

2010 Health disparities-related projects

The projects listed below were taken from the data collected for the 2010 IACC ASD Research Portfolio Analysis reports. The projects are grouped by funding agency/organization.

Autism Speaks

Eastern Kentucky Autism Training Project

PI: Rich Mancil, Kentucky Autism Training Center

Funding: Autism Speaks, FY10 \$300,000 (award period: 2009-2010)

This proposed new initiative will address the need for ongoing, autism-specific training of parents, educators, and service providers in rural Appalachia. The primary goals of this Training of Trainers (TOT) project include providing families and providers in this rural region with access to practical research-based information, offering comprehensive workshop modules based upon the needs of local providers and parents/caregivers, and developing a network of local service providers with ASD-specific training to build the capacity for support of families in the region. Ultimately, this pilot project will serve as the beginning of a statewide training network.

Early intervention in an underserved population

PI: Catherine Lord, University of Michigan

Funding: Autism Speaks, FY10 \$73,763 (award period: 2010-2012)

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, 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.

University of Georgia – Carolina Autism Resource and Evaluation Center (UGA-CARES): A collaborative autism screening project utilizing web-based technology

PI: Jonathan Campbell, University of Georgia

Funding: Organization for Autism Research, FY10 \$40,000 (award period: 2010-2011)

The primary aim of this study is to compare the predictive validity of three parent-report autism spectrum disorder (ASD) screening instruments for preschoolers and young children. The researchers are interested in comparing and contrasting screeners' predictions of results from a standardized diagnostic assessment, which includes a "gold standard" diagnostic measure. Researchers will also be examining whether the predictive validity of screening measures differs across racial/ethnic groups and social economic status (SES). A secondary aim of the study targets application of a web-based video analysis tool to confirm results from diagnostic evaluations.

Training rural providers in the assessment and treatment of emotional and behavioral disorders in autism

PI: Caroline Magyar, University of Rochester

Funding: Autism Speaks, FY10 \$0 (award period: 2009-2010)

This program is targeted toward school psychologists and community mental health practitioners in rural New York and aims to increase knowledge of best practices in the assessment and treatment of emotional and behavioral disorders in school-aged children with autism spectrum disorders (ASD). The University of Rochester will develop a training manual and provide training, complete with evaluation of changes in the participants' knowledge of best practices (through pre/post knowledge tests, Case Study Scenario Checklists, etc.). The grantee will also evaluate the content and format of training to prepare it for use in future community education activities. There is a great need for capacity building programs targeted toward these professionals in rural New York as well as effective training resources that can be replicated for larger groups and disseminated across other geographical areas.

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, FY10 \$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, Tennessee Department of Education

Funding: Department of Education, FY10 \$1,027,927 (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.

Creating instructional leaders for students with low-incidence disabilities

PI: Carol Davis, University of Washington

Funding: Department of Education, FY10 \$571,142 (award period: 2006-2011)

This project will address the complex issues and requirements of educating students with severe and multiple disabilities and other low-incidence disabilities, especially those who live in poverty. These are students in 'double jeopardy': They are already at risk due to environmental issues, and their disability status may put them even further at risk for school failure. This project will prepare 32 candidates across 4 years to be evidence-based instructional leaders and effective teaming partners who have the skills and competencies needed to educate challenging populations of students, including those with autism, behavior issues, sensory and motor impairments, and limited English proficiency. Recruiting people from underrepresented groups will be a priority of this project. To maximize learning and retention in the program, each candidate will be paired with a mentor on the basis of such variables as similar interests and career goals. The program will consist of a 2-year practicum and seminar series ('Instructional Leaders' seminar and 'Teaming' seminar) that focuses on learning and using the knowledge and skills needed to implement evidence-based strategies in school, home, and community settings. Also emphasized will be the skills of collaboration, with students focusing on learning and practicing team roles and responsibilities, developing shared goals, working with families, conflict resolution, communication, and how to work with paraprofessionals. Field experiences will ensure exposure to the full age range of students (preschool, elementary, middle and high school, and postsecondary vocational and transitional). Online modules will also be developed and utilized as a means of providing exposure and instruction.

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, FY10 \$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.

Finding and keeping the best: A rural regional partnership for recruiting and retaining teachers for children with low incidence disabilities

PI: Michelle Cepello, California State University Chico Research Foundation

Funding: Department of Education, FY10 \$200,000 (award period: 2009-2013)

The project will train 64 college graduates to receive California Education Specialist certification in moderate to severe disabilities. The project will focus on addressing the needs of children with low incidence disabilities, including autism, significant cognitive impairments, multiple disabilities, orthopedic impairments, and simultaneous vision and hearing impairments. The project will prepare participants for teaching certification through: (a) release day seminars; (b) interactive online instruction; (c) regional training sites; and (d) intensive summer sessions. The project aims to ensure teacher retention by providing a support network beginning in the recruitment phase and early field experiences, continuing through the on-the-job training period, and extending five years beyond certification.

Leadership training in severe disabilities/autism

PI: Craig Kennedy, Vanderbilt University

Funding: Department of Education, FY10 \$200,000 (award period: 2006-2011)

This project will increase capacity for conducting intervention research that improves student outcomes and bridges the research-to-practice gap; forge stronger partnerships between colleges/universities and public schools; prepare leadership personnel from diverse backgrounds to work effectively in developing and supporting programs for students in inclusive settings; and prepare prospective college/university special education faculty and LEA/SEA administrators of diverse backgrounds in these areas. The methods of this project include aggressively recruiting 9 students, a process that will include cooperation with historically black colleges/universities in Nashville, and building on strong partnerships with local schools, school districts, and the Tennessee special education agencies to develop research experiences, including partnerships that will facilitate cross-cultural understanding and competence. Student doctoral training will include learning experiences and collaborative efforts with general educators who teach students with severe disabilities/autism. Trainees will also participate in special monthly seminars on research, teacher training, and policy making designed to bridge the research-to-practice gap.

Project STARS: Specialized Training in Autism for Rural Schools

PI: Barbara Ludlow, West Virginia University Research Corporation

Funding: Department of Education, FY10 \$199,980 (award period: 2007-2011)

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, FY10 \$199,980 (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.

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

PI: Rita Brusca-Vega, Purdue University

Funding: Department of Education, FY10 \$ 192,675 (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.

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, FY10 \$1,989,276 (2009-2011)

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.

Tele-health delivery of a family-focused intervention to reduce anxiety in youth with autism spectrum disorders in rural Colorado

PI: Susan Hepburn, University of Colorado Denver

Funding: Health Resources and Services Administration, FY10 \$400,000 (award period: 2009-2010)

This project will develop and evaluate use of interactive video conferencing to deliver a manualized coping skills program (Face Your Fears, Reaven et al., 2008) to families of children with autism spectrum disorder (ASD) who live in rural Colorado. The intervention is delivered to an underserved population of rural families of children with ASD who have difficulties accessing specialized mental health supports.

Parent-mediated vs. center-based intervention for toddlers with ASD: An RCT

PI: Rebecca Landa, Kennedy Krieger Institute

Funding: Health Resources and Services Administration, FY10 \$400,000 (award period: 2009-2010)

This randomized controlled trial will compare two different early intervention approaches for minority and underserved toddlers with autism spectrum disorder (ASD): 1) a home-based model emphasizing caregiver-mediated intervention (including one-on-one therapist-provided intervention serving the dual purpose of promoting child development and modeling for the parent); and 2) a combined model emphasizing center-based professional-mediated intervention (including parent training). The study will evaluate the relative impact of these two interventions on social and communication development of minority and underserved toddlers with ASD and on their primary caregivers.

Improved early identification of autism in Latino children

PI: Bruno Anthony, Georgetown University

Funding: Health Resources and Services Administration, FY10 \$299,993 (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.

Medical service utilization by Medicaid-eligible children with autism in Georgia: An analysis of one year of claims and provider data

PI: Daniel Crimmins, Georgia State University Research Foundation

Funding: Health Resources and Services Administration, FY10 \$100,000 (award period: 2010)

This secondary data analysis project examines the medical service utilization patterns of children diagnosed with autism living in urban and rural areas of Georgia using Medicaid fee-for-service data.

Racial/ethnic disparities in family burden & health care of children with autism

PI: Susan Parish, Brandeis University

Funding: Health Resources and Services Administration, FY10 \$98,962 (award period: 2010)

This secondary data analysis project uses data from the 2005-2006 wave of the National Survey of Children with Special Health Care Needs to examine racial/ethnic disparities in family burden & health care of children with autism.

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), FY10 \$2,823,814 (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 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.

Autism in urban context: Linking heterogeneity with health and service disparities

PI: Olga Solomon, University of Southern California

Funding: National Institutes of Health (NIMH), FY10 \$613,127 (award period: 2009-2011)

Although heterogeneity inherent in autism spectrum disorders (ASDs) has long been recognized, little is known about ways in which race, gender, socio-economic status, family culture, and communication during clinical encounters affect the acquisition of diagnosis and related services. The project examines disparities in ASDs diagnosis and services for African American children in an urban setting by following a cohort of African American children living in the Los Angeles metropolitan area diagnosed with ASDs, their primary caregivers, and the practitioners who serve them. Results of the project will help caregivers and practitioners to better communicate and partner during clinical encounters. The project

will facilitate earlier diagnosis and services for African American children with ASDs, which will help improve their developmental outcomes.

Disseminating scientific information on autism to the Latino community

PI: Clara Lajonchere, University of Southern California

Funding: National Institutes of Health (NIMH), FY10 \$466,538 (award period: 2009-2011)

This project focuses on translating scientific information on autism spectrum disorders into everyday language so that Latino families can understand and utilize scientific discoveries in their health decision-making process. This research is done in partnership with Fiesta Educativa, a community-based education, advocacy, and support organizing serving Latino families who have children with disabilities. The most effective strategies to translate scientific information about autism research and bring it into the hands of consumers, Latino families, will be developed and studied. The long term goal is to develop a model for academic institutions nationwide.

Behavioral treatment for autism in community settings using a telehealth network

PI: Scott Lindgren and David Wacker, University of Iowa

Funding: National Institutes of Health (NIMH), FY10 \$373,763 (award period: 2009-2011)

The proposed research will study the effectiveness of delivering behavioral treatment for autism through telehealth methodology, which has the potential to overcome barriers that limit access to care in rural and other underserved areas. The study will target parents of children (ages 1 to 6 years) with autism. This study focuses on testing whether functional behavioral analysis and functional communication training, conducted through telehealth coaching, is effective in reducing disruptive behavior and increasing positive social behaviors in young children with autism spectrum disorders. The results of the proposed study should provide an evidence base on which to expand behavioral treatment options for families of children with autism spectrum disorders.

Early social communication characteristics of ASD in diverse cultures in the US and Africa

PI: Amy Wetherby, Florida State University

Funding: National Institutes of Health (NIDCD), FY10 \$226,872 (award period: 2009-2011)

There is a pressing need to improve early detection of autism spectrum disorders (ASD) so that families can access intensive, appropriate intervention services as early as possible. However, studies indicate

that important racial and ethnic disparities exist in the identification and diagnosis of children with ASD in the US, which impact access to services. This research investigation is a foundational study of early social communication markers of ASD in children from two diverse cultures from two different countries- Latino immigrants in Southeastern U.S. and the KwaZulu-Natal (KZN) province of South Africa. The expected outcomes of this study will have significance for the field by identifying behavioral markers that distinguish young Latino children in the Southeastern U.S. and African children from KwaZulu-Natal with ASD from children with typical development from those cultures. Cultural differences may be evident in the behavioral phenotype of ASD, recognition and interpretation of symptoms by caregivers, the decisions parents make regarding evaluation and treatment, and interactions between families and the healthcare system. The results of this research will lead to culturally sensitive screening and evaluation methods that may decrease the age at which all children with ASD are diagnosed.

Epidemiological research on autism in Jamaica

PI: Mohammad Rahbar, University of Texas Health Science Center at Houston

Funding: National Institutes of Health (NICHD), FY10 \$131,010 (award period: 2009-2012)

The prevalence of autism spectrum disorders (ASD) appears to be on the rise in developed countries and has become a serious public health concern. In most developing countries, however, the nature and prevalence of factors associated with ASDs are unknown. The long term goal of this planning project is to develop capacity for conducting large scale population-based ASD studies in Jamaica. First, the diagnostic criteria used in Jamaica and the United States will be compared. Then, questionnaires regarding the demographic and socioeconomic position, occupation, and drinking habits of each child's parents will be used, and information will be gathered about family history of developmental disorders, family size, birth order of the affected child, and whether the child is taking any medications. An age and sex matched case-control study, including a dietary questionnaire, will also be conducted to investigate whether environmental exposures to mercury, lead, arsenic, and cadmium play a role in autism. Blood and saliva samples will be collected to determine if any DNA polymorphisms that might affect interactions with heavy metals are present in children with ASD. New knowledge of potential environmental risk factors for ASD may arise from this research, thereby reducing physical, psychological, and economic burdens on the child, family, and society and helping parents make decisions about avoiding exposure to environmental contaminants.

Population genetics to improve homozygosity mapping and mapping in admixed groups

PI: Amy Williams, Harvard Medical School

Funding: National Institutes of Health (NHGRI), FY10 \$45,590 (award period: 2010-2013)

This is an individual National Research Service Award for post-doctoral research training, which provides support for promising Fellowship Applicants with the potential to become productive, independent investigators in scientific health-related research fields. Population genetics is a crucial tool for facilitating medical genetics and disease gene mapping studies. This proposal includes two novel population genetic techniques that each facilitate disease gene mapping in different ways. First, a probabilistic technique for detecting the proportion of homozygosity (having two identical alleles of the same gene) an individual is likely to have based on single nucleotide polymorphism (SNP) microarray data will be used. This method is useful for prioritizing disease case sample individuals for whole genome sequencing and subsequent homozygosity mapping to identify recessive disease genes. This scheme will be applied to a dataset of individuals with autism to identify individuals that will be the best candidates to resequence their genes and perform homozygosity mapping to locate recessive disease genes. The second part of the project will develop methods to permit combined admixture mapping and genome-wide association (GWA) of Latinos, a population for which current admixture mapping methods fail. This will be applied to study the genetics of type 2 diabetes, a disease with higher prevalence among Latinos. The technology developed through these two methods will be applicable to a variety of disease gene mapping studies.

Remote parent training project

PI: Daniel Openden, Southwest Autism Research & Resource Center

Funding: Southwest Autism Research & Resource Center, FY10 \$0 (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.