### 2011 Health disparities-related projects

The projects listed below were taken from the data collected for the 2011 IACC ASD Research Portfolio Analysis reports. The projects are grouped by funding agency/organization.

## **Autism Speaks**

### Deployment focused model of JASPER for preschoolers with autism spectrum disorders

PI: Connie Kasari, University of California, Los Angeles

Funding: Autism Speaks, FY 11 \$150,000 (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.

### Early intervention in an underserved population

PI: Catherine Lord, University of Michigan

Funding: Autism Speaks, FY11 \$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.

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

PI: Rita Brusca-Vega, Purdue University

Funding: Department of Education, FY11 \$191,381 (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.

## **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, FY11 \$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, FY11 \$1,471,361 (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.

### Preparation of leaders across the lifespan for autism

PI: Jennifer Ganz, Texas A&M University

### Funding: Department of Education, FY11 \$500,000 (award period: 2011-2016)

This project will prepare six doctoral leaders in the area of autism spectrum disorders (ASD) so that they can have the skills to investigate and provide evidence based practices to individuals with ASD and families across their lifespan and in rural communities. METHOD: Activities of this project include: (a) providing expertise in applied behavioral methodology within general and special education learning environments; (b) providing competence in quantitative analysis of single-case research and meta-analysis; (c) producing productive, independent researchers who have connections with senior researchers in autism, behavioral methodology, and transition; and (d) providing key competencies valued in higher education leadership positions (research, grantsmanship, teaching and supervision, and field consultation).

# 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, FY11 \$297,730 (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.

### Training & research for autism & collaboration in kinesiology

### PI: Rebecca Lytle, Chico Research Foundation

Funding: Department of Education, FY11 \$250,000 (award period: 2012-2016)

This project will prepare 80 adapted physical education (APE) specialists highly trained in working with individuals with low-incidence disabilities from birth through their transition into adulthood, including specialized training in autism and cultural diversity. Discipline-specific, research-based, and collaborative training will be provided. METHOD: Activities of this project include: (a) preparing APE teachers with the skills required to meet the needs of youth from diverse cultural and language backgrounds, including students from low-income/high poverty families and English learners with disabilities; (b) providing

field-based experiences for preservice students specifically addressing the needs of children with disabilities including autism, early intervention, school-aged populations, and transitions programs in rural areas of poverty; (c) integrating intensive yet accessible training in research-based practices that improve outcomes for children with disabilities into the program curriculum; and (d) designing a support network to ensure scholars retention and success in the preparation program and in the profession following graduation in order to improve outcomes for children with disabilities.

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

PI: Nora Griffin-Shirley, Texas Tech University

Funding: Department of Education, FY11 \$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, FY11 \$249,272 (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.

# 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, FY11 \$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.

# 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, FY11 \$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 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.

### Project DART: Distance Education for Autism Personnel in Rural Texas

PI: Smita Mehta, University of North Texas

Funding: Department of Education, FY11 \$200,000 (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, FY11 \$191,381 (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.

### Creating instructional leaders for students with low-incidence disabilities

PI: Carol Davis, University of Washington

Funding: Department of Education, FY11 \$0 (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.

### Leadership training in severe disabilities/autism

### PI: Craig Kennedy, Vanderbilt University

Funding: Department of Education, FY11 \$0 (award period: 2006-2012)

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-topractice gap.

### **Project STARS: Specialized Training in Autism for Rural Schools**

PI: Barbara Ludlow, West Virginia University Research Corporation

Funding: Department of Education, FY11 \$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 Mosaic: Preparing highly qualified educators to meet the unique needs of students with autism in diverse settings

PI: Pamela Wolfberg, San Francisco State University

Funding: Department of Education, FY11 \$0 (award period: 2006-2011)

Throughout the nation, and most notably in Northern California, the incidence of children identified with Autism Spectrum Disorders (ASD) has been on the rapid rise and is reaching epidemic proportions. There is a pressing need to increase the number, quality, and diversity of educators who are fully credentialed and competent to serve students with ASD from diverse ethnic, cultural, and linguistic backgrounds in diverse settings. This 4-year project responds to that need by adding a new program emphasis in ASD to an established Master of Arts and Credential special education programs (K-12/transition) at San Francisco State University. Project Mosaic will be carried out in partnership with local schools, university/medical centers, and community-based programs serving children, families, and adults with ASD. Specialized coursework (4 core methods) and supervised field experiences in diverse, urban settings will be provided over 3 semesters to 80 full-time students, with an emphasis upon recruiting those who have disabilities or who are from underrepresented ethnic, cultural, and linguistic groups. The project will develop specialized research-based curricula and pedagogy that allows 20 candidates each project year to provide services and instruction to students with autism (including core academic areas and English language learning). The project will also evaluate its activities, candidate knowledge and skill, and associated outcomes for students with autism, and will disseminate the program model at the local, state, and national levels.

## **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, FY11 \$ 1,930,288 (2008-2011)

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 Fesko, University of Massachusetts Boston

Funding: Health Resources and Services Administration, FY11 \$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, FY11 \$299,955 (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.

### Autism intervention challenges for low-income children

PI: Alice Kuo, University of California, Los Angeles

Funding: Health Resources and Services Administration, FY11 \$99,988 (award period: 2011)

This secondary data analysis project seeks to identify the challenges to accessing ASD interventions and services that children with ASD from underserved families are facing. The study utilizes the MCHB-funded AIR-B Network data collected across 5 sites

# 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, FY11 \$0 (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, FY11 \$0 (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.

### Leadership Education in Neurodevelopmental Disabilities

### PI: Sydney Rice, University of Arizona

### Funding: Health Resources and Services Administration, FY11 \$0 (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), FY11 \$2,759,732 (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 covariants, 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.

### Cultural equivalence of autism assessment for Latino children

PI: Sandra Magana, University of Wisconsin- Madison

Funding: National Institutes of Health (NICHD), FY11 \$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**

# 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, FY11 \$0 (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.

### Southwest Autism Research & Resource Center

### Remote parent training project

PI: Daniel Openden, Southwest Autism Research & Resource Center

Funding: Southwest Autism Research & Resource Center, FY11 \$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.