for improving care. Our academic–community
...16 people who had experience supporting autistic adults in healthcare settings.
...autism-related factors that impact healthcare interactions

Appendix C

PubMed



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#7	Add	Search **((((((autistic disorder) OR autism spectrum disorder)) AND ((((primary care) AND physicians) OR providers) OR nurse practitioners))) AND adult) OR adults**	6721779	19:19:58
#5	Add	Search **(((autistic disorder) OR autism spectrum disorder)) AND ((((primary care) AND physicians) OR providers) OR nurse practitioners)**	258	19:19:00
#6	Add	Search **(((autistic disorder) OR autism spectrum disorder)) AND ((((primary care) AND physicians) OR providers) OR nurse practitioners)** Filters: **Humans**	208	19:18:57
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#2	Add	Search **(autistic disorder) OR autism spectrum disorder**	27251	19:15:25
#1	Add	Search **autistic disorder**	19857	19:14:52

Appendix D

Rating System for the Hierarchy of Evidence of Intervention/Treatment Questions

Level 1: Evidence of a systematic review or meta-analysis of all relevant randomized control trials (RCT's).

Level 2: Evidence obtained from well-designed Randomized Control Trials (RCT).

Level 3: Evidence obtained from well-designed control trials without randomization.

Level 4: Evidence from well-designed case-control and cohort studies.

Level 5: Evidence from systematic reviews of descriptive and qualitative studies.

Level 6: Evidence from a single descriptive or qualitative study.

Level 7: Evidence from the opinions of authorities and/or reports of expert committees.

Above information from "Evidence-based practice in nursing and healthcare: a guide to best practice, 3rd edition" by Bernadette M. Melnyk and Ellen Fineout-Overholt. 2015, page 11.

Appendix E

Evaluation Table

Citation: author(s) & date of publication, title, funding agency, country	**Conceptual framework**	**Study design**	**Sample description**	**Major variables studied & defined**	**Measurement of each variable**	**Data analysis used**	**Study findings**	**Worth of the study to practice**
Ailey, et al. (2015), Factors related to complications among adult patients with intellectual disabilities hospitalized at an academic medical center. Funded by Center for Clinical Research and Scholarship at Rush University Medical Center, Gamma Phi Chapter of Sigma Theta Tau	Social Determinants of Health	**Design**: Exploratory retrospective review **Method**: retrospective chart review **Purpose**: To analyze data from reviews of academic medical center charts about complications and to examine patient and hospitalization characteristics in relation to complications among adult	N=217 n=70 **Setting**: Data collected from chart reviews over a two-year period at an academic teaching medical center in the Midwest. **Inclusion Criteria**: adults over 18 years old, and one of the following secondary diagnosis codes	IV-ID adults DV-Hospitalization Complications	Data extracted from chart review of patients with ID admitted for medical or surgical reasons for complications.	Chi-square and binary logical regression tests	IV-22.9% Twice as likely to have complications and 4 times as likely to have complications with surgical procedures.	**Level 4** **Strengths**: Data was collected over two years. **Weaknesses**: Sample size, study site may not be representative of other medical centers or geographic regions, 25% of admissions with ID came from other hospitals, all patients with ID may not have been identified with a

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No conflicts or biases recognized. USA		patients with ID hospitalized for nonpsychiatric reasons.	based on ICD-9: 317-mild mental retardation, 318.x-other specified mental retardation, 319-unspecified mental retardation **Exclusion Criteria:** psychiatric admissions					secondary diagnosis. **Clinical Significance**: Demonstrates the need for those with ID including autism to have a primary care provider.
Bordini, et al. (2015), Impact of training in autism for primary care providers: A Pilot study Funding: none disclosed No conflicts or biases recognized.	Transtheoretical model	**Design:** PTPT Intervention /Longitudinal Study **Method**: Pre-test given followed by 3 hours of weekly training and an immediate post-test	N=29 n=22 primary care providers 15 of them (68.2%) were female, mean age was 46 years old, mean time since graduation was 20.7 years; 16 pediatricians and six general practitioners	IV1-referrals to mental health service for evaluation IV2-mean score comparison between pre-test and post-test DV-ASD training	Survey of how many suspected ASD cases were referred 4 months after training was completed. Pretest and posttest with 13 MC questions and vignettes of clinical ASD cases.	Wilcoxson test	IV1 – 1 referral for autism before training and 6 referrals after the training. IV2 – ASD knowledge increased from 6.73 to 9.18 with a p <0.01. Total number of correct answers increased 37.1%	**Level 4** **Strengths –** training program can be replicated, increased ASD knowledge **Weaknesses** – pilot study conducted at a single location, small sample

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Brazil		**Purpose**: Evaluate the impact of a training program on ASD identification.	completed the study. **Setting**: Primary care providers from the Sao Paulo, Brazil area. Training was conducted at a CAPSI in Sao Paulo. **Inclusion Criteria**: primary care providers					size limits generalization, limited results on specific knowledge acquisition due to limited numbers of items. **Clinical Significance –** autism education increased provider knowledge.
Bruder, et al. (2012), Brief report: The medical care of adults with autism spectrum disorders: Identifying the needs.	Observational Inductive Framework	**Design**: Cross-sectional data survey **Method**: electronic survey sent to primary care physicians in Connecticut	N-1,580 n=346 30 responses were discarded because respondents did not meet the inclusion criteria Survey was initially mailed	IV-serving adults with ASD	14 MC questions, 3 with multiple response and 4 with open-ended response.	Descriptive statistics for the data and open-ended responses were summarized.	IV – 40% served adults with ASD. 36% have had some training in ASD. Over 50% would like more training in caring for adults with ASD via	**Level 4** **Strengths –** 376 respondents with a 23.8% return rate. Identified the need for more training as there is only a small

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Citation: author(s) & date of publication, title, funding agency, country	**Conceptual framework**	**Study design**	**Sample description**	**Major variables studied & defined**	**Measurement of each variable**	**Data analysis used**	**Study findings**	**Worth of the study to practice**
Funding: none disclosed No conflicts or biases recognized. USA		**Purpose**: To obtain data on adults with ASD including reasons for visits, living arrangements, employment, and any services received.	to 600 randomly selected physicians but due to a poor response (n=94 for a 15.6% return), they survey was then mailed to all 1,580 physicians. **Inclusion Criteria**: adult primary care providers				workshops or conferences.	cohort of providers that care for adults with ASD. **Weaknesses –** Study was done in only 1 state, survey respondents were voluntary and those who chose not to respond may have different views, respondents were anonymous so additional key data may have been missed. **Clinical Significance –** identified inadequate

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Citation: author(s) & date of publication, title, funding agency, country	**Conceptual framework**	**Study design**	**Sample description**	**Major variables studied & defined**	**Measurement of each variable**	**Data analysis used**	**Study findings**	**Worth of the study to practice**
								training for providers and a desire for more training.
Croen, et al., (2015), The health status of adults on the autism spectrum. Funding: Special Hope Foundation No conflicts or biases recognized. USA	Social determinants of health	**Design**: NRCT **Method**: Chart review of study group of adults with autism and control group of adults without autism. **Purpose**: to describe the frequency of psychiatric and medical conditions among a population of adults with autism in the USA.	N=1507 in study group N=15,070 in control group Control group was sampled at a 10:1 ratio. Controls were frequency matched to cases on sex and 5-year age group. **Inclusion Criteria**: adult members of Kaiser Permanente Northern California enrolled from 2008-2012 with an ICD-9	IV-ASD adults DV1-psychiatric conditions DV2-medical conditions	5-year Chart review for adults with autism to identify medical and psychiatric diagnoses.	Chi-square test $p<0.01$statistically significant multivariate logistic regression model	IV-DV1 – significant ↑ psychiatric disorders (depression, anxiety, bipolar disorder, OCD, schizophrenia, & suicide attempts). IV-DV2 - significant ↑ in medical conditions (immune conditions, gastrointestinal & sleep disorders, seizure, obesity, dyslipidemia,	**Level 3** **Strengths** – large, ethnically diverse study population with a significant population of Medicaid recipients, included adults of all ages, cases and controls were matched. 5-year span, size of study groups, confirmed findings from a previous study from another state

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Citation: author(s) & date of publication, title, funding agency, country	**Conceptual framework**	**Study design**	**Sample description**	**Major variables studied & defined**	**Measurement of each variable**	**Data analysis used**	**Study findings**	**Worth of the study to practice**
			diagnosis of ASD.				hypertension & diabetes).	**Weaknesses** – ASD was determined by diagnoses in the EMR and not by a standardized clinical exam. ASD may have been under-reported in medical records **Clinical Significance** – there is a need for health education and health care for adults with autism.
Kuhlthau, et al. (2015), Pediatric provider's perspectives on the transition to	Framework Approach	**Design**: Grounded Theory **Method**: Semi-structured	N=17 n=16 13 sites in the USA and Canada agreed to participate. 3 of	IV-strategies for a successful transition for ASD population.	Semi-structured interviews by phone lasting 1 hour from 16 sites.	Framework approach using 3 stages: 1. Data management – 2 team	1.Interventions and strategies identified: EMR's, resource links, care coordination,	**Level 6** **Strengths** – diversity of providers interviewed,

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adult health care for youth with autism spectrum disorder: Current strategies and promising new directions. Funded by the U.S. Department of Health and Human services, Health Resources and Services Administration, Maternal and Child Health Research Program No conflicts or biases identified USA		interviews using an interview guide **Purpose**: 1. What are the current strategies or interventions taking place in ASD-specific pediatric settings to assist in a successful transition from pediatric to adult care for teens with ASD? 2. What strategies or interventions are needed or would be helpful in facilitating pediatric to adult healthcare transition for teens with ASD?	the sites had an additional site where transition planning occurred for a total of 16 sites. 19 respondents representing all 16 sites were interviewed. (5 physicians, 5 psychologists, 7 social workers or care coordinators, and 2 RN's **Setting**: semi-structured interviews over the phone taking about one hour. **Inclusion Criteria**: All sites were ATN treatment			members who conducted interviews read the transcripts. 2. Descriptive accounts -2 different members of research team review transcripts and refine initial categories. 3. Explanatory accounts – analyze data to identify associations and patterns in categories and across categories.	transition-specific appointments, specific written materials, education for families, training for adult providers, and creating transition centers. 2.Results of framework analysis: **strategies currently in place**-medical records to pass along, written materials, transition appointments, education for families	findings may be applicable to other types of disability. **Weaknesses –** all providers were recruited through the ATN, other specialties such as family medicine or internists may have a different perspective, some sites have more than 1 provider interviewed, no data was gathered about the consistency of interventions. **Clinical Significance –**

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Citation: author(s) & date of publication, title, funding agency, country	**Conceptual framework**	**Study design**	**Sample description**	**Major variables studied & defined**	**Measurement of each variable**	**Data analysis used**	**Study findings**	**Worth of the study to practice**
			centers. Participants must be the most knowledgeable person(s) at the site about the transition process for those with ASD.				**Needed strategies with a pediatric focus**- written materials, family and individual training, create resource links. **Needed strategies outside of pediatrics**-adult provider training, training for medical students & residents, **Needed strategies internal & external to pediatrics**- Care coordination & transition centers	identifies practices that may be helpful assisting the transition process.
Liu, et al. (2017), A profile on	Social Cognitive Theory	**Design**: Exploratory	N=56,266,305	IV-ASD DV-ED visits	Review through the MarketScan Commercial	Chi-squared test Fisher's exact test	Adolescents used the ED 4 times	**Level 4**

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Citation: author(s) & date of publication, title, funding agency, country	Conceptual framework	Study design	Sample description	Major variables studied & defined	Measurement of each variable	Data analysis used	Study findings	Worth of the study to practice
emergency department utilization in adolescents and young adults with autism spectrum disorders.		Retrospective Study **Method**: used the MarketScan Commercial Claims and Encounters as the database for the review. **Purpose**: To examine the rates of ED utilization over 9 years in adolescents and young adults with ASD.	**Setting**: Claim audit **Inclusion Criteria**: 12-21 years old. Each annual cohort is divided into ASD and non-ASD groups. Individuals covered by private insurance plans.		Claims & Encounters database to identify patients with ASD who visited the ED by linking in-patient and out-patient claims from 2005-2013 to explore the proportion of patients with ASD vs. Non-ASD that visited the ED.	*t* test/Wilcoxon rank sum test Multivariable analysis by logistic regression model.	as often as those without ASD. Older adolescents & those in rural areas had a significant ↑ in ED visits. ↑ED use for females and behavioral ED services.	**Strengths**: Findings from study confirm previous similar studies. Findings show an ↑ trend in ED use.in ASD vs non-ASD population. Confirmed the use of the ED for behavioral health issues is ↑. **Limitations**: Claims were from private insurers and no data from Medicare, Medicaid and the uninsured. There were fluctuations in health plan

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								enrollment that may have affected sample sizes. ASD cases and ED visits were ascertained without any clinical event records. **Clinical Significance**: Adolescents and young adults with ASD have a greater reliance on the ED for primary care medical and mental health care.
Nicolaidis, et al. (2015), "Respect the way that I need to communicate	Postpositivist	**Design**: Phenomenonology	N= 39 autistic adults and 16 support persons	IV-healthcare experiences	Used a co-created interview guide with a focus on making questions	Thematic analysis with an inductive approach using Text Analysis	Common themes identified: Autism-related factors affecting healthcare:	**Level 6** **Strengths:** demonstrates how at CBPR

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Citation: author(s) & date of publication, title, funding agency, country	Conceptual framework	Study design	Sample description	Major variables studied & defined	Measurement of each variable	Data analysis used	Study findings	Worth of the study to practice
with you”: Healthcare experiences of adults on the autism spectrum. Funded by the National Institute of Mental Health, OCTRI, NCRR, a component of the NIH, and NIH Roadmap for Medical Research No conflicts or biases recognized. USA		**Method**: Interviews of various kinds to accommodate communication needs (telephone, instant messenger, email, or in person) **Purpose**: To gain a deep understanding of autistic adults’ healthcare experiences and suggestions for improving care.	**Setting**: in person, by phone, or via electronic communication. **Inclusion Criteria**: at least 18 years old, communicate in written or spoken English, or American Sign Language, a formal diagnosis of autism, Asperger’s, PDD-NOS, or ASD. Four spots were reserved for persons without a formal diagnosis & scored 32 or higher on the Autism Quotient.		concrete and specific without compromising the open-ended nature of the interview.	Markup System Software. Used an iterative process to create a preliminary coding scheme, code transcripts & revise codes. They identified common themes with clinical or policy implications about healthcare for adults with ASD.	verbal communication skills, sensory sensitivities, challenges with body awareness, slow processing speed, atypical nonverbal communication, & challenges with organization. Provider-level factors: knowledge about ASD in adults, incorrect assumptions about specific patients, willingness to allow written communication, use of accessible language, openness to	approach can enable ASD individuals to participate in a research project **Limitations**: Not a random sample of the ASD adult population. Sample was largely non-Latino white & may not be transferrable to other racial and ethnic minorities. Study is limited to the US and findings may not transfer to other countries. **Clinical Significance**:

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Citation: author(s) & date of publication, title, funding agency, country	**Conceptual framework**	**Study design**	**Sample description**	**Major variables studied & defined**	**Measurement of each variable**	**Data analysis used**	**Study findings**	**Worth of the study to practice**
			The secondary sample had people with experience in supporting autistic adults in healthcare settings.				providing other accommodation, & a skill in appropriately incorporating supporters. System-level factors: availability of supporters, complexity of the healthcare system, accessibility of healthcare facilities, & stigma about ASD.	Stresses the importance of individual strategies and accommodation Healthcare systems need to find ways to make care more accessible for adults with ASD.
Nicolaidis, et al. (2016), The development and evaluation on an online healthcare toolkit for autistic adults and their	Transtheoretical Model	**Design**: Cross-sectional data survey **Method**: Toolkit development – cognitive interviewing and test-retest	N=259 autistic adults N=51 PCP's **Inclusion Criteria**: participants for all 3 studies were >18 years old,	IV-AHAT DV1-content validity and stability DV2-barriers to healthcare	DV1-Evaluation of toolkit using a mixed-methods, single arm PTPT DV2-pre and post checklist previously developed	Cronbach's alphas for DV3 & DV4 Paired *t* tests for pre- and post-intervention outcomes. Thematic analysis for	Over 90% would recommend the toolkit to a friend or healthcare provider. Mean barriers to healthcare decreased.	**Level 4** **Strengths**: 1st intervention specifically developed to improve primary care

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Citation: author(s) & date of publication, title, funding agency, country	**Conceptual framework**	**Study design**	**Sample description**	**Major variables studied & defined**	**Measurement of each variable**	**Data analysis used**	**Study findings**	**Worth of the study to practice**
primary providers. Funding: National Institute of Mental Health No conflicts or biases identified. USA		reliability studies. Evaluation – mixed methods, single-arm PTPT intervention comparison. **Purpose**: To use a CBPR approach to develop and evaluate tools to facilitate the primary healthcare of autistic adults.	live in the USA and speak English. For autistic adults on the autism spectrum (autistic disorder, Asperger's, PDD-NOS, or ASD). In the toolkit evaluation study, a designated PCP.	DV3-healthcare self-efficacy DV4-PCP communication	DV3-using a 21 item scale using a 4 point Likert scale created de novo. DV4-eight item five point Likert scale adapted from the 2007 Health Information National Trends Survey.	response to open-ended survey items using an inductive approach on a semantic level and a constructivist paradigm	Healthcare self-efficacy increased. Satisfaction with PCP communication improved.	services for autistic adults. Toolkit has good content validity and test-retest reliability, is easily accessible. **Limitations**: Evaluation study not designed to rigorously test the effectiveness of the toolkit in changing health or healthcare outcomes. Recruitment was non-systematic and may have biased the sample to those who were more

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Citation: author(s) & date of publication, title, funding agency, country	**Conceptual framework**	**Study design**	**Sample description**	**Major variables studied & defined**	**Measurement of each variable**	**Data analysis used**	**Study findings**	**Worth of the study to practice**
								open to this type of intervention. ASD diagnosis was not confirmed independently. Response rate was moderate and those who did not find the toolkit useful may not have responded. **Clinical Significance**: Patients and clinicians may benefit from the healthcare toolkit. Providers should do their best to provide accommodation & support the

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Citation: author(s) & date of publication, title, funding agency, country	**Conceptual framework**	**Study design**	**Sample description**	**Major variables studied & defined**	**Measurement of each variable**	**Data analysis used**	**Study findings**	**Worth of the study to practice**
								ASD client's self-advocacy, self-efficacy, & self-management attempts. Healthcare systems should try & incorporate tools like this in protocols, training, & medical records.
Rogers, et al. (2015), Systematic review of medical home models to promote transitions to primary adult health care for adolescents living with	Melnyk and Fineout-Overholt framework	**Design**: Systematic Review **Method**: Literature review search from 1/2013 to 5/2103. Searches were completed in 6 databases: CINAHL,	N=9 N=4 **Inclusion Criteria**: research articles within the past 10 years with reported outcomes of the implementation of a medical	IV-autistic adults DV-Medical home models	Survey with Likert scale, Survey, Timing, Health transition planning algorithm.	Logistical regression-odds ratio, prevalence rates & percentages to core outcomes, qualitative analysis	Nine articles reviewed, 4 met criteria. None addressed medical home models to transition adolescents living with ASD's into primary	**Level 5** **Strengths:** highlights the need for more education for adult providers **Limitations**: publication bias – no gray literature,

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Citation: author(s) & date of publication, title, funding agency, country	**Conceptual framework**	**Study design**	**Sample description**	**Major variables studied & defined**	**Measurement of each variable**	**Data analysis used**	**Study findings**	**Worth of the study to practice**
autism spectrum disorder. No funding. No conflicts or biases identified.		Medline, ERIC, PsycINFO, Pub Med, and Psychology & Behavioral Sciences. Key words were: Autism, adolescent, young adult, transition, medical home, healthcare model, and intervention.	home transition model for adolescents and young adults with ASD from international English language publications. **Exclusion Criteria**: educational, behavioral, and medical transition models from other chronic conditions such as sickle cell, asthma, cystic fibrosis, and non-English language publications.				healthcare services.	conference proceedings or e-mail lists that might contain information; limited to English language journals **Clinical Significance**: nursing needs to work with other disciplines to educate adult healthcare providers on the needs of adolescents living with ASD & evaluate medical home transition models for this population.

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Citation: author(s) & date of publication, title, funding agency, country	**Conceptual framework**	**Study design**	**Sample description**	**Major variables studied & defined**	**Measurement of each variable**	**Data analysis used**	**Study findings**	**Worth of the study to practice**
Warfield, et al. (2015), Physician perspectives on providing primary medical care to adults with autism spectrum disorders (ASD). Funded by U.S. Department of Health and Human Services, Health Resources & Services Administration, Maternal & Child Health Research Program	Framework approach	**Design**: Grounded Theory **Method**: Structured Interview Guide **Purpose**: To understand provider experiences in providing care to adults with ASD, the training they have received and suggestions to encourage more providers to provide this care.	N=23 n=8 (sample 1) n=2 (sample 2 – one interview was not used as the provider mainly worked with infants and children) **Setting**: Data was collected using phone interviews with adult primary care providers in the US and Canada. **Inclusion Criteria**: identified as a family practitioner or internist, cared for patients with ASD and/or	IV – Provider experiences caring for adults with ASD. DV – Autism training received EV – Suggestions to increase provider care of adults with ASD	Qualitative data gathered using a structured interview guide.	Framework approach with 3 inter-connected stages: data management, descriptive accounts, & explanatory accounts.	Provider experience & background with ASD – limited knowledge, training during and post-residency Practice environment & provision of care-treating adults with ASD have different treatment needs & can be challenging during visits. Care coordination & interactions with other medical providers-fewer health services for adults than children with ASD,	**Level 6** **Strengths** – diversity of providers interviewed, findings may be applicable to other types of disability. **Weaknesses** – all adult healthcare providers were recruited through the ATN pediatricians who had participated in a previous study. **Clinical Significance** – identifies

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No conflicts or biases recognized. USA			Asperger's Syndrome				standardizing care is difficult, there are reimbursement challenges due to the extra time needed for visits, care coordination is needed, lack of knowledge of available resources in the community, complex care needs for these clients. Recommendations to ↑ the number of adult providers willing to care for adults with ASD- increase awareness of the needs for adults with ASD and set expectations	practices that may be helpful assisting the transition process and training for adult care providers.

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Citation: author(s) & date of publication, title, funding agency, country	**Conceptual framework**	**Study design**	**Sample description**	**Major variables studied & defined**	**Measurement of each variable**	**Data analysis used**	**Study findings**	**Worth of the study to practice**
							of caring for this population, provide training early & often, train other staff as well.	

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Appendix F

Synthesis Table

Author	Ailey	Bordini	Bruder	Croen	Kuhlthau	Liu	Nicolaidis	Nicolaidis	Rogers	Warfield
Year	2015	2015	2012	2015	2015	2017	2015	2016	2015	2015
Design	Exploratory retrospective review	PTPT Intervention/Long. Study	Cross-sectional Data Survey	NRCT	Qual.	Exploratory retrospective review	Qual.	Cross-sectional Data Survey	SR	Qual.
Levels of Evidence	4	4	4	3	6	4	6	4	5	6
Number of Subjects	70	22	346	1507	16	56,266,305	55	310	13	10
Independent Variables										
ID Adults	X									
MH Referrals		X								
PTPT comparison		X								
ASD Adults			X	X		X			X	
Transition strategies					X					
Healthcare experiences							X			
AHAT								X		
Provider comfort with ASD										X
Dependent Variables										
Hospitalization Complications	X									
ASD Training		X							X	X
Psychiatric Conditions				X						
Medical Conditions				X						
ED Visits						X				
Toolkit validity								X		

Key: **AHAT**-Autism Healthcare Accommodations Toolkit; **ASD** – Autism Spectrum Disorders**;** **ED**-emergency department**;** ; **ID**-intellectual disabilities; **Long.-** longitudinal; **MH**- Mental Health; **NRCT**-non-randomized control trial; **PCP**- primary care provider; **Qual.**- qualitative; **SR**- Systematic Review

Barriers to healthcare							X	X		
Self-efficacy								X		
PCP communication								X		
Findings										
↑complications	X									
↑ referrals		X								
ASD training needed			X		X		X	X	X	X
↑ medical conditions				X						
↑ psychiatric conditions										
↑ ED use						X				
Setting										
Primary Care		X	X		X		X	X	X	X
Acute Care	X			X		X				

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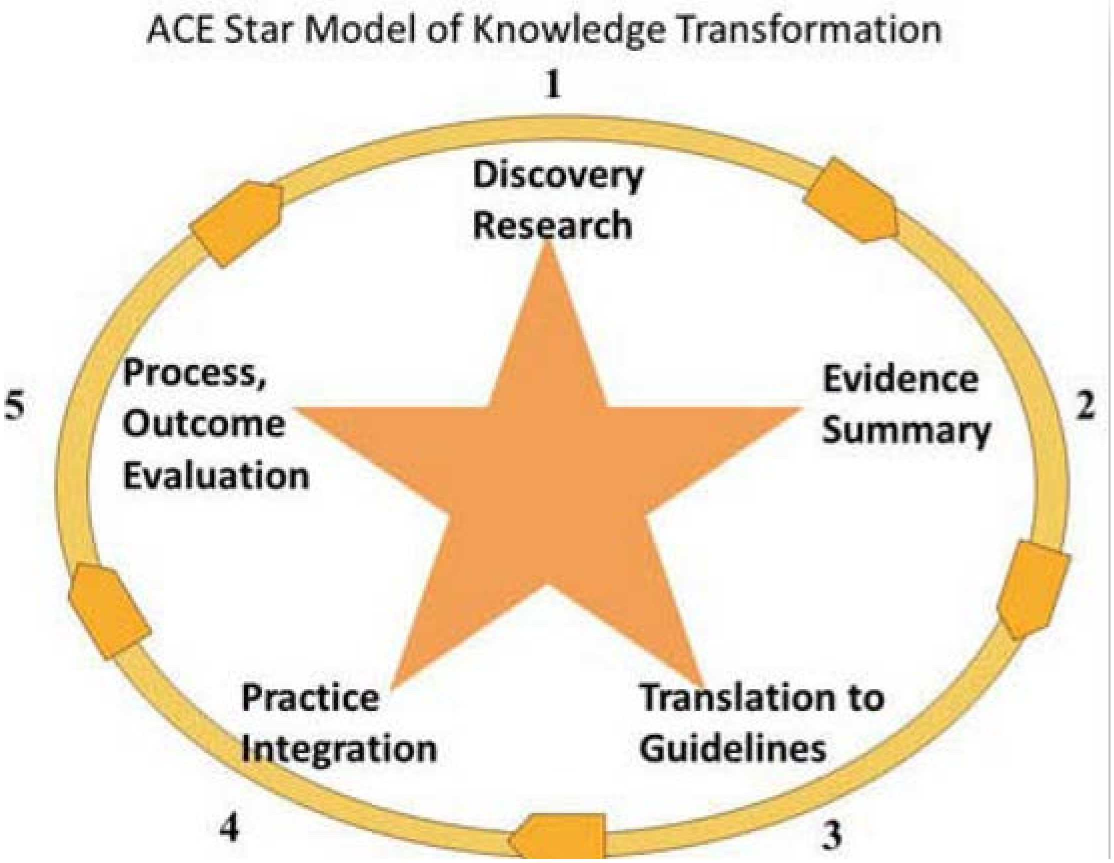
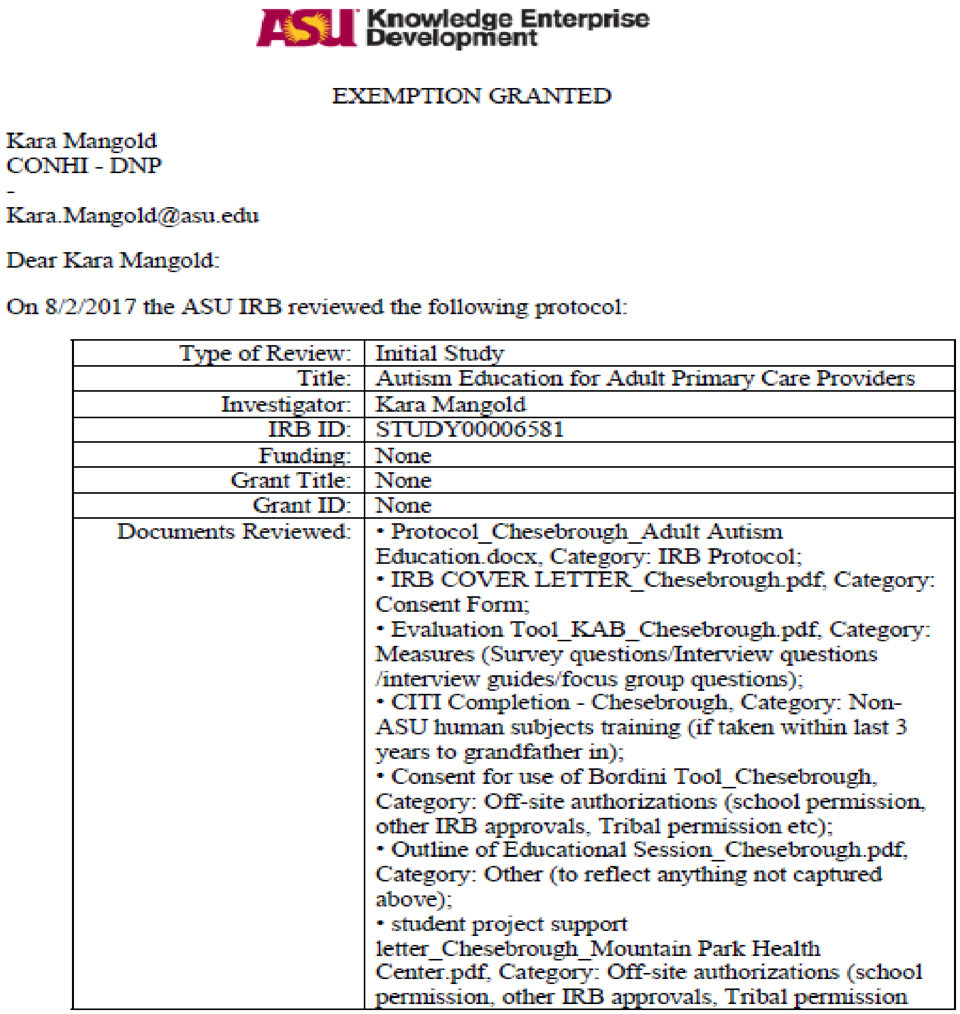
Appendix G



From: *Evidence-based practice in nursing & healthcare: A guide to best practice* (Third ed.).

Appendix H

IRB Approval Letter from Arizona State University



ASU Knowledge Enterprise Development

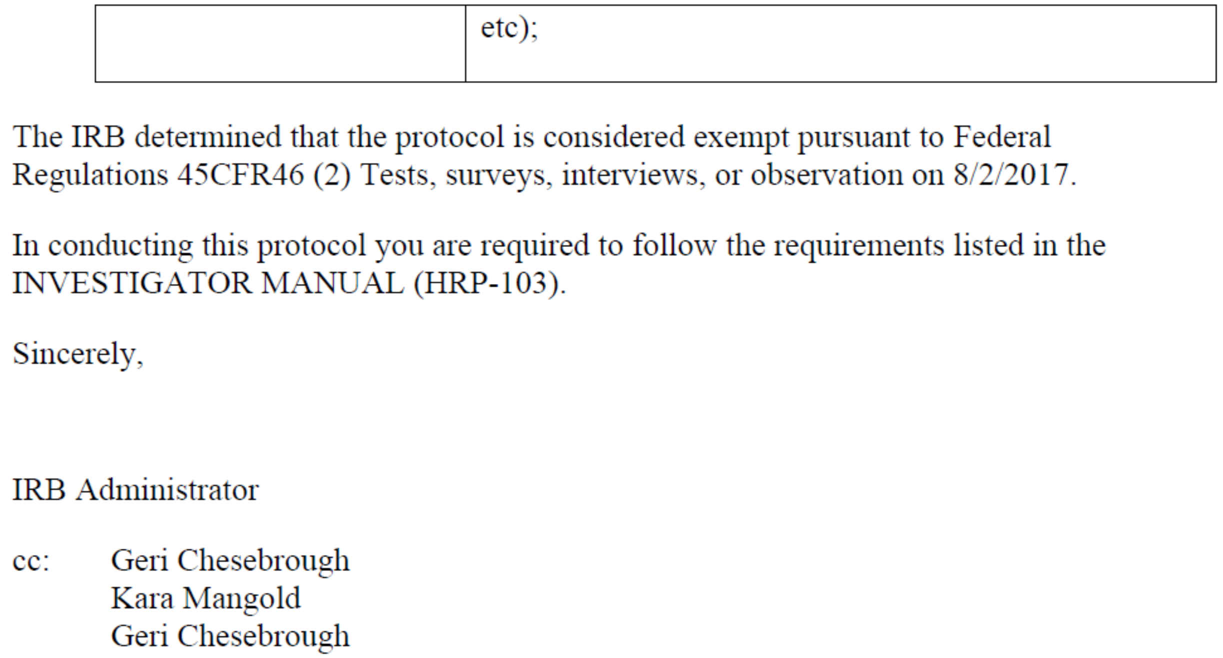
EXEMPTION GRANTED

Kara Mangold
CONHI - DNP
-
Kara.Mangold@asu.edu

Dear Kara Mangold:

On 8/2/2017 the ASU IRB reviewed the following protocol:

Type of Review:	Initial Study
Title:	Autism Education for Adult Primary Care Providers
Investigator:	Kara Mangold
IRB ID:	STUDY00006581
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	• Protocol_Chesebrough_Adult Autism Education.docx, Category: IRB Protocol; • IRB COVER LETTER_Chesebrough.pdf, Category: Consent Form; • Evaluation Tool_KAB_Chesebrough.pdf, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions); • CITI Completion - Chesebrough, Category: Non-ASU human subjects training (if taken within last 3 years to grandfather in); • Consent for use of Bordini Tool_Chesebrough, Category: Off-site authorizations (school permission, other IRB approvals, Tribal permission etc); • Outline of Educational Session_Chesebrough.pdf, Category: Other (to reflect anything not captured above); • student project support letter_Chesebrough_Mountain Park Health Center.pdf, Category: Off-site authorizations (school permission, other IRB approvals, Tribal permission



	etc);

The IRB determined that the protocol is considered exempt pursuant to Federal Regulations 45CFR46 (2) Tests, surveys, interviews, or observation on 8/2/2017.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

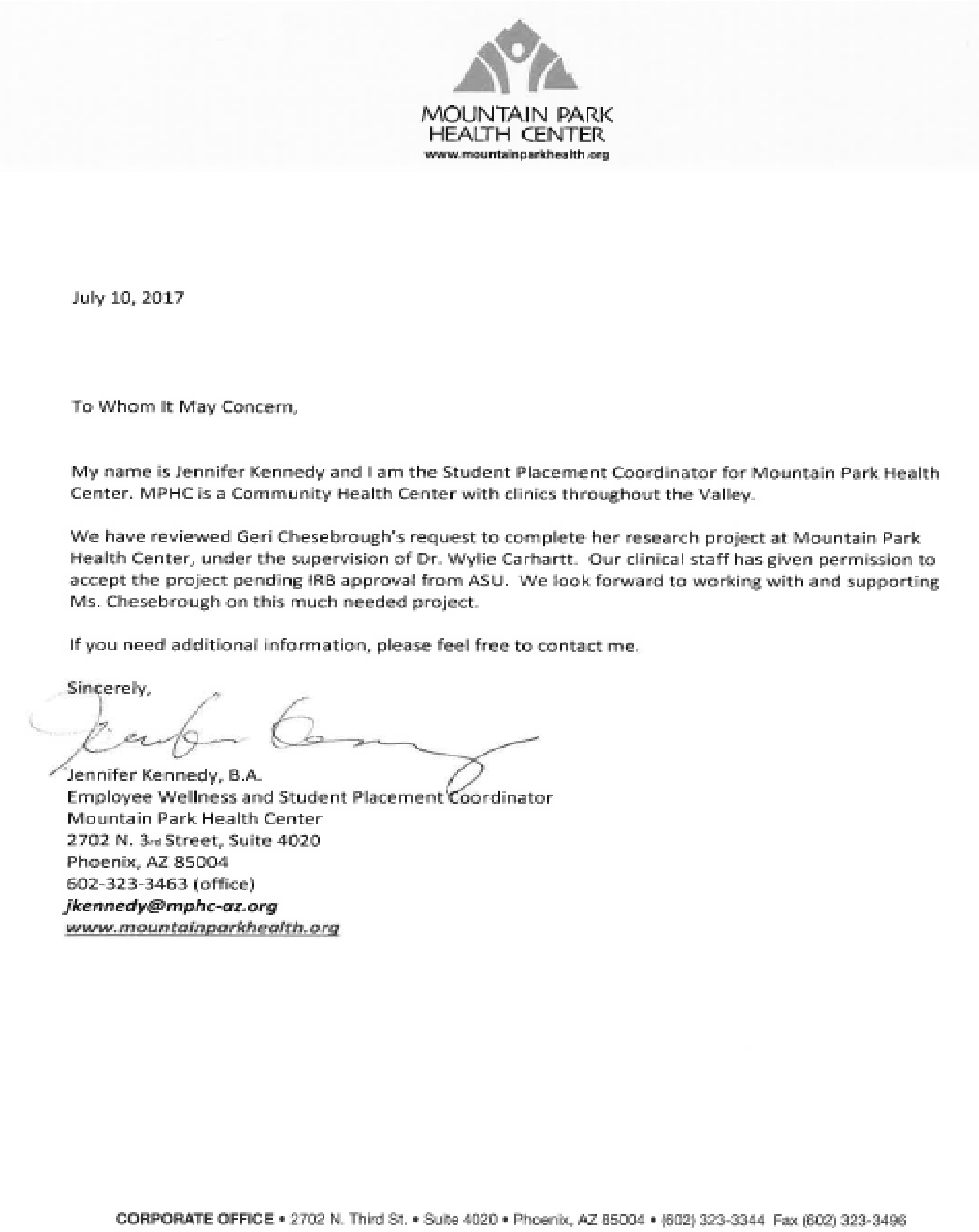
Sincerely,

IRB Administrator

cc: Geri Chesebrough
Kara Mangold
Geri Chesebrough

Appendix I

Mountain Park Health Center Approval Letter



MOUNTAIN PARK
HEALTH CENTER
www.mountainparkhealth.org

July 10, 2017

To Whom It May Concern,

My name is Jennifer Kennedy and I am the Student Placement Coordinator for Mountain Park Health Center. MPHC is a Community Health Center with clinics throughout the Valley.

We have reviewed Geri Chesebrough's request to complete her research project at Mountain Park Health Center, under the supervision of Dr. Wylie Carhartt. Our clinical staff has given permission to accept the project pending IRB approval from ASU. We look forward to working with and supporting Ms. Chesebrough on this much needed project.

If you need additional information, please feel free to contact me.

Sincerely,

Jennifer Kennedy, B.A.
Employee Wellness and Student Placement Coordinator
Mountain Park Health Center
2702 N. 3rd Street, Suite 4020
Phoenix, AZ 85004
602-323-3463 (office)
jkennedy@mphc-az.org
www.mountainparkhealth.org

CORPORATE OFFICE • 2702 N. Third St. • Suite 4020 • Phoenix, AZ 85004 • (602) 323-3344 Fax (602) 323-3496

Appendix J

Autism Education for Adult Primary Care Providers

Date: October 11, 2017

Dear Participant,

I am a graduate student under the direction of Dr. Kara Mangold in the College of Nursing and Health Innovation at Arizona State University.

I am inviting you to participate in an evidence based educational program to see if autism education for adult primary care providers will improve knowledge and comfort in caring for adults with autism. I will be providing an education session to adult primary care providers regarding an overview of autism, medical co-morbidities, healthcare experiences, and strategies to improve care and outcomes. This will involve participating in an educational class and completing a survey before, after and 4-6 weeks after the class. The total time required to complete the survey before education will be approximately 15 minutes, the education time will be 30 minutes and the post-education surveys will be 15 minutes each. Pre and post survey will be done at separate times before provider education and after intervention of education to patients by the health care team. There will be additional time allowed to answer any questions you may have.

Your participation in the evaluation of the program is voluntary. You can skip questions in the survey if you wish. If you choose not to participate or to withdraw from the program at any time, there will be no penalty. You must be 18 years of age or older to participate in this program. Responses to the questionnaires will be used to evaluate the effectiveness of an autism education program for adult primary care providers.

Your responses on the questionnaires will be anonymous and will be identified only by a number that will not be connected to your name or other personal identifying information. The results of this study may be used in reports, presentations, or publications, but your name will not be known or used.

This study has been reviewed and approved by the Arizona State University Institutional Review Board. If you have questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788.

If you have any questions concerning this program, please contact the following team members:

Kara Mangold, DNP, RN-BC, CCTN, CNE

Kara.Mangold@asu.edu

507-358-2861

Geri Chesebrough, MSN, RN, CNE

gchesebr@asu.edu

913-972-4894

Your attendance at the session/ participation in intervention/ and finishing the pre education and post education survey will be considered your consent to participate.

Sincerely,

Geri Chesebrough, MSN, RN, CNE

Appendix K

Modified Knowledge/Attitudes/Beliefs Questionnaire

This is a survey designed to evaluate various aspects of autism care for adults. Please answer truthfully (i.e. Do not tell us what you THINK we want to hear, rather tell us what YOU really believe) and complete all the questions.

All responses will be treated in strict confidence and seen only by independent research assistants. All individual identities will be masked and the analysis of the data will be blinded. Only the aggregate results will be published.

Thank you for your participation.

For the purposes of the rest of this questionnaire, we define Autism Spectrum Disorder (ASD) using Autism Speaks definition as follows:

Autism, or autism spectrum disorder, refers to a range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication, as well as by unique strengths and differences.

Directions: **Please *circle* the number that indicate how much you agree/disagree with the following statements.**

		Strongly Agree	Moderately Agree	Somewhat Agree	Neutral	Somewhat Disagree	Moderately Disagree	Strongly Disagree
1	I am confident in my ability to provide care to ASD patients.	7	6	5	4	3	2	1
2	Using ASD knowledge increases certainty that the proposed treatment is effective.	7	6	5	4	3	2	1
3	I consider medical comorbidities unique to ASD when seeing a patient	7	6	5	4	3	2	1

4	I know the diagnostic criteria for ASD	7	6	5	4	3	2	1
5	I understand the most common conditions associated with ASD.	7	6	5	4	3	2	1
6	I am aware of online resources for providers and ASD patients.	7	6	5	4	3	2	1
7	I know what kind of sensory accommodations might be needed with ASD patients.	7	6	5	4	3	2	1
8	I know what kind of communication accommodations might be needed with ASD patients.	7	6	5	4	3	2	1
9	I am confident that I will provide instructions and follow up that ASD patients will understand	7	6	5	4	3	2	1
10	I am able to easily research what I need to know about ASD.	7	6	5	4	3	2	1
11	I know how to modify my plan of care for adults with ASD.	7	6	5	4	3	2	1
12	I welcome adults with ASD into my practice.	7	6	5	4	3	2	1
13	There are both risks and benefits to adult ASD diagnosis	7	6	5	4	3	2	1

***Directions*: The following questions are asking about your personal opinion about ASD. There are no correct answers. Please *circle* the number that indicate how much you agree/disagree with the following statements.**

		Strongly Agree	Moderately Agree	Somewhat Agree	Neutral	Somewhat Disagree	Moderately Disagree	Strongly Disagree
14	There is an ASD Epidemic	7	6	5	4	3	2	1
15	Childhood vaccines can cause autism.	7	6	5	4	3	2	1

16	Autistic individuals are geniuses	7	6	5	4	3	2	1
17	Autistic individuals do not feel emotions.	7	6	5	4	3	2	1
18	Autistic individuals cannot speak.	7	6	5	4	3	2	1
19	Autism can be cured.	7	6	5	4	3	2	1

The main objective of this section is to assess the level of knowledge of adult health care professionals in the area of autism spectrum disorders (ASD) in order to improve health care for this population. *Directions*: Please *circle* the best answer.

20) What is the current estimated prevalence of autistic spectrum disorders?

a) 1 in each 38 children
b) 1 in each 1100 children
c) 1 in each 68 children
d) 1 in each 100,000 children
e) I don't know

21) What is the approximate distribution by sex of autistic disorders?

a) 1 male for each 4 females
b) equal among the sexes
c) 1 female for each 4 males
d) 1 female for each 10 males
e) I don't know

22) What is the probable etiology of autism?

a) Unaffectionate parents with an unfavorable family environment
b) Childhood vaccines
c) Genetic-environmental interaction
d) Completely genetic
e) I don't know

The main objective of this section is to assess the level of knowledge of adult health care professionals in the area of autism spectrum disorders (ASD) in order to improve health care for this population. ***Directions*****: Please** ***circle*** **the best answer.**

23) Which of the criteria below make up part of the autism diagnosis by the DSM-IV?

I) Repetitive and stereotypical motor mannerisms

II) Lack of social or emotional reciprocity

III) Restricted, repetitive patterns of behavior, interests or activities which appeared before 4 years of age

IV) Retarded or absence of language development

V) Presence of mental retardation

a) I, II, III

b) I, II, IV, V

c) I, II, IV

d) All of the above

e) I don't know

24) In relation to an autism diagnosis, which statement is true about additional diagnoses?

a) 90% of autism cases present some degree of associated mental retardation

b) 30% have associated epilepsy

c) 50% of autistic patients never speak

d) 5-10% present with a stop or regression of language after 2 years of age.

e) I don't know

The main objective of this section is to assess the level of knowledge of adult health care professionals in the area of autism spectrum disorders (ASD) in order to improve health care for this population. ***Directions*****: Please *circle* the best answer.**

25) What is the principal therapeutic approach recommended for autistic disorders?

a) Ludo therapy

b) Psychoanalysis

c) Behavioral Therapy

d) Psychotropic Medications

e) I don't know

26) Which of the following symptoms can be minimalized by the use of medications?

a) Stereotyped movements, visual contact, repetitive speech

b) Insomnia, hyperactivity, aggressiveness

c) Visual (eye) contact, aggressiveness, verbalizations

d) Stereotyped movements, insomnia, repetitive speech

e) I don't know

1-3 Months Post Education Session

27) Have you cared for somebody with ASD since the education session?

a) Yes

b) No

		Strongly Agree	Moderately Agree	Somewhat Agree	Neutral	Somewhat Disagree	Moderately Disagree	Strongly Disagree
28	I was able to use this education in planning and delivering care.	7	6	5	4	3	2	1
29	I found this education helpful.	7	6	5	4	3	2	1
30	I would recommend this training to others.	7	6	5	4	3	2	1

Thank you for taking the time to complete this survey.

Appendix L

Demographic Questionnaire

1. **What is your gender?**

- ○ Male
- ○ Female

2. **What is your race/ethnicity?**

- ○ American Indian/Native American
- ○ Asian or Pacific Islander
- ○ Black/African American
- ○ Hispanic/Latino
- ○ White/Caucasian
- ○ Other

3. **What is your age? ______________**
4. **What type of provider are you?**

- ○ Nurse Practitioner
- ○ Physician
- ○ Physician's Assistant
- ○ Other __________________________________

5. **What is your clinical specialty?**

- ○ Family Practice
- ○ Internal Medicine
- ○ Other __________________________________

6. **How many years have you been in practice? ___________________**

7. **Have you previously taken any autism education?**

- ○ Yes
    - ○ If yes, please describe ____
- ○ No

8. **How often do you see a patient with known or suspected ASD?**

- ○ Daily
- ○ Weekly
- ○ Monthly
- ○ Every 2-3 months
- ○ Every 4-6 months
- ○ Yearly
- ○ Never

9. **Clinic Site**

  - Baseline
  - Gateway
  - Goodyear
  - Maryvale
  - Tempe

Appendix M

Demographics

Age and Years in Practice

	N	Minimum	Maximum	Std. Deviation
Age	15	29	50	5.287
Years in Practice	17	.00	40	9.546

Characteristic	Frequency	Percent	Cumulative Percent
Race/Ethnicity			
Asian/Pacific Islander	4	23	23
Black/African American	1	6	29
Hispanic/Latino	1	6	35
Non-Hispanic White	11	65	100
Gender			
Male	9	53	53
Female	8	47	100
Provider Type			
Nurse Practitioner	5	29	29
Physician	11	65	94
Physician Assistant	1	6	100
Previous ASD Education			
No	13	76.5	76.5
Yes	4	23.5	100
ASD Visit Frequency			
Weekly	1	6	6
Monthly	5	29	35
Every 2-3 Months	2	12	47
Every 4-6 Months	6	35	82
Yearly	2	12	94

Never	1	6	100
Clinic Site			
Gateway	7	41	41
Maryvale	5	29.5	70.5
Tempe	5	29.5	100

Appendix N

Friedman Test

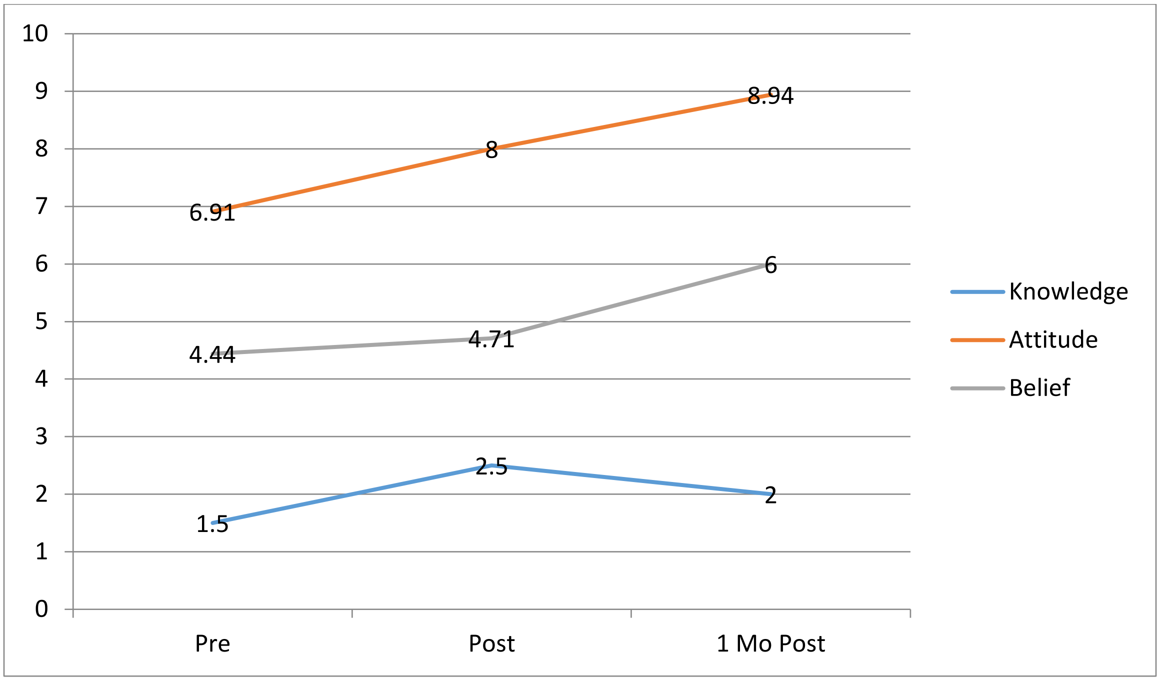
Statistics

		Pre-test Attitude	Post-Test Attitude	1-month Attitude	Pre-test Belief	Post-test Belief	1-month Belief
N	Valid	17	17	17	17	17	17
	Missing	0	0	0	0	0	0
Mean		57.49	74.31	87.32	25.77	26.71	33.67
Median		56	75	88	30	33	40
Std. Deviation		11.9191	5.0463	9.8948	11.1665	11.0610	11.0632
Minimum		36	65	70	7	8	14.4
Maximum		72.3	83	105	38	38	45

Statistics

		Pre-test Knowledge	Post-test Knowledge	1-month Knowledge
N	Valid	17	17	17
	Missing	0	0	0
Mean		3.59	4.94	4.12
Median		4	5	4
Std. Deviation		1.3257	.6587	1.6156
Minimum		1	4	1
Maximum		5	6	6

Ranks



Test Statistics - Friedman Test	
N	17
Chi-Square	130.483
df	8
Asymp. Sig.	.000