2012 Health disparities- related projects

The projects listed below were taken from the data collected for the 2012 IACC ASD Research Portfolio Analysis reports. The projects are grouped by funding agency/organization.

Autism Speaks

Increasing ASD screening and referral among NYC's Korean Americans

PI: David Mandell, University of Pennsylvania

Funding: Autism Speaks, FY12 $320,320 (award period: 2012-2013)

The purpose of this project is to develop and test the effectiveness of materials designed to increase the identification and referral to early intervention of Korean-American children with suspected autism or other developmental delays. Growing evidence suggests that earlier identification of autism results in earlier entry into treatment and more positive outcomes than for children for whom diagnosis is delayed. While there has been an increase in general awareness of the signs of autism and the need for early intervention, significant disparities in age of diagnosis have been observed among traditionally underserved minority groups, including those for whom English is a second language. This study is one of the first to systematically develop and evaluate the effects of a population-based intervention to improve the timeliness and referral of autism in one such group in the United States. The project builds on existing English language materials, including the 100-day kit developed by Autism Speaks, and includes partnerships with physicians, early childcare workers, faith leaders and Korean-American parents of young children. The investigators are collaborating with these stakeholders to develop materials that are linguistically and culturally appropriate. Materials will be pilot tested and refined, after which they will be disseminated through doctors' offices, early childcare settings and churches. The investigators will evaluate program effects through quantitative evaluation of changes in referrals of Korean-American children to New York's early intervention system, and through qualitative interviews of professional and lay community members. This project is squarely in line with Autism Speaks' 'Move the Needle' initiative, which is designed to increase the quality of care individuals with autism receive in their communities.

Community-based study of autism spectrum disorders among 7-9 y old children in rural Bangladesh

PI: Parul Christian, Johns Hopkins University

Funding: Autism Speaks, FY12 $196,051 (award period: 2012-2014)

Little is known about autism spectrum disorders (ASD) in most low income countries, especially in underserved South Asia, where access to health professionals to diagnose and treat child development disorders, like autism, are virtually non-existent. This study describes an attempt to screen, diagnose, and estimate the prevalence of ASD among ~11,000 children 7-9 years of age within 600 villages located in a rural area in northwest Bangladesh. This study will be conducted as a two-phase screening and diagnostic survey, carried out by well-trained staff, using accurately translated forms, following highly standardized methods guided by a joint Johns Hopkins-Bangladeshi scientific team. In addition, the

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health, dietary and socioeconomic histories of the children under study are known, via assessments of the mothers in pregnancy, and the children themselves in infancy. This was done as part of two earlier field trials between 2001 and 2007 that evaluated the health and survival rates of children following maternal vitamin A and beta-carotene supplementation during pregnancy and administration of a large dose of vitamin A to the baby at birth. Thus, the results of this study will include the first estimates of the prevalence of autism in South Asia by using globally recognized methods as well as data collected during fetal life, at birth and in early infancy. This study has the potential to impact our understanding of why some children develop, and others do not develop this developmental disorder.

Improving educational identification in rural communities

PI: Susan Hepburn, University of Colorado, Denver

Funding: Autism Speaks, FY12 $100,000 (award period: 2012-2014)

The overall goal of this research project is to test the effectiveness of a distance learning model to improve educational identification of autism in rural and underserved areas. Building on a 10-year training collaboration with the Colorado Department of Education, the investigators will provide three levels of professional development and support to school districts across the state. These levels are: (1) web-based modules on screening/assessment for autism in school settings; (2) supported implementation of a teacher nomination strategy to screen children for ASD school-wide; and (3) case consultation to school teams via secure/confidential videoconferencing. To measure the impact of this approach, the investigators will collect data on the number of schools and educators who agree to participate, the number of children nominated (i.e., deemed "at risk" for possible ASD) per school, the number who participate in an assessment, and the number who are identified as having an ASD. The investigators plan to document the amount of personnel time required to implement the screening protocol and follow-up case consultations, as well as gather data on feasibility and acceptability from educational team members and parents in participating districts. The overall effectiveness of this approach will be assessed by examining objective Child Count data collected through Part B, with the goal of increasing the number of students with autism who receive the appropriate and timely educational eligibility by 30% (above data reported for school year 2009, which will be available in July, 2011). Implementation and program evaluation are the final steps of the program of technical assistance in educational identification. This project is endorsed by the Colorado Department of Education Autism Task Force, the Colorado Autism Commission, and several special education directors in districts around the state.

Increasing autism awareness in Ethiopia: The HEAT+ project

PI: Rosa Hoekstra, The Open University

Funding: Autism Speaks, FY12 $100,000 (award period: 2012-2014)

The Open University created the Health Education and Training (HEAT) program to train and support community health workers (HEWs) in Africa. HEAT started in Ethiopia, a low-income country with a severe shortage in provision for people with mental health problems and autism. Working with the Ethiopian Ministry of Health, UNICEF, AMREF and the World Health Organization (WHO), currently over

1,000 Ethiopian HEWs are upgrading their existing training using the HEAT program. The curriculum includes an extensive mental health module, covering general mental health management and assessment, mental illness prevention strategies, and a chapter on childhood developmental problems including autism. After evaluation of the pilot the program will be extended to further cohorts of up to 33,000 HEWs in Ethiopia. Plans are in progress to adapt the HEAT modules for use in other developing countries in Africa and elsewhere. All HEAT material is freely available, both on-line and in print. This project aims to tailor and evaluate the effectiveness of the HEAT mental health module in raising general mental health awareness and knowledge about autism and to support further development of this part of the curriculum to ensure maximum impact. This study includes four phases that: 1) Provide a baseline analysis (through a survey and interviews with parents of children with autism) of the current services available at community level in Ethiopia and the attitudes, knowledge and skills of HEWs regarding mental health problems in general and childhood developmental problems, including autism, in particular. 2) Based on findings from phase 1, enhance the mental health module in the current HEAT study material. 3) Implement the revised mental health module in the curriculum. 4) Follow-up assessment through a survey in HEWs, allowing for an evaluation of the effectiveness of the revised HEAT mental health module to raise mental health awareness and improve HEWs' knowledge about autism. This project has the potential to provide a wealth of knowledge on how to improve mental health awareness in general, and autism awareness and subsequent care for children with autism in particular, in one of the most underserved countries of the world. The successful approach in Ethiopia can subsequently be applied in other developing countries, using HEAT's open educational resources, through collaboration with Autism Speaks and HEAT's extensive network of partners in Africa and more widely.

Comprehensive parent-mediated intervention for children with autism in southern Taiwan

PI: Li-Ching Lee, Johns Hopkins University

Funding: Autism Speaks, FY12 $100,000 (award period: 2012-2014)

Research evidence shows that timely access to early intervention is associated with positive cognitive, adaptive behavior and language outcomes for children with autism spectrum disorders (ASD). Pingtung is the most southern county of Taiwan and is one of the lowest socioeconomic stats (SES) regions in the country. No health care or education programs are available to provide diagnoses, treatment, or intervention for children with ASD or other behavior problems in Pingtung as there are no clinicians who specialize specifically in developmental disabilities, including ASD, nor are there available intervention programs for families after their child is diagnosed with ASD. Thus, there is a pressing need to provide families who reside in Pingtung and have a child with ASD a feasible and low-cost intervention. Due to a lack of existing infrastructure and no available resources to deliver a clinic-based or school-based intervention for autism, in-home parent-mediated intervention and behavioral management are particularly suitable for families who have a child with autism in Pingtung. Training families is a practical option as compared to establishing ongoing programs in clinics or schools, given space limitations and the large expense of running an ongoing program at local facilities. Furthermore, clinic- or school-based interventions would be unrealistic given the size of the county - a large number of programs would have to be established throughout a large area so families in need who do not have the resources to travel long distances could benefit from the program. This project will continue the collaborative effort between the Johns Hopkins University, Kaohsiung Medical University and the Calo Hospital from the team's Prevalence of Autism Spectrum Disorders in Taiwan (funded by Autism Speaks). The overall

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objective is to develop, implement, and evaluate a comprehensive and culturally sensitive ASD intervention that will be carried out by parents at home for their child diagnosed with autism. By having parents act as the therapist who implements the intervention, barriers to access will be overcome in this underserved population. If successful, this program could become a model for populations in other regions of Taiwan, or other Asian countries that share a similar cultural background, on how to efficiently and effectively provide an evidence-based behavioral intervention that will improve the health and well-being of children and their families who are affected by ASD.

PASS: Parent-mediated intervention for autism spectrum disorders (ASD) in South Asia

PI: Atif Rahman, University of Liverpool

Funding: Autism Speaks, FY12 $149,993 (award period: 2012-2014)

The majority of children with Autism Spectrum Disorders (ASD) live in low and middle-income countries and have little access to effective interventions or services. Most research in interventions for ASD has been conducted in richer countries with relatively large numbers of ASD specialist therapists. One of the best-researched interventions, in which parents are trained to help their children communicate, has been found to work very well in the UK (the PACT intervention). The aim of this project is to adapt this intervention carefully so that it can be used by parents of children in low-income countries. Because there are very few specialists in these settings, the project will explore the impact of the delivery of the intervention by trained and supervised non-specialists. The project will be conducted in Goa, India, and Rawalpindi, Pakistan. These two countries are home to the largest number of children in the world, and have very large unmet needs for care for autism. Partners in each site have an established world-class record of research to improve access to care for mental and developmental disorders and will be supported by experts in a high-income setting (the UK). The project will have three Phases. In the first phase, the investigators will talk to parents of children with ASD about their experiences, to people who may have tried to help these parents and their children, and to local experts who are involved in developing services for children. Using this information, UK team will work with local experts to make necessary changes to the intervention so that it can work in these South Asian settings. In the second phase the investigators will test the intervention to find out if it works, by delivering it to 30 children with ASD and comparing them to 30 children who will not receive the intervention. The children, who will be recruited from Goa and Rawalpindi, will be divided into treatment and control groups in such a way each child has an equal chance of being in either group. The study aims to evaluate the effects after 6 months by carrying out a number of tests for parent-child interaction and the child's social functioning. In the third phase, data analysis will be performed with the aim of disseminating the results. This project is important because it aims to develop an intervention that has the potential to be used in settings where there are few specialist autism service providers, a challenge faced by most of the developing world.

Screening, diagnosis and parent training for young children with ASD in Albania

PI: Deborah Fein, University of Connecticut

Funding: Autism Speaks, FY12 $99,960 (award period: 2012-2014)

Families with autism are underserved in Albania, a country of 3,000,000 in southeast Europe. In 2009-2011, partnership between Autism Speaks and the Albanian Children's Foundation (ACF) raised public autism awareness, conducted educational symposia, translated and pilot tested an autism screener, translated a diagnostic instrument, and obtained a private foundation grant to conduct intensive therapist and parent training in evidence-based therapy. The aims to maintain and accelerate these gains, and make autism capacity in Albania self-sustaining are: 1) continue raising awareness by having Dr. Ariel Como, child psychiatrist of the ACF and director of Tirana's academic medical center, conduct educational symposia on ASD for parents and professionals: 2) study the performance of the translated screener for autism in young children in pediatric clinics; 3) complete training on the diagnostic instrument to enable future diagnostic services and research; 4) provide supervision by credentialed experts for the Albanian therapists as they take formal coursework in evidence-based therapy, which will, within the grant period, make them independent of supervision from outside the country, and able to train other Albanian therapists; 5) disseminate and evaluate a parent-training program to teach effective strategies for parenting children with ASD; and 6) establish and evaluate a support network for parents who are using the training material. The research is directly relevant to the 2010 Autism Speaks priorities of: 1) early detection, 2) development and evaluation of novel treatments, and 3) dissemination of empirically-validated screening, diagnostic and treatment approaches to community settings. It is also directly relevant to the Global Autism Public Health priorities of screening, diagnostic, and intervention services that will be fully sustainable, testable in a scaled-down version, and with a strong commitment from the local, Albanian stake-holders, in a region of the world where the autism community is underserved, and has the potential to greatly influence autism services throughout the country.

Early intervention in an underserved population

PI: Catherine Lord, University of Michigan

Funding: Autism Speaks, FY12 $73,219 (award period: 2010-2013)

The prevalence of Autism Spectrum Disorder (ASD) has increased dramatically in recent years, with recent data reporting one out of every 150 children being affected (CDC MMWR, 2007). Although our understanding of the cause, course, and prognosis of ASD has developed greatly in past decades, there has been a significant lack of research focusing on sociodemographic factors that may influence rates of identification and subsequent treatment. This is of particular concern because significant social disparities in autism services have been identified (Mandell, et al., 2009). Families of racial/ethnic minority, lower levels of education, and those who live in non-metropolitan areas experience greater limitations in accessing services for ASD (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). The purpose of the proposed project is to expand, adapt, and evaluate a modified version of an early intervention working with caregivers from a low-income, underserved population. This study proposes a randomized group crossover experimental design with 60 children randomly assigned to receive either a caregiver-implemented intervention or community support. The study aims 1) to compare of the effectiveness of the two treatment conditions on outcome measures of social communication skills,

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autism symptoms, developmental levels, and adaptive behavior; 2) to identify specific child and family characteristics that predict response to intervention, as well as providing a preliminary examination of how factors at the caregiver level mediate child outcome measures; and 3) to test the overall applicability of the early intervention in the targeted population. The study will begin to investigate moderating and mediating factors of service utilization, satisfaction, and adherences.

Deployment focused model of JASPER for preschoolers with autism spectrum disorders

PI: Connie Kasari, University of California, Los Angeles

Funding: Autism Speaks, FY12 $0 (award period: 2011-2014)

Children with autism have difficulty in social communication skills, particularly joint attention and play skills. Joint attention refers to the ability of the child to share attention with another person around an event or a toy. Play skills are often limited for children with autism with less ability to engage in social and symbolic play. Interventions can improve these core problems, and improvement can lead to better language outcomes. However, these interventions are often carried out by expert research staff, and are less often evident in community preschools where children with autism spend the most time. Thus, the goal of this project is to deploy effective interventions for core symptoms of autism into community based preschool programs. A second goal of the project is to use community partnered participatory research practices to create a sustainable intervention in community preschools that largely serve underrepresented children with autism. Goals of the project are to determine if the intervention results in teachers delivering a greater dose of social communication curricula and if the children develop better social, communication and language outcomes. Participants in this project will include 60 teachers and 60 children with ASD randomly selected from preschool classrooms in the Los Angeles Unified School District, an urban district where three quarters of children are Hispanic, and less than ten percent are White. Interventions will be delivered to half of the sample first using a randomized wait list control design. Interventions will be implemented for three months, and children and teachers will be followed up in another three months to determine how effective the intervention is for teacher and child outcomes. This project addresses multiple priority areas of Autism Speaks including deployment of effective interventions into underserved communities, and a focus on core symptoms. The results of this intervention could have far reaching effects on community interventions and potential outcomes for children with autism.

Dissemination of multi-stage screening to underserved culturally-diverse families

PI: Frances Martinez-Pedraza, University of Massachusetts, Boston

Funding: Autism Speaks, FY12 $0 (award period: 2011-1213)

Although there have been many efforts to identify children with autism spectrum disorders (ASD) in the first years of life, children from ethnic minority groups are still diagnosed later, are less likely to be diagnosed, and have more limited access to proper services. This is of great concern because early identification provides the opportunity for children to benefit from early intervention (EI). This project involves working with pediatricians and early intervention providers to improve their skills to identify children with ASD early enough to benefit from EI services. The particular focus on Latino families is

based on their growing numbers and the multiple barriers they face. The aims will be accomplished with the following activities: 1) interviewing parents and providers to identify barriers for early screening; 2) adapting screening tools to use with Latino families; 3) using screening practices that take cultural factors into account; and 4) determining the percentage of families that complete the screening across racial and ethnic groups. The first step of the research is to interview parents and providers to identify screening barriers. During the second stage of the study we will implement a protocol for screening children with ASD in EI and pediatric settings. The final stage will involve interviews of providers to learn about their experiences with the use of this protocol. This research promises to enhance the services provided to these children and improve providers' skills in identifying children with ASD. Results from the study should also help in reducing the differences by race and ethnicity that exists in identifying and treating children with ASD.

Department of Defense

Development of an internet-based parent training intervention for children with ASD

PI: Brooke Ingersoll, Michigan State University

Funding: Department of Defense, FY12 $0 (award period: 2010-2013)

The Autism Research Program (ARP) Idea Award calls for high-impact, innovative research that leads to improved quality of life for individuals with autism spectrum disorders (ASD). Research indicates that early and intensive intervention can lead to significant improvement in long-term outcomes for children with ASD. However, the growing numbers of young children with ASD and their significant educational needs make it a challenge for public agencies to provide services at the needed level of intensity. Parent training is a cost-effective approach to intervention that can improve child outcomes by increasing the number of hours of intervention a child with ASD receives. Parent training has also been shown to decrease parent stress and depression. Although parent training is considered an essential component of early intervention programs for children with ASD, it is rarely provided in community-based early intervention settings due to a lack of appropriately trained providers. Further, effective parent training programs for children with ASD require frequent parent coaching by a therapist. Thus, the absence of reliable transportation, lack of child care, cost of treatment, and limited flexibility in scheduling, can significantly affect access to these services. These barriers are particularly a problem in rural and underserved areas. The development of more sophisticated technology has created the opportunity for distance learning of intervention strategies. Thus, the objective of this project is to develop and pilot an internet delivered parent training program for caregivers of children with ASD. The intervention will be based on an evidence-based curriculum that uses a blend of developmental and behavioral intervention strategies during daily routines and activities.

Department of Education

Tennessee State Personnel Development Grant

PI: Veronica McDonald, Department of Education, FY12 $492,630 (award period: 2009-2013)

This project will conduct professional development activities in the areas of reading, math, and positive behavioral supports, all based on a Response to Intervention framework. The aim is to facilitate a statewide network of professional development providers to maximize the reach of professional development efforts. An early childhood component will focus on literacy and behavior outcomes for young children diagnosed with autism. A teacher equity initiative will identify and remedy existing inequities in the distribution of highly qualified special education teachers, ensuring that low-income and minority children with disabilities are not taught at higher rates than other children by unqualified teachers. Woven through the initiatives is a strong emphasis on collaboration with higher education, technology, and family involvement.

Live Interactive Broadcast Equalizing Rural Access to Teacher Education (LIBERATE) - Training personnel to serve school-age children with low incidence disabilities

PI: J. Matt Jameson, University of Utah

Funding: Department of Education, FY12 $297,000 (award period: 2010-2014)

This project will deliver a comprehensive post-Bachelor teacher licensure program in low-incidence disabilities to two cohorts of 15 teacher candidates located in a minimum of four rural local education agencies. The overall aim is to increase the number of highly qualified teachers in rural areas able to work with students with significant cognitive impairments, which can include sensory impairments, autism, and other developmental disabilities. Activities of this project include: (a) recruiting and preparing 30 full-time teacher candidates in 4 cooperating rural school districts (two high-need) during the project period (15 candidates in two consecutive cohorts) with focuses on individuals who have Bachelor degrees, live in the communities served, and are from underrepresented populations; (b) delivering the teacher licensure program in low-incidence disabilities to teacher candidates via synchronous interactive video conferencing, web-based support resources, and onsite supervision and support; and (c) conducting a comprehensive evaluation of the effectiveness of teacher candidates to meet the needs of students with low-incidence disabilities through ongoing structured field experiences.

Project SASI: Students with Autism & Sensory Impairments - Addressing the personnel shortages of rural, remote and high-need areas

PI: Nora Griffin, Texas Tech University

Funding: Department of Education, FY12 $249,999 (award period: 2011-2016)

This project will alleviate the need for professionals trained in the areas of visual impairment, deafness, deaf blindness, and orientation and mobility, as well as for professionals with expertise in the dual

diagnosis of autism and sensory impairments in rural, remote, and high-need areas in the states of Arkansas, Idaho, Mississippi, Montana, Texas, and Wyoming. The aim is to train 40 effective teachers during the life of the project. METHOD: Activities of this project include: (a) identify, recruit, and train professionals in rural, remote, and high-need locations to increase the capacity to serve students with sensory impairments from birth through secondary transition age; (b) providing specialized training in effective strategies for working with students with sensory impairments and autism spectrum disorder, ending in a graduate certificate in sensory impairment and autism spectrum disorder; (c) providing a high quality personnel preparation program to scholars via a hybrid program that uses distance education, face-to-face instruction, and local support; and (d) establishing and maintaining ongoing collaboration between Texas Tech University and each participating state to meet the current and future personnel needs for students with sensory impairments and those who may have autism.

Project Common Ground: Preparing highly qualified speech-language pathologists to meet the communication needs of children with autism spectrum disorder in diverse setting

PI: Betty Yu, San Francisco State University

Funding: Department of Education, FY12 $248,180 (award period: 2012-2016)

This project will provide a master's degree program focused on preparing speech-language pathologists (SLPs) to work effectively with a diverse population of children with autism spectrum disorder (ASD) from birth to 21 years of age across home, school and community settings. The program will train 16 students each year, yielding a total of 80 highly qualified professionals over 5 years, with targeted recruiting among underrepresented minorities. METHOD: Activities of this project include: (a) training that aligns with the standards and guidelines for SLPs working with individuals with ASD; (b) providing a partnership experience for scholars to work with a family of a child with ASD; (b) expanding the curriculum to include specialized courses in ASD and augmentative and alternative communication; and (c) offering an integrated play group seminar. Scholars will complete a practicum with infants/toddlers with ASD and a school internship with school-aged children with ASD. Formative and summative evaluations will focus on the number of personnel graduated, the quality of the program, scholar and graduate competencies, and associated outcomes for children and their families.

Examination of the use of a Spanish version of the Online and Applied System for Intervention Skills (OASIS) Training Program with parents of children with an autism spectrum disorder

PI: Linda Heitzman-Powell, University of Kansas Medical Center

Funding: Department of Education, FY12 $200,000 (award period: 2011-2014)

This project seeks to address the access and training deficit for Spanish-speaking parents of children with autism spectrum disorders (ASD) by adapting the Online and Applied System for Intervention Skills (OASIS) Training Program for use with parents who speak Spanish and have a child with an ASD to teach them how to implement empirically-based interventions with their child. The development of this program proceeds across five phases: (1) initial project development, (2) translation and adaptation of existing training resources for Hispanic caregivers, (3) formative evaluation and revision, (4) full program

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evaluation and revision, and (5) final analysis and preparation for dissemination. During training, parents practice the techniques discussed in that week's online tutorials with their child while receiving guidance and immediate feedback from a bilingual clinician with a background in behavior analysis and trained to implement OASIS. Program effectiveness is evaluated based on: parental knowledge and skill fluency, child adaptive behaviors, and reported family quality of life. In addition, families complete exit surveys to elicit feedback regarding program improvement and any problems they experienced, particularly regarding cultural and/or language barriers experienced.

Training personnel in minority institutions to serve infants, toddlers, and children with disabilities

PI: Rita Brusca-Vega, Purdue University

Funding: Department of Education, FY12 $194,826 (award period: 2009-2013)

This project will provide a graduate level course of study to 40 candidates leading to state licensure in Special Education: Intense Interventions. These individuals will serve students with autism spectrum disorders, severe emotional disorders, moderate and severe mental retardation, traumatic brain injury, multiple disabilities, and other health impairments. Activities of the project include: (a) recruiting for application a diverse group of candidates; (b) providing specialized training in autism and related conditions; (c) provide preparation on meeting the needs of diverse students and their families; (d) providing an interdisciplinary perspective on serving students with intense needs by integrating training from education, medical, and mental health professionals, and (e) Purdue University Calumet (PUC) School of Education special education faculty collaborating with experts from the Riley Child Development Center of Indiana University Medical Center, the Northwest Indiana Roundtable of Special Education Administrators, the PUC School of Nursing, and the PUC Institute for Social Policy and Research.

Project STARS: Specialized Training in Autism for Rural Schools

PI: Barbara Ludlow, West Virginia University

Funding: Department of Education: FY12 $0 (award period: 2007-2013)

The purpose of this project is to: (a) develop a new personnel preparation program to prepare autism specialists to provide effective educational interventions for students with autism spectrum disorders (ASD); (b) develop and field test a unique online distance education model for rural personnel preparation combining desktop videoconferencing and online supervision of practica; and ¼ prepare 60 educators to become fully certified and highly qualified in Autism and to implement evidence-based practices for ASD in rural schools and agencies. This project will modify an existing distance learning program to utilize online delivery of coursework and online supervision of practicum experiences to incorporate content on evidence-based practices for ASD as well as provide training across the state through content on evidence-based practices for ASD as well as provide training across the state

through a combination of desktop videoconferencing and other online activities for course offerings and local supervision and online mentoring for practicum experiences.

Project DART: Distance Education for Autism Personnel in Rural Texas

PI: Smita Mehta, University of North Texas

Funding: Department of Education, FY12 $0 (award period: 2008-2012)

This project will recruit, prepare, retain, evaluate, mentor, and graduate highly qualified personnel from rural communities of Texas in the area of autism spectrum disorders (ASD), by using distributed learning technologies and instructional methods. The aim is to reach out to special education teachers and parents who live in rural parts of Texas and who do not have access to high-quality, comprehensive autism training. The project will use distributed educational technologies and instructional formats (including trigger video, blogging, journaling, role playing, simulations, scenarios, games and peer evaluation of products, video streaming, and video-conferencing and teleconferencing) to provide expert preparation in the area of ASD, including mild, moderate, and severe levels of disability. The project will utilize all of the courses in the existing Autism Intervention Master's Degree and redesign the instructional delivery model from face-to-face to distributed learning technologies to provide effective preparation of personnel in rural parts of Texas. In addition to the required coursework, the project will also fund an intensive one-week summer institute at the University of North Texas, Denton for all program participants, in order to provide additional hands-on training and mentorship. A minimum of 65% of the total annual funds is designated for personnel support. Finally, when students graduate from this program, regional and local experts will mentor them during their first year of teaching to ensure retention.

Special educator preparation in autism spectrum disorders

PI: Wilfred Wienke, University of Central Florida

Funding: Department of Education, FY12 $0 (award period: 2007-2012)

The project is designed to address two identified gaps in service that persist in the field: (a) the need to increase the quality and diversity of special education teachers prepared to serve the increasing numbers of students identified with autism spectrum disorders (ASD); and (b) the need to increase the qualifications of special educators to implement evidence-based practices for comprehensive instructional programming for students with ASD. This project leads to teacher certification in Exceptional Education and endorsement in Autism. The project will increase the quantity and diversity of special educators through a multifaceted recruitment model targeting uncertified special education teachers from underrepresented populations. Qualifications of special educators will be increased by

incorporating a Graduate Certificate in ASD into the university's existing Exceptional Education Master's program. Partnerships with local agencies and school districts will assist in the development of a strong mentorship program to provide enhanced support to beginning special education teachers of students with ASD and will also provide demonstration sites for field experience and supervised evidence-based practice.

Health Resources and Services Administration

Autism Intervention Research Network on Behavioral Health (AIR-B network)

PI: Connie Kasari, University of California, Los Angeles

Funding: Health Resources and Services Administration, FY12 $1,405,365 (award period: 2008-2013)

Part of the Autism Intervention Research Network on Physical Health (AIR-P network). This multi-site research network addresses interventions, guidelines, tool validation, and dissemination for children with autism and their families, with a particular focus on underserved and under-represented populations.

Studying the impact of service-learning on career development, self-determination, and social skill building for youth with autism spectrum disorders

PI: Sheila Fresko, University of Massachusetts, Boston

Funding: Health Resources and Services Administration, FY12 $300,000 (award period: 2011-2013)

This Service-Learning intervention project for 100 youth with ASD who represent underserved populations in three Florida counties will explore the impact of service learning on career development, self-determination, and social skill building for youth with ASD.

Improved early identification of autism in Latino children

PI: Bruno Anthony, Georgetown University

Funding: Health Resources and Services Administration, FY12 $297,752 (award period: 2010-2012)

This project addresses disparities in rates of autism diagnosis and service utilization for Latino children as compared to non-Latino white children. The overall goal of the present project, a collaboration of researchers, primary care providers and families, is to provide evidence for the effectiveness of a "Supported Screening" model to enhance identification and successful referral for Latino children.

Leadership Education in Neurodevelopmental Disabilities

PI: Sydney Rice, University of Arizona

Funding: Health Resources and Services Administration, FY12 $3,392 (award period: 2011-2016)

This reflects the portion of LEND training grant devoted to support Improving Early Screening and Diagnosis of Autism in Underserved Populations. The purpose of this project is to determine if providing training and technical assistance on developmental delay and autism screening improves the overall timeliness of the American Academy of Pediatrics (AAP) recommended well-child visit screenings and referrals in rural communities. In an effort to improve the timing of screening diagnosis for children aged birth to 36 months from underserved populations, specifically minorities, low income, and rural families, who are at-risk for developmental delays and autism spectrum disorders, AZLEND trainees provide training and collect data at rural community health centers. Currently, six clinics in Santa Cruz and Yuma counties participate in this project. Interdisciplinary teams conducted in-depth interviews with each clinic to discuss process flows and determine the most feasible and least intrusive method for incorporating developmental screening into standard operating practice. Teams also trained all clinical staff to use the PEDS, PEDS-DM, and M-CHAT. Prior to training, baseline referral and diagnostic evaluation information was collected for all patients that were birth through 24 months of age. These data are part of traditional reports generated by the early intervention program and can be tracked by the diagnosing physician. In March and April 2013, the same data will be collected to determine if providing technical assistance and training improves timely developmental screening and referral. Assisting already overextended rural clinics integrate screening and referral practices into daily operations will ensure children from underserved populations receive timely diagnosis and intervention and reduce disparities typical for these groups. This project also supports physicians to follow the AAP recommendation of early screening and referral.

National Institutes of Health

ACE Network: A comprehensive approach to identification of autism susceptibility genes

PI: Daniel Geschwind, University of California, Los Angeles

Funding: National Institutes of Health (NIMH), FY12 $2,631,440 (award period: 2008-2013)

This study is part of an Autism Centers of Excellence (ACE) Network. Although autism spectrum disorders (ASD) have a multifactorial etiology they have a large genetic component. It is also becoming clear that comprehensive efforts involving large sample sizes and methods to reduce heterogeneity are necessary to achieve maximal power to identify disease critical regions narrow enough to permit positional cloning of autism susceptibility genes. The investigators in this application aim to continue their collaborative effort that has produced and enhanced a highly successful open data and biomaterials resource for the research community, the Autism Genetic Resource Exchange (AGRE). This collaborative network application, involving six research sites and the AGRE DCC, will systematically and comprehensively investigate the genetics of ASD to identify rare mutations, chromosomal abnormalities, and common variation contributing to ASD susceptibility. The investigators will then perform follow up linkage studies to confirm several new loci identified based on autism-related endophenotypes or co-variants, such as language delay, sex, and head circumference. Genetic risk factors identified in the

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mostly white European sample will be tested for association in the African American sample to determine whether these cohorts share the same genetic risk factors. All phenotypic and genotype data will be made accessible via the Internet on a rolling basis, including minority families, further enhancing the value of this resource to the community.

The effects of State and Federal insurance policies on quality of care for autism

PI: Douglas Leslie, Pennsylvania State University

Funding: National Institutes of Health (NIMH) FY12 $450,534 (award period: 2012-2015)

The challenges in identifying, accessing, navigating and paying for autism spectrum disorder (ASD) services available in a given community, given the complexity of a child's needs, available services, and financing arrangements, can place a substantial burden on parents and caregivers of children with ASD. Although previous studies have examined satisfaction with care and the impact of having a child with ASD on parental income and employment, little is known about the effects of state policies regarding coverage and financing of services for children with ASD on these outcomes, or whether these effects differ by race/ethnicity. This study would explore these effects using data from multiple waves of two national surveys of children's health: the National Survey of Children with Special Health Care Needs and the National Survey of Children's Health. We will examine the effects of these policies on access to care, satisfaction and family burden among children with ASD and their families in both publicly and privately insured populations. We will also explore whether characteristics of the waivers or of the mandates are associated with changes in access to care, family burden and satisfaction, and whether these effects differ by race/ethnicity. In addition to informing future Medicaid waivers and insurance coverage mandates, the results of the study will be instrumental in implementing the Federal Mental Health Parity and Addiction Equity Act and health care reform.

ACE Network: A comprehensive approach to identification of autism susceptibility genes (supplement)

PI: Daniel Geschwind, University of California, Los Angeles

Funding: National Institutes of Health (NIMH), FY12 $442,627 (award period: 2012-2013)

This is a supplement to project 5R01MH081754-05. This study is part of an Autism Centers of Excellence (ACE) Network. Although autism spectrum disorders (ASD) have a multifactorial etiology they have a large genetic component. It is also becoming clear that comprehensive efforts involving large sample sizes and methods to reduce heterogeneity are necessary to achieve maximal power to identify disease critical regions narrow enough to permit positional cloning of autism susceptibility genes. The investigators in this application aim to continue their collaborative effort that has produced and enhanced a highly successful open data and biomaterials resource for the research community, the Autism Genetic Resource Exchange (AGRE). This collaborative network application, involving six research

sites and the AGRE DCC, will systematically and comprehensively investigate the genetics of ASD to identify rare mutations, chromosomal abnormalities, and common variation contributing to ASD susceptibility. The investigators will then perform follow up linkage studies to confirm several new loci identified based on autism-related endophenotypes or co-variants, such as language delay, sex, and head circumference. Genetic risk factors identified in the mostly white European sample will be tested for association in the African American sample to determine whether these cohorts share the same genetic risk factors. All phenotypic and genotype data will be made accessible via the Internet on a rolling basis, including minority families, further enhancing the value of this resource to the community.

Do access barriers to autism care persist despite autism insurance mandate?

PI: Li Wang, Pennsylvania State University

Funding: National Institutes of Health (NIMH), FY12 $295,367 (award period: 2012-2015)

Access barriers to treatment care of Autism Spectrum Disorders (ASD) persist despite autism insurance mandates in states that require private insurers to provide autism care coverage. Using a large, unique multi-state private insurance claims database, this research will 1) be the first study to use nation-wide post-mandate private insurance claims data to measure actual (rather than projected) changes in autism services use, costs and health benefits after the mandate; and 2) be the first study to explore access barriers that persist despite autism insurance mandates. Findings from this study will 1) help evaluate autism mandates and design future autism mandates, and 3) help decision makers identify the next essential steps following insurance mandate enactment to further remove access barriers and better serve children with ASD.

The use of interactive television in identifying autism in young children

PI: R. Matthew Reese, University of Kansas Medical Center

Funding: National Institutes of Health (NIMH), FY12 $188,750 (award period: 2012-2014)

Early detection and early intervention significantly improves developmental outcomes for children with autism spectrum disorder (ASD), however, availability and access to trained professionals who provide diagnostic and clinical services for children with ASD are limited, particularly in rural areas. This project will evaluate the use of interactive television (ITV) in evaluation procedures for children suspected of having autism to ensure greater access to trained professionals. Investigators will employ telemedicine, a form of interactive television that uses real-time video conferencing for clinical purposes, on a cohort of participants consisting of 46 children ages 2-5 that are suspected of having ASD. Participants will be randomly assigned to interact with a lead psychologist via ITV or in person and assessed standard diagnostic scales (ADOS and ADI), fulfillment of the DSM-IV criteria for ASD, and overall diagnostic measures.   Results of this study will be utilized to identify empirically validated practices for early detection of ASD in rural communities. Through the outcomes of this research, the identification of a reliable and valid protocol for ASD diagnosis via ITV would allow greater access to quality health care for individuals in rural and underserved areas, with greater access to early intervention and improved developmental outcomes.

Reducing barriers to autism care in Latino children

PI: Katherine Zuckerman, Oregon Health & Science University

Funding: National Institutes of Health (NIMH), FY12 $179,521 (award period: 2012-2017)

This is a mentored Research Career Development Award to support the career development of clinical investigators in patient-oriented research. Latino children are diagnosed with autism spectrum disorders (ASD) at older ages and typically demonstrate more severe symptoms, putting them and their families at significant disadvantage. Interventions addressing family, community, and health care systems factors hold promise for improving access to ASD diagnostic services for minority children. The goal of this project is to develop an evidence-based intervention to reduce ethnic differences in ASD care among Latinos. Investigators in this study will develop a survey of 350 Latino parents of typically-developing children and children with ASD to assess common beliefs about autism in Latino communities, and to determine which community factors, health beliefs, and health care system factors are associated with delays in ASD diagnosis. With the study's findings, researchers will then develop a pilot community-based patient navigator intervention designed to reduce barriers to care. In addition to developing an evidence-based intervention to improve diagnosis and treatment of ASD in Latino children, this project will also help such children achieve earlier diagnosis and better long-term prognosis.

Cultural equivalence of autism assessment for Latino children

PI: Sandra Magana, University of Wisconsin- Madison

Funding: National Institutes of Health (NICHD), FY12 $74,250 (award period: 2010-2012)

The proposed study will provide a body of data from which significant future research on Latinos (including those who are Spanish speaking) with an autism spectrum disorder may be built by examining the cultural equivalence of the Autism Diagnostic Interview Revised (ADI-R), one of the most widely accepted autism diagnostic instruments. Such data are particularly relevant as Latinos are the fastest growing minority group in the U.S. and have been underrepresented in autism diagnosis and services.

Organization for Autism Research

Identifying disparities in access to treatment for young children with autism

PI: Lucy Bilaver, University of Chicago

Funding: Organization for Autism Research, FY12 $20,000 (award period: 2012)

The purpose of the proposed study is to identify disparities in access to treatment for young children with autism spectrum disorders (ASD). In particular, this project will identify treatment that occurs both inside and outside the school system. This study will focus on disparities across multiple dimensions including race, region, socioeconomic status, and type of health insurance. While previous research has documented disparities in the age at diagnosis, an understanding of how this phenomenon translates to service use for children in early elementary school is lacking. The study design is observational and longitudinal relying on unique, nationally representative data generated from the Pre-Elementary

Education Longitudinal Study (PEELS). The PEELS followed a nationally representative sample of over 3,000 preschool aged (age 3-5) children receiving special education services through 5 waves of data collection beginning in 2003-2004. The unweighted study sample includes approximately 450 children ever identified as having autism during the first 4 waves of data collection. Generalized estimating equations will be used to identify disparities in receipt of treatment services including speech, occupational, and physical therapies, behavior therapy or behavior management program, play therapy or group, and psychological or mental health services. The results of this analysis can be used to identify targets of intervention to reduce service disparities.

Southwest Autism Research & Resource Center

Remote parent training project

PI: Daniel Openden, Southwest Autism Research & Resource Center

Funding: Southwest Autism Research & Resource Center, FY12 $50,000 (award period: 2009-2013)

The purpose of the current study is to measure the effects of providing support to parents via telemedicine after they have participated in a week long intensive parent training session. This project will attempt to improve access to intervention for families living in remote or rural regions, where identifying an interventionist is difficult.