

Supporting Diversity in the Developmental Disabilities Network through Minority Partnerships

UCEDD Minority Partnership Grants Evaluation Report



UCEDD Resource Center
A project of AUCD, in partnership with AIDD, to strengthen and support the network of UCEDDs



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Introduction

Over the years, much attention has been placed on reducing or eliminating racial and ethnic disparities amongst Americans. Although there has been improvement, racial and ethnic disparities persist. For example, the life expectancy for White/Caucasians with Down syndrome is about 55 years compared to 25 years for Blacks/African Americans⁵. This suggests that current approaches and strategies are not producing the kinds of results needed to ensure that all Americans are able to achieve the same quality and years of healthy life, regardless of race/ethnicity or other variable⁷.

Nevertheless, eliminating disparities remain a top priority for the rapidly changing demographics of the U.S. The Administration on Intellectual and Developmental Disabilities (AIDD) (formerly the Administration on Developmental Disabilities) identified the need for more targeted efforts such as a partnership reaching across federal initiatives that addressed disparities that exist for minority populations, most particularly those with disabilities¹, was one way to address this persistent issue.

With the understanding that such an effort could not be accomplished by any one entity³, AIDD announced the availability of the University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs) Minority Partnership Grants in 2009. These new awards provided funding to two UCEDDs to develop partnerships with minority-serving institutions (MSIs), which are defined by the Higher Education Act of 2008 as institutions of higher education whose enrollment of a single minority or a combination of minorities exceeds 50 percent of the total enrollment⁸ (e.g. Hispanic Serving Institutions (HSIs) and/or Historically Black Colleges and Universities (HBCUs)). In the UCEDD Minority Partnership Grants funding opportunity announcement (FOA), AIDD highlighted that these partnerships would result in multiple beneficiaries; minority-serving institutions would have access to the vast knowledge, interdisciplinary approaches, and best practices available within the UCEDD network that can be applied within their own settings, and UCEDDs would be better positioned to enhance capacity and responsiveness to minority populations with disabilities¹.

In September of 2009, AIDD announced that the Center for Leadership in Disability (CLD) at Georgia State University, and the University of Southern California UCEDD (USC UCEDD) at the Children's Hospital of Los Angeles would each be awarded a \$225,000/year grant to fund a 36-month project (with three 12-month budget periods). They were to take on the call for action to develop partnerships, referenced hereafter as "minority partnerships," with MSIs and contribute to addressing disparities experienced by minority populations by working towards equal access to information and use of the myriad of publicly and privately funded community-based services¹. The CLD UCEDD developed a partnership with Satcher Health Leadership Institute (SHLI) at Morehouse School of Medicine (MSM) and the USC UCEDD partnered with California State University, Los Angeles (CSULA).

This report highlights findings obtained from the leaders engaged in the two minority partnerships. The report also identifies recommended practices that UCEDDs can model to foster partnerships and greater involvement with minority-serving institutions to further impact the supports and services to underrepresented populations, and furthermore, increase the diversity of populations entering the disability field and the UCEDD network.

Why the UCEDD Minority Partnerships?

It is well documented that minority populations are at increased risk for developmental and other disabilities or for developing secondary conditions¹. Unfortunately, these disparities are expected to expand as the U.S. becomes a “majority-minority” population in less than 30 years³. At the time these projects were initiated, the US Census Bureau data indicated that the minority population of the United States totaled more than 100 million, or 34% of the US population³.

In addition, the Developmental Disabilities Bill of Rights and Assistance Act of 2000 (DD Act) identifies the need for “greater effort to recruit individuals from minority backgrounds into professions serving individuals with developmental disabilities and their families” [DD Act, section 101(a)]². According to the HHS Advisory Committee on Minority Health, there is compelling research that racial and ethnic minority health care providers are more likely to serve minority and medically underserved communities, thereby reducing cultural and linguistic barriers, improving cultural competence, increasing access to care, and increasing patient satisfaction⁴. Research shows that:

- More than 40 percent of Hispanic patients in one survey said that a doctor’s ability to speak the patient’s language was a significant consideration in choosing a physician⁴.
- Minority patients are more likely to choose health care professionals from their own ethnic groups and are more satisfied with the care that they receive from them⁴.
- Evidence indicated that patient-physician communication, trust and understanding increase when patients share the same ethnic, racial, or cultural or primary language background; this improves the accuracy of diagnoses and frequency of patient compliance⁴.

Furthermore, a review of the research on addressing health disparities documents evidence on the importance of working together to transcend boundaries and impact more individuals in order to eliminate disparities amongst this growing population. In fact, there is encouragement for researchers to not only work more collaboratively across governmental departments and agencies and state, local, tribal, and territorial entities but also to include nontraditional community partners to ensure concrete and lasting accomplishments³.

The work of the national network of UCEDDs, authorized by the DD Act under Subtitle D, embodies collaboration. Comprised of many projects, disciplines, research interests, academic institutions, and networking agencies and organizations, UCEDDs work towards a shared vision that foresees a nation in which all Americans, including Americans with disabilities, participate fully in their communities⁹. A key to fulfilling that vision includes access to culturally appropriate supports that lead to independence, productivity, and a healthy and satisfying quality of life universally available across the life span⁹.

There are currently 67 federally funded and university-affiliated UCEDDs across the United States, with at least one Center in every state and territory. The UCEDDs are overseen by AIDD in the Administration for Community Living (ACL), the U.S. Department of Health and Human Services (HHS). The Association of University Centers on Disabilities (AUCD) serves as the technical assistance provider for the UCEDD network, under contract from AIDD.

AIDD is the lead agency in administering the DD Act which identifies a need to ensure that services, supports and other assistance are provided in a “culturally competent” manner [DD Act, section 101(a)]². The term culturally competent, in this context, refers to services, supports, or other assistance that is conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports, or other assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved [DD Act, section 102(7)]². Unfortunately, disparities prevent many from full attainment of the assurances of the DD Act and things such as optimal health and access to health care still eludes millions of Americans³.

The Minority Partnership grants were driven by the potential benefits that could be derived from innovative partnerships between UCEDDs and MSIs. Both parties were positioned with the opportunity to exchange knowledge and transfer strategies that promote and create interdisciplinary approaches to research, training, and services to minority populations with disabilities¹. The Joint Explanatory Statement for the fiscal year 2009 appropriation authorized AIDD to establish new grants to work with minority-serving institutions to focus on research, training, and services related to minority populations with disabilities¹.

As directly stated in the UCEDD Minority Partnership Grants FOA, AIDD anticipated that the Minority Partnership grants would:

"Minority populations are at increased risk for developmental and other disabilities or for developing secondary conditions."

- use a variety of strategies to exchange and transfer knowledge between the UCEDDs and the minority-serving institutions, such as faculty and student exchanges, course exchanges, joint course offerings, joint course development, joint research, collaborative community based training, and/or joint service projects;
- expose faculty and students from minority-serving institutions to the benefits of interdisciplinary research, training (e.g., pre-service, continuing education, community-based), and service;
- expose faculty and students from UCEDDs to the importance of culture, custom, and tradition in reaching out to and seeking the involvement of minority individuals with disabilities and their families in initiatives that could affect their lives;
- expose faculty and students from minority-serving institutions to the range of funding opportunities that UCEDDs pursue and how to do the same, especially through partnerships;
- provide UCEDDs with assistance of faculty and students from minority-serving institutions to recruit from minority populations with disabilities to (1) obtain greater minority participation in ongoing UCEDD research, training (e.g., pre-service, continuing education, community-based), and/or service project(s); (2) launch a new one that includes a minority cohort; or (3) launch one focused exclusively on a minority population with disabilities;
- create a basis for future collaboration between members of a partnership; and
- share experiences from the partnership with other UCEDDs and minority-serving institutions that serve as a catalyst for replication

Approach to Implementation: Highlighting Partner Assets

The minority partnerships were implemented in fiscal year 2010. The participating UCEDDs were expected by AIDD to plan for two-way knowledge exchange and transfer, undertake efforts in outreach and involvement of minority populations with disabilities, to integrate knowledge, and to share their experience through presentations and technical assistance to non-partnership entities to promote partnership and replication.

The partnerships were structured around the 3-year grant period with each year having a new focus. Year one, described as the “grant writing” or “exploratory” year, consisted of mapping out and listing each school’s assets (e.g. clinics, faculty, diversity of student body, partnership building) and identifying collaborative opportunities with a focus on potential outcomes, as well as reflecting on what worked and ways to improve. Year two, described as the “minority pipeline” year, consisted of seeking out pipeline grant opportunities (e.g. exploring careers, education and training missions, additional funding). Finally, year three, described as the “institutional agreements” year, focused on sustainability and seeking out committed funding to continue partnerships (e.g. teaching courses at MSIs), as well as investigating funding sources for disparities research.

Though they had the same obligations and grant structure, the Center for Leadership in Disability (CLD) at Georgia State University (GSU), and the University of Southern California UCEDD (USC UCEDD) at the Children’s Hospital of Los Angeles (CHLA) developed varied models of implementation based on their individual assets and that of their partnered MSI.

Center for Leadership in Disability (CLD) at Georgia State University

Building relationships is probably the most daunting and time consuming challenge partnerships face but it is nonetheless essential to ensure a lasting and proactive partnership with a university or other entity⁶. Dr. Daniel Crimmins, Director of the CLD UCEDD, reported a positive history with their partnering institution, Satcher Health Leadership Institute (SHLI) at Morehouse School of Medicine (MSM). In fact, discussions of potential collaboration began two years before the FOA for partnerships between MSIs and UCEDDs was released. Leaders of SHLI also participated in an AIDD technical assistance site visit for the UCEDD in 2007, which included further discussions about strategic alignments and the potential for collaborating on a Leadership Education in Neurodevelopmental and Related Disabilities (LEND) application for Georgia. When the opportunity arose to establish the minority partnership, Dr. Crimmins and his willing partners from SHLI submitted an application and were awarded with the opportunity to improve the lives of individuals from racially and ethnically diverse backgrounds with developmental disabilities in Georgia, a state with approximately 40% minority membership.



GSU, the home of the CLD UCEDD, is a large public, minority-serving university with a historical emphasis on professional preparation and an increasing emphasis on research. The CLD is organizationally housed within the Center for Healthy Development and Institute of Public Health. They have built a presence in the university

and the community by developing a series of graduate courses on disability and health within the Institute of Public Health, and providing extensive community outreach to individuals with developmental disabilities and their families. MSM, directed by Surgeon General Dr. David Satcher, is a relatively small private medical school and research institution that is a designated HBCU. It has a growing body of programs promoting leadership development particularly for professionals from historically under-represented racial and ethnic groups.

Utilizing the disability expertise of CLD, the expertise in culture and tradition of SHLI, and their joint competence in professional education, this team developed a partnership that entwined the principles of culture and disability into the mission and everyday operations of both respective organizations. Their efforts focused on 1) strengthening disability and disparity emphases within ongoing activities at GSU and MSM; and 2) jointly developing projects that examine the intersection of disability and ethnic identity.

Partnership Goals:

- Interdisciplinary Training – train future professionals in evidence-based services and supports
- Community Service – improve access to quality health care and health promotion across the lifespan for people with intellectual and developmental disabilities (I/DD) from minority populations
- Research – jointly develop health services research on disability and disparity
- Dissemination – promote understanding of health and disability by individuals with I/DD, their families, and policy makers

Themes of Partnership Activities:

- Reducing disparities in access, quality, and outcomes
- Living well with disability
- Cultural competence
- Reaching the historically underserved

University of Southern California UCEDD (USC UCEDD) at the Children’s Hospital of Los Angeles (CHLA)

Dr. Barbara Wheeler, Associate Director of the USC UCEDD, also reported on collaboration and the path to synergy with their partnered institution, CSULA. The USC UCEDD’s relationship began with an accepted invitation by the Dean of CSULA to tour the UCEDD and CHLA, to meet with key faculty, and to explore possible collaborations. This initial contact resulted in trainees from the CSULA audiology program attending a day on USC’s campus. The student’s day included touring the USC Psychology Services Center and other off-site clinics. The opportunity for continued collaboration arose with the FOA of the Minority Partnership grants and CSULA accepted USC UCEDD’s invitation to partner.

The USC UCEDD is housed within a large university and operates several graduate and post-graduate training programs in the health and related fields to prepare professionals to serve individuals with or at risk for behavioral, neurodevelopmental, and special healthcare needs. CSULA is a Minority/Hispanic Serving Institution, the most diverse campus of the California State University system, with 83.5% students from underrepresented ethnic groups--51% Latinos, 20% Asian/Pacific Islanders, and 7% African Americans. CSULA had the diverse student population but limited graduate programs on campus for their students.

CSULA and the USC UCEDD, though distinctly different institutions of higher education, recognized that a partnership could lead to mutually beneficial outcomes. Partnering with the USC UCEDD provided the opportunity to expose CSULA students to possible careers they had not considered before. This is beneficial

to the UCEDD and disability community because a major need in the disability service system is racial, ethnic, and linguistic diversity in the workforce. In fact, the HHS Advisory Committee on Minority Health reported that African-American physicians in California were five times more likely than their white peers to practice in largely African-American communities while the proportion of African-American physicians to the general population and commensurate with their portion of population is shrinking⁴.

"A major need in the disability service system is racial, ethnic, and linguistic diversity in the workforce."

Partnership Goal:

- The ultimate goal and long term benefit of this partnership was for CSULA graduates to enter graduate programs, return to serve their communities, and impact the Health Professional Shortage Areas (HPSAs) in Los Angeles.

Themes of Partnership Activities:

- Education and training through faculty and student exchange
- Grant writing and establishing funding for minority pipeline projects
- Cross-institutional collaborative projects
- Faculty development

Evaluation of the Minority Partnerships

In response to a request by AIDD for technical assistance (TA), AUCD began an evaluation of the minority partnerships to identify the processes and impacts on the participating UCEDDs and MSIs. This report is a result of said evaluation which also responds to technical assistance needs related to increasing diversity in the network of UCEDDs, and providing strategies that UCEDDs can implement to develop partnerships with MSIs within their states. In addition to this report, the two participating UCEDDs will submit their own detailed evaluation of their projects to AIDD.

The 3-part approach to this evaluation consisted of phone interviews by AUCD staff with the identified leaders of each UCEDD and MSI participating in the minority partnerships. Part 1 consisted of a collaborative discussion with the UCEDD and MSI partner. Part 2 consisted of an interview with each UCEDD and MSI partner separately. Finally, additional questions were later asked (Part 3) via email to further assess the partnerships and inform the report.

The feedback and responses from Parts 1 through 3 of the evaluation informed the content of this report, but the report does not provide a section for each question. The evaluation questions are listed below.

Evaluation – Interview Part 1:

1. What were some strategies used for exchanging knowledge and building capacity within each entity?
2. What were the challenges faced during the partnership and how were they addressed, overcome, or not?
3. What are some lessons learned from this minority partnership project that might be effectively applied across the UCEDD network?
4. What are some recommended partnership practices for other UCEDDs?
5. What impacts did the partnership have on health disparities and diversity of professionals in the field?
6. What potential TA activities would be helpful for supporting minority partnerships?
7. What resources would you suggest to inform the UCEDD network?

Evaluation - Interview Part 2:

1. What was your previous experience with the other organization?
2. What came out of this partnership that you feel was valuable?
3. What did you get from the UCEDD/MSI that made a difference, something that you couldn't do without them?
4. What do you think was most important in making this partnership a success?
5. Are there any additional resources you suggest for the UCEDD network?

Evaluation - Interview Part 3:

1. What were the major achievements and outcomes from the partnership (i.e., administrative, operational, programmatic changes in the UCEDD and the HBCU/MSI which seemed to be tied to this partnership project)? Examples may include but are not limited to:
 - Funds leveraged
 - Development of disability studies courses and minors, minority pipeline grants, community trainings, collaborative research, info dissemination activities, shared faculty, shared students, etc.
 - Administrative enhancement (did MSIs learn how to establish a UCEDD – e.g. how UCEDDs operate, how they are structured, and how the CORE grant and Minority Partnership grants from AIDD are administered)
 - Other
2. What factors (people, institutional, economic context, synergy, collaborative efforts, key leadership strategies) or events seemed related to these outcomes?
3. What is the partnership history?
4. What barriers were encountered that other UCEDDs and MSIs can learn from in the future?
5. This partnership is a two way street: the MSIs have expertise in disparities and importance of culture and tradition, and the UCEDDs can help expose students from MSIs to the field of disabilities, the importance of graduate education, and a range of graduate training opportunities and potential funding opportunities for collaborative activity. What are some valuables that MSIs and UCEDDs gained from each other?
 - Did the UCEDD build capacity in the MSI?
 - Did the MSI incorporate culture and tradition of minority communities in UCEDD activities?
6. How replicable are these partnerships and should these efforts be continued and why?
7. What did we learn from these partnerships that could inform future efforts?
 - Might the call for proposals be modified?
 - What can UCEDDs do now to prepare for partnership building?
 - What are some activities UCEDDs can engage in to develop capacity in MSIs without grant money

Impact of the Minority Partnerships

Based on the three-part evaluation of the minority partnerships, it is evident that through these two partnerships, the UCEDDs and MSIs achieved what Lasker et al described as partnership synergy, which refers to a power underlying collaboration which combines the diverse perspectives, resources, and skills of two or more organizations to form a combined advantage, not possible by each institution alone.⁶

Center for Leadership in Disability (CLD) at Georgia State University/ Satcher Health Leadership Institute (SHLI) at Morehouse School of Medicine (MSM)

It is interesting to note that though this report continues to reference this effort as a “minority partnership” for the sake of consistency, CLD referred to their project as a “disability partnership” rather than a minority partnership. MSM as an HBCU and GSU which has a significant minority enrollment are both committed to serving minority communities. They reported that the partnership provided a mechanism for broadening and deepening a focus on the respective campuses on developmental disabilities and minority communities. Their list of achievements continues below.

Faculty and Student Exchange: GaLEND Program and Shared Fellow

A major achievement that can be attributed in part to this partnership and that will provide a mechanism for continued collaboration was the initiation of the Georgia Leadership Education in Neurodevelopmental Disabilities (GaLEND) Program as a partnership between the CLD/GSU and SHLI/MSM. In May 2010, the Maternal Child Health Bureau (MCHB) announced the availability of one-year planning grants for the LEND interdisciplinary training program. The planning grants were restricted to states without a current LEND program and minority-serving institutions were encouraged to apply alone or in partnership with another entity. CLD applied as the lead entity with SHLI as partner. They were awarded the grant and developed a proposal for a full LEND program that was submitted in February 2011. They were awarded five years of funding as a LEND beginning in July 2011 to establish the GaLEND Program. A sub-award to MSM covers the cost of their faculty time for participation with GaLEND, as well as support for a jointly-appointed fellow with the SHLI Health Policy Leadership Program.

The GaLEND Program generated a substantial interest on the respective campuses and beyond. In late August 2011, the first GaLEND cohort began their leadership seminars, core courses, and a range of clinical and community activities which occurred throughout the week and continued over the academic year. The cohort included 17 racially, ethnically, professionally, and ability diverse trainees and fellows from nine MCHB core and related disciplines, along with a self-advocate, and three parent advocates. One trainee was the shared fellow with SHLI and two fellows were early career scientists from the National Center on Birth Defects and Developmental Disabilities (NCBDDD) of the Centers for Disease Control and Prevention (CDC). A notable aspect of the GaLEND program is their commitment to assessing the impact of interdisciplinary training on their participants. Another emphasis is on addressing health disparities experienced by individuals with disabilities from diverse backgrounds. In August 2012, the second GaLEND cohort began with 14 new trainees and fellows, and two trainees continuing for a second year.

Pipeline Activities with Undergraduate Students

Morehouse College, Spelman College, and Clark Atlanta University are three HBCUs with largely undergraduate student bodies that are members of the Atlanta University Center (AUC). All three campuses are located in Southeast Atlanta in close proximity to MSM. The AUC hosts a Public Health Institute, which offers lectures, workshops, and internship experiences for students interested in entering health professions. SHLI and CLD faculty presented on careers in disability to students during the 2011 and 2012 summer intensive sessions. In addition, faculty from SHLI also lectured on developmental disabilities and health disparities to the undergraduate course offered under the auspices of the Institute in the fall and spring of 2011-12 and 2012-13.

Course Development

One significant deliverable for the minority partnership was the development of a graduate course, *Disability, Racially and Ethnically Related Disparities in Public Health*, which SHLI and CLD faculty worked together in developing a syllabus for. The course was approved and was taught in the fall semesters of 2011 and 2012 as an in-person class to a total of 20 students in the MSM Master of Public Health (MPH) program. They are now exploring the potential for the course to be taught as an on-line course at four other HBCUs. They have been working with the Southeast Disability and Business Technical Assistance Center for the Americans with Disabilities Act, which has expressed interest in restructuring the course to reach a broader audience through on-line learning. A proposal was submitted to the National Institute on Disability and Rehabilitation Research to support the development, dissemination, and evaluation of this course.

GSU's Second Century Initiative

The GSU President and Provost announced an initiative in 2009 to hire 100 new faculty members in the next five years under what was called the Second Century Initiative (2CI). Thinking about sustainability, CLD proposed a faculty cluster devoted to eliminating disparities in health care access and outcomes for individuals with developmental disabilities from diverse backgrounds. In 2011, CLD received approval of their application for a 2CI "cluster hire" of three new tenure-track professors. The award provides funding for three faculty members in the Departments of Communication Disorders, Psychology, and Public Health. An added benefit of the award plan is that each cluster is able to appoint nine doctoral-level university fellowships to work in the overall area of the cluster. This initiative offers the potential for continued CLD/GSU and SHLI/MSM collaboration.

Developing a Shared Research Agenda

In June 2011, partners of the minority partnership hosted a research retreat with additional invited faculty from GSU and MSM, and representatives of the CDC's NCBDDD and the Atlanta Census Research Data Center. They identified steps in developing a research agenda on disparities in health access, outcomes, and quality care experiences by people with I/DD from racial and ethnic minority groups. CLD and SHLI have committed to conducting two additional research retreats. One will be on the specific topic of race and disability, the second on disparities in intimate partner violence experienced by people with disabilities from diverse backgrounds. The goal of these retreats will be to provide a framework and set of activities for future research on race, ethnicity, disparity, and disability; identify one to three fundable projects and potential funding sources; and enhance syllabi on the topic for public health and disability series of courses at CLD and MSM. The retreat will include leading scholars on these topics from across the nation, as well as CDC scientists and MSM colleagues.

Community Service

CLD and SHLI each have distinct areas of expertise related to community supports and technical assistance. The partnership led SHLI to increase its focus on developmental disability in some of its activities related to sexual health, mental health, and sickle cell disease. CLD personnel developed targeted outreach activities to minority populations in areas such as positive behavior intervention and supports, person-centered planning, and family supports. CLD staff also developed a training program examining the intersection of racial and ethnic identity, family culture, and disability that was delivered to school personnel in an effort to increase the engagement of families in their children's education.

Infusing Culture and Tradition

In October 2010, the partnership hosted a hip-hop festival and panel discussion about people with disabilities in the music industry. The event was a great success with over 100 people attending from diverse backgrounds.

Dissemination

CLD and SHLI committed to disseminating information on the minority partnership through a variety of outlets, including several peer-review articles. CLD hosted campus disability awareness events, as well as lectured and networked with constituents in the community and within their respective academic institutions. They also developed an active presence through social media. Currently, they have active pages on Facebook, Twitter, YouTube, and Pinterest. Each portal features news and information about people with disabilities from diverse backgrounds. They have seen tremendous growth in the number of followers or fans of their pages since the inception of the partnership. For example, CLD's Facebook Fan page grew from a viewership of 500 individuals to over 1,600 from state, national, and international settings. They are also reaching just over 6,000 people with over 200 people tagging/talking about CLD in posts on other pages.

University of Southern California UCEDD (USC UCEDD) at the Children's Hospital of Los Angeles (CHLA)/ California State University, Los Angeles (CSULA)

Both CSULA and the USC UCEDD expanded their scope of activity and reach in ways that were not possible before the partnership, with meaningful value added across both institutions. Creating financial and programmatic mechanisms (e.g. funds leveraged through grants, course development, and faculty and student exchanges) made a tremendous impact on the diversity of UCEDD faculty and healthcare professionals who specialize in disability. As a result of the minority partnership, CSULA students participated in courses that could enhance their applications to graduate school or employment. Furthermore, they were exposed to professions that could shape their graduate school decisions and career goals.



Funds Leveraged: Minority Pipeline Grants & Tuition Recovery

Perhaps the most important outcome of the partnership between CSULA and the USC UCEDD was funding for and experience with two Minority Pipeline grants.

1. Exploring Careers in Maternal Child Health and Neurodevelopmental Disabilities--an Undergraduate Minority Pipeline Grant (Funding Source: California Office of Statewide Health Planning and Development--Office of Workforce Development Health Careers Training Project, 2011-2012)

The USC UCEDD, in partnership with CSULA, proposed a 1-year pilot course, *Exploring Careers in Maternal Child Health and Neurodevelopmental Disabilities* (HHS 395), to systematically expose undergraduate students in health and human services majors to careers in maternal child health and neurodevelopmental disabilities, with the goal of increasing the number of undergraduates from CSULA who go on to graduate programs where they specialize in these two areas, and eventually join the MCH/neurodevelopmental disabilities workforce. While not a required course, the potential value of this course was reflected in 17 students taking the course for 4 units (120 hours of classroom and observation) and 21 students taking the course for 2 units (60 hours of classroom and observation). These are sizable hours for students to take on an elective basis. Student enrollment consisted of the following majors: Kinesiology (23.6%); Nursing (15.7%); Public Health (13.5%); Child Development (10.5%); Communication Disorders (7.89%); Sociology (7.89%); Biology (7.89%); Nutritional Science (5.2%); Criminal Justice (2.63%); and Social Work (2.63%). Also reflective of the impact of the program was the student evaluation at the end of the course where 63% of the students stated they were interested in having careers in the maternal child health field and/or focus on children with special needs, and 95% stated they wanted to go on to graduate school because they wanted careers similar to the professionals they observed.

2. Maternal Child Health Careers Research Initiatives in Student Enhancement (MCHC/RISE-UP) (Funding Source: National Minority Undergraduate Program--A Public Health Workplace. Centers for Disease Control Office of Minority Health and Health Equity, 2011-2016)

The MCHC/RISE-UP Program provides undergraduate students from disadvantaged and/or under-represented racial and ethnic groups with 400 hours of enhanced public health and related training through a Summer Leadership Training Institute to encourage and support the pursuit of graduate degrees in public health and related fields. Four grantees received awards: Columbia University Medical College (NY), University of Michigan School of Public Health (Ann Arbor), Morehouse College (Atlanta, GA), and Kennedy Krieger Institute (KKI) at Johns Hopkins University. The KKI program is operated by a consortium of three UCEDD/LEND programs at KKI (Baltimore, MD), the University of South Dakota, and the USC UCEDD and partners of Historically Black Colleges and Universities, Minority-Serving Institutions, and Tribal Colleges.

In the first year, summer 2012, students spent one week at the Kennedy Krieger Institute at Johns Hopkins for an introduction to the program at the beginning of the summer, participated in 16 hours of internship activity per week in a variety of areas related to public health, and then spent one week at the Centers for Disease Control with students from the three other grantees at the end of the summer. Student internships included:

- Violence Prevention Coalition of Greater Los Angeles
- Project Legacy (an HIV prevention program for homeless youth)
- Center for Young Women of the CHLA Division of Adolescent Medicine
- High-Risk Infant and Child Abuse Clinics of CHLA
- Altamed's Advocacy and Legislative Unit
- Obesity Prevention
- USCUCEDD/Garvey Head Start
- MEND Obesity Prevention Program
- Weingart ELA YMCA: Los Angeles Centers for Alcohol and Drug Abuse (LACADA)
- Autism and Related Disorders
- USC UCEDD Mental Health Program
- Health Impact Studies
- Community Health Councils of South Central Los Angeles

The LA site was funded to host 16 interns during the first Summer of the five year program and 18 during the second Summer through the KKI National collaborative. All 34 students successfully graduated and several have since applied to graduate school or medical school. One student was accepted into all 7 schools to which she applied and in fall 2013 will be starting the doctoral program (AuD) in Audiology offered jointly at the University of California San Diego (UCSD) and San Diego State University (SDSU). Another student who was considering going to medical school in Cuba received offers to medical school at the University at Buffalo, the State University of New York, also commonly known as SUNY Buffalo, and New York Medical College (NYMC). He will likely attend SUNY Buffalo. Two other students are expected to apply to medical school in fall 2013.

CSULA was also able to recover tuition fees for 36 students enrolled in three academic quarters of *Community Service in Health and Human Services* (HHS 395), which was the vehicle for training CSULA students under the first minority pipeline grant from CA OSHPD. The USC UCEDD taught the courses using the small OSHPD grant enhanced by the Minority Partnership grant, and CSULA kept the tuition fees students paid to take the course for credit.

"The partnership provided a mechanism for broadening and deepening a focus on the respective campuses on developmental disabilities and minority communities."

Table 1 on the following page shows that for every dollar spent to date, the USC UCEDD recovered half of those expenditures through new grants, contracts, and student fees for new courses started under the partnership. It is anticipated that additional funds will be leveraged through student tuition once the Minor in Developmental Disabilities is implemented during their year four no-cost extension from AIDD; this will benefit both institutions.

**Table 1. Total Dollars Leveraged—USC UCEDD/CSULA Minority Partnership Grant (2009-2012)
One Year No-cost Extension Approved for 2012-2013**

Name of Grant	Funding Source	Total # of Years	Annual Award	Total Award
Exploring Careers in Maternal Child Health and Neurodevelopmental disabilities--an Undergraduate Minority Pipeline Grant	California Office of Statewide Health Planning and Development--Office of Workforce Development Health Careers Training Project	1 year (2011-2012)	\$12,000	\$12,000
Exploring Careers--HHS 395	Tuition Recovery ¹ 36 students over 3 quarters	1 year (2011-2012)	\$35,984	\$35,984
Maternal Child Health Careers Research Initiatives in Student Enhancement (MCHC/RISE-UP)	National Minority Undergraduate Program--A Public Health Workplace. Centers for Disease Control Office of Minority Health and Health Equity	5 years (2011-2016)	\$60,000 Year 1 \$54,000 Year 2 Est. \$50,000 Years 3,4,5	\$264,000
Total Dollars Leveraged				\$311,984
Total Dollars spent ²				\$620,187
Dollar Leveraged for Each Dollar Spent				1:2

¹Based on \$346 cost per unit for 104 units (36 students).

²The USC UCEDD/CSULA Minority Partnership Grant had \$154,813 unexpended at the end of Year 3, for a total of \$620,187 spent to date. The program period has been extended to September 30, 2013.

Course Development

With the synergy that came from the two minority pipeline grants, the partnership resulted in the development of five new courses and a university approved Minor in Developmental Disabilities at CSULA to be jointly taught by CSULA and USC UCEDD faculty. The USC UCEDD will be actively involved in developing and/or being primary lead in three of the five courses. The minor was approved during year two of the partnership.

Table 2 on the following page outlines the requirements of the approved Minor in Developmental Disabilities, how the UCEDD is actively involved, and how the minor will be sustained financially over time.

Table 2. New Courses and Academic Programs Developed by the USC UCEDD/CSULA Minority Partnership Grant, 2009-2012, Which are Being Sustained

CSULA Course Established	Description	Sustainable Funding
1. HHS 395. Exploring Careers in Maternal Child Health and Neuro-developmental Disabilities	A 2-unit (60 hours) or 4-unit (120 hours) course which exposes students to didactic content and observations in clinical and community settings where children with or at risk for disabilities are served.	Tuition for students enrolled in the Minor in DD, where this course will be a regular offering.
2. Minor in Developmental Disabilities (College of Health and Human Services) approved by CSULA in 2012.	<p>The Developmental Disabilities Minor degree program will require 31-32 total units. The courses are as follows:</p> <p>1. Required Core (11-12 units)</p> <ul style="list-style-type: none"> • <u>PSY 160</u> (existing CSULA course) - Psychology of the Developing Person (4) • <u>EDSP 400</u> - Foundations of Special Education (4) • <u>EDSP 301</u> - Individuals with Disabilities in Contemporary Society (3) or • <u>HHS 310</u> (new USC UCEDD course) - Historical and Social Context of Disability (4). Explores societal perceptions of disability from historical and social contexts to establish a framework for understanding key concepts and factors which have shaped the evolution of service systems. <p>2. Foundations of Program Delivery, Management and Advocacy (12 units)</p> <p>Students select one class from a list of existing courses in the following areas: a) Policy/Leadership/Professional and Cultural Competencies.; b) Broad Themes/Theory; and c) Impairment Specific/Depth Area</p> <p>3. Practicum/Internship in DD (8 units)</p> <ul style="list-style-type: none"> • <u>HHS 311</u> (new USC UCEDD course) - Clinical and Community Services for Individuals with Neurodevelopmental Disabilities (4). Exposes students to professionals and careers in maternal child health and neurodevelopmental disabilities, and related services for those with neurodevelopmental and related disabilities. • <u>HHS 312</u> (new USC UCEDD course) - Internship in Developmental Disabilities (4). Supervised by experience services delivery settings, clinical or community-based, advocacy , and policy. 	

An Opportunity for UCEDD Leadership Development

The USC UCEDD Co-Director plans to develop the course, *Historical and Social Context of Disability* (HHS 310), in collaboration with a junior faculty person from the USC UCEDD who has an interest in I/DD and related disorders. Many of the USC UCEDD's young faculty are strong clinically but have limited experience teaching courses; therefore, this will provide an opportunity to assist the selected person to develop their academic and scholarship portfolio. The CSULA Dean has also offered the enrollment of this junior faculty person in CSULA's program, Center for Excellence in Teaching, which orients all new CSULA faculty in developing course syllabi, using technology in teaching, etc. – a resource not available through the USC UCEDD or CHLA.

Faculty and Student Exchange

The minority partnership opened doors for hands-on exposure for the USC UCEDD faculty and staff to understand the academic needs of students from underrepresented racial and ethnic populations and dispel myths about their capacity to succeed in advanced practice professions. After receiving the two minority pipeline grants, it was easier to recruit student audiences and faculty lecturers using “minority pipeline into the DD and Public Health fields” as the banner, which led to a significant increase in lectures and internships provided by USC UCEDD personnel for CSULA undergraduate students, through which students received information and experiences not previously available to them. Moreover, many of the lectures for HHS 395 were provided by USC UCEDD CA-LEND and Psychology interns and fellows, which provided a new opportunity for USC UCEDD graduate students to teach undergraduate students through formal courses. The USC UCEDD's graduate students had first-hand experience teaching undergraduate students which was not previously available to them. This was also true of their clinical staff (Masters and Ph.D. levels) that had limited teaching experience.

The combined advantage of the partnership came from the USC UCEDD and the resources of its institutional home, Children's Hospital of Los Angeles, and its academic home, the University of Southern California, providing CSULA students with exposure to careers in fields many were not aware of. Moreover, when graduate students participated in the teaching of CSULA undergraduate students, CSULA students were exposed to role models currently in graduate programs.

Infusing Culture & Tradition

The Grandparents Raising Grandchildren symposium featuring Dr. Susan Kelley, national expert and Dean at Georgia State University, is another successful example of the minority partnership which was arranged by CSULA, and attended by USC UCEDD faculty, students, and partner agencies. The event was infused with the culture and tradition of the minority communities served by the UCEDD.

Building Capacity

The success of the partnership in getting grants to allow for work beyond classroom teaching provided an avenue for CSULA faculty to build their research and publication portfolios and to engage in systems change activities, for which they have great expertise. These projects provided faculty with community experiences which informed their teaching.

Did the Partnerships Build Capacity for MSIs to Compete for UCEDD Funding?

SHLI operates like many UCEDDs; it is a university program largely funded through a mixture of research, demonstration, and service grants, in addition to charitable gifts from individuals, corporations, and foundations. Dr. Crimmins reports that if funding was available for UCEDD expansion, SHLI would have the capacity to put a competitive proposal together for funding. However, while the partnership raised the profile of disability at MSM, there is not yet an individual on the SHLI or MSM faculty who has devoted a significant portion of his or her career to developmental disability who would be considered a strong candidate to serve as UCEDD director. According to Dr. Crimmins, it would require more than the three-year joint partnership to develop this role, and would likely require a greater investment in time than the grant allowed.

Dean Yorker of CSULA reported that because the California State University System (23 campuses, of which CSULA is mid-sized) does not provide doctoral education except for the Doctor of Education (Ed.D.) and the Doctor of Nursing Practice (DNP), the possibility of becoming a UCEDD would not fit the mission of CSULA. However, the nature of the UCEDD's soft-money funding brought expertise in grant writing to the partnership. According to Dean Yorker, UCEDD's grant writing capacity is an invaluable asset to the MSI, which faces budget cutbacks from the State along with a commitment to keep tuition affordable. The USC UCEDD has built great capacity to increase the numbers of racially, ethnically and linguistically diverse professionals seeking a graduate career in fields that address the needs of the DD population through the partnership and other grants. The USC UCEDD expanded CSULA's undergraduate programs by introducing content on neurodevelopmental and related disabilities and exposed students to professions and careers in the neurodevelopmental and long-term care fields. The addition of UCEDD faculty to three of the core courses in the Minor has greatly enhanced CSULA's capacity for theory and clinical content and experience in DD.

Lessons Learned

The successes that were achieved through these partnerships included activities around the four core functions of the UCEDD: interdisciplinary trainings, community service, research, and dissemination. However this was an innovative partnership which meant that there would be lessons to learn. Overall, the partnering institutions learned the relevance in finding the right fit, building a relationship, collaborating and utilizing the strengths of those at the table, going deeper, and most importantly, understanding that roadblocks may cause detours but it's not the end of the road.

Find the Fit

Dr. Crimmins identified that SHLI operates much like many UCEDDs in that it is a grants-and-contract-funded center within a private medical school looking for opportunities that are aligned with their overall mission. SHLI's mission makes explicit reference to the ultimate elimination of health disparities with a particular focus on underserved communities. The addition of disability as a major focus of SHLI's work in leadership and policy was a natural extension of Dr. Satcher's long-term commitment to the resolution of health disparities. On the other hand, CSULA has a rich pool of undergraduate talent from diverse populations, which with appropriate support, may begin to populate the workforce in the DD field (e.g. service, policy, advocacy, research and administration). Dr. Wheeler spent a significant amount time getting to know the CSULA campus and meeting with key stakeholders. She studied their curriculum and faculty expertise to ensure that every possible avenue of engagement could occur during the grant period. In fact, many new ideas for moving students into graduate programs emerged.

"The MSIs' expertise in disparities, culture and tradition, along with the UCEDDs' expertise in disability and link to a national network provided a mechanism for a successful two-way partnership."

Commit to Building a True Relationship

A prolonged set of one-sided interactions will not lead to true partnership and collaboration. Time is required to build meaningful collaboration with each party - learning about what is important to the other organization, how each institution will benefit, how to use its assets for collaborative activity, and most importantly, being able to think outside the box. Meaningful collaboration also takes trust and getting to know people at a more personal level rather than treating the partnership as a series of business transactions, which does not guarantee trust and true caring for the welfare of the other organization. Sharing dollars is critical as is sharing responsibility for creating a joint product that is the best it can be.

Collaborate and Utilize the Strengths of those at the Table

Dr. Daniel Crimmins was the driving force behind the partnership of the Center for Leadership in Disability (CLD) at GSU, reaching out to colleagues at SHLI and MSM. However, having Dr. David Satcher affiliated with their work raised the visibility of the project. Dr. Satcher's leadership as the 16th Surgeon General of the United States in examining health disparities provided a specific call to action in addressing disparities experienced by individuals with disabilities.



In addition, Drs. Mitch Tepper and Yvonne Fry-Johnson from MSM each brought expertise to the partnership – Dr. Tepper in the area of sexual health and disability and Dr. Fry-Johnson in sickle cell disease, cultural competence, and the National Children's Study. Dr. Tepper collaborated with Dr. Crimmins at the onset of the partnership to develop a work scope that built on the skills of each organization, and outlined a common future agenda that addressed areas of critical need in Georgia. Dr. Sunny Onyeabor who was part of the initial cohort of GaLEND and also a faculty at MSM, was the instructor for the disability and disparity course in the MSM MPH program and also lectured regularly for the undergraduate disability epidemiology class at Morehouse

College. Furthermore, Ms. Stacey Ramirez of CLD brought expertise in person-centered planning and culturally-competent family support. Ms. Bethany Stevens of CLD came to the partnership from a sexual health fellowship at SHLI and served as liaison to SHLI throughout the project. Ultimately, they became a resource for each other on disability both within and between institutions for workshops, lectures, and presentations.

Likewise, Dr. Robert Jacobs, Dr. Barbara Wheeler, and the UCEDD faculty and staff worked diligently to ensure the success of the USC UCEDD/CHLA and CSULA partnership. CSULA's President Rosser, Provost Ashish Vaidya, Associate Provost Cheryl Ney, Dean Yorker and the faculty all commended and recognized the partnership as an integral way to achieving CSULA's strategic plan of student engagement, community engagement, and collaborative culture.

The USC UCEDD reported that Dean Yorker of CSULA's College of Health and Human Services was a quintessential collaborator who saw positive intent in everything the UCEDD did and opportunities with every proposal suggested. She is relayed as a strong advocate for her students and faculty who helped the project to navigate and find common working ground between two institutions with very different organizational cultures.

Go Deeper, Broaden the Scope, and Reach More

Among the numerous accomplishments of the partnerships was the number of future leaders that benefited from the partnerships. It is commendable to note that some of the efforts went further than developing programs for students currently enrolled in graduate programs.

The USC UCEDD/CSULA, for example, utilized the resources available to them as a result of the partnership to educate students on the availability of forgivable loans for practitioners who commit to work in medically under-served areas – helping students to consider graduate education. A better understanding of the scholarships and financial aid packages of USC is being explored for the minority pipeline students. This was valuable because one barrier to USC admission is the cost of a private university. Furthermore, they also helped guide CSULA students to the public university system in California and in other states.

Recognize that a Roadblock is Not the End of the Road

Collaborations that bring together diverse people, organizations, and sectors, such as the minority partnerships, can change the way communities conceptualize and solve problems⁶. However, a large contributor to such a successful collaboration comes from the ability to experience and maneuver together through challenges and roadblocks, including rigid administration and management. The partnering institutions shared some of the roadblocks they experienced and how they were resolved, or not, so others might learn and plan accordingly.

Marketing and Building Momentum

The FOA for the minority partnerships called for knowledge exchange and transfer between the institutions. For the USC UCEDD and CSULA partnership, the execution of this exchange was slow; partially because the first 18 months of the grant period was spent marketing topics to audiences to meet grant objectives. However, when they received the two minority pipeline grants, there was tangible reason for collaboration and clear mutual benefits to both institutions; this facilitated the knowledge exchange and transfer.

Institutional Factors

Inter-institutional partnerships by definition have multiple bureaucracies. The partnering institutions experienced multiple institutional hurdles such as difficulties in developing sub-award contracts, renewing contracts, receiving timely invoices, obtaining position clearances for human resources, and course approvals from departmental review committees.

Another element that presented a barrier for CLD was the cross-registration process. They wanted very much to have students participate in courses on the campus of the other program however the mechanism for cross-registration for Atlanta colleges and universities is difficult to access and also has very early deadlines. As an example, the deadline for cross-registration for the fall semester at MSM was only a day or two after the release of the fall schedule. Unfortunately, this meant that there was just not enough time to have GSU students register and participate in MSM courses.

Competing Demands

One barrier faced by the USC UCEDD and CSULA was negotiating differences in institutional culture between the two organizations. CSULA operated on an academic schedule of 3 quarters and a summer session with faculty who did not visit campus every day or were on break when students were on break. The USC UCEDD on the other hand is grant funded with a provision of clinical services on a year-round schedule. Someone from the CSULA faculty (Dean Yorker) had to commit to being available during semester breaks to meet grant deliverables and deadlines.

Budget

When CLD and SHLI conceptualized the project, they identified programmatic activities in each site that required roughly equal budgets; CLD retained somewhat more than half of the total funding to support the grant management responsibilities. In their initial discussion about budget, personnel from SHLI thought there would be greater institutional commitment if the project had a full community service indirect cost rate (approximately 28% at the time). This achieved a desired outcome of buy-in from institutional leadership, but it came at a cost of being able to afford less personnel time in support of the project and subsequently limiting the scope of the project.

Staff Involvement & Turnover

Building capacity at MSIs requires time for the development of individuals committed to disability issues, in terms of the focus of their work and ability to make meaningful contributions consistent with the priorities of the institution (i.e., research, teaching, service, external funding). Fractional proportions of positions at the MSIs (i.e. 20%) stood in contrast to most UCEDD staff who were 100% funded through varied sources that enabled them to maintain a focus on developmental disability. In addition, the partnerships had to withstand staff turnover where several key leaders from the MSIs left the project before its completion for various reasons.

Enacting and Maintaining Systems of Accountability

Increased accountability measures and extensive reporting under the grant, although necessary, were often times difficult to keep up with due to lack of resources and time. In some instances, meeting the grant objectives conflicted with the needs identified by each of the institutions. However, in light of the partnership structure and other challenges that arose, the UCEDDs and MSIs worked together to accomplish their successes and outcomes by sharing their resources and skills, and explored constructive solutions that went beyond the vision of each individual partner⁶.

Additional lessons learned by each partner are outlined on the following page in Table 3.

"The minority partnerships showed that there is great potential in partnerships that enable different people and organizations to support each other by leveraging, combining, and capitalizing on their complementary strengths and capabilities."

Table 3. Lessons Learned from the Minority Partnerships

CLD/GSU – SHLI/MSM Lessons Learned

The value and importance of:

1. Allowing time to develop relationships and positive rapport with the people necessary to make the partnership prosper.
2. Accepting and understanding ahead of time that things don't always work out as planned.
3. Understanding the need to run with changes, and be flexible when roadblocks or changes arise.
4. Aligning the mission and values to provide a great starting place (e.g. shared interest and focus on health equity, social justice, and cultural competence, which led to the sharing and expanding of networks as each partner included the other in their outreach activities).

USC UCEDD – CSULA Lessons Learned

The value and importance of:

1. Brokering relationships, handling conflict and resistance (including when to start in a new direction), and putting one's own agenda on the back burner for the sake of the greater partnership.
2. Defining what each partner is bringing to the table before entering into a sub-contract agreement.
3. Maintaining open lines of communication while growing and learning from conflict.
4. Forming a web of alliances at the partner institution, and bringing outside alliances to the table that mean something to the partner institution.
5. Sharing resources generously with the partner.
6. Sharing the credit given to the project with all involved.

The opportunities for overcoming challenges facilitated true collaboration as the partners developed strategies to incorporate needed supports and communication strategies, utilize their limited resources by sharing and allocating human resources, and welcome the additional expertise from new staff. The minority partnerships showed that there is great potential in partnerships that enable different people and organizations to support each other by leveraging, combining, and capitalizing on their complementary strengths and capabilities⁶.

Next Steps

Leaders of the Minority Partnership grants came to the project with unique and complementary areas of expertise, which through collaboration fostered comprehensive, practical, and transformative thinking⁶. Furthermore, all parties report that crucial elements that lead to successes for the minority partnerships were passion, focus, and a common goal to eliminate disparities in the lives of people with disabilities from diverse racial and ethnic backgrounds. However, recognizing that this partnership effort was only a starting point for reducing disparities, these institutions reported plans for continued collaboration.

Center for Leadership in Disability (CLD) at Georgia State University/ Satcher Health Leadership Institute (SHLI) at Morehouse School of Medicine (MSM)

CLD is the second UCEDD in Georgia and thus had the strategic priority to grow and move into areas of unmet need. They worked to strengthen the relationship between GSU and other institutions in the state, developing a relationship with a medical school that is also a HBCU, and developing a capacity to increase the diversity of the workforce through this relationship. Leaders of the CLD/GSU and SHLI/MSM partnership revealed that their three-year investment produced a long-term collaboration. They achieved their numeric targets in each year of the project for faculty exchange in providing lectures and workshops and the partners remain committed to a continued relationship. They are in the process of developing a Memorandum of Agreement (MOA) that specifies their joint commitment to collaborative research and program development. Their Second Century Initiative search committee also remains active in recruiting and vetting candidates to fill their three 2CI “cluster hire” tenure-track professor positions. The 2CI mandate requires that the new faculty individuals be appointed as senior associate or full professor level with significant commitments of external research funding. Dr. Satcher and the MSM faculty have cooperated with the search process, assisting in disseminating the position announcements, and offering to assist in interviews. They are hopeful that hire of the new 2CI faculty will provide a fruitful area of collaboration for the minority partnership.

University of Southern California UCEDD (USC UCEDD) at the Children’s Hospital of Los Angeles (CHLA)/ California State University, Los Angeles (CSULA)

The USC UCEDD and CSULA faculty and administrators believe that there is still great potential to expand their collaborative efforts. The success of their two minority pipeline grants has stimulated the CA-LEND and other graduate training programs to consider the critical role of minority pipeline programs into their respective fields. There is potential for collaboration with the Gerontological Institute at CSULA to address the USC UCEDD’s interest in tackling the major demographic shift of many aging caregivers from diverse cultures caring for adult children with I/DD. Their combined expertise could likely lead to new grant funding and needed information to help plan for the large mass of family caregivers who are aging. In addition, CSULA’s longstanding relationship with the Children’s Court and their newly built Forensics Institute is also a great source of potential collaboration for addressing the needs of individuals with disabilities in the juvenile and dependency court system, and prevention of dependent youth who “cross over” into delinquency. Parties report that over time, with continued collaboration, both of their institutional cultures will meld to a joint culture of robust partnership activity, with each of their institutions changing a little in the direction of their partner.

"Crucial elements that lead to successes for the minority partnerships were passion, focus, and a common goal to eliminate disparities in the lives of people with disabilities from diverse racial and ethnic backgrounds."

Recommendations

The minority partnership served not only to alert minority-serving institutions and UCEDDs of the value of collaboration to assist minority populations with disabilities, but a substantial goal was to “serve as catalysts and models.” Following are broad recommendations to guide future partners and provide principles and suggestions for future partnership development. Recommendations are provided for UCEDDs, for AIDD, and for AUCD Technical Assistance.

Recommendations to UCEDDs

1. Recruit team members who have a true passion and interest for the subject matter.
2. Maintain the shared foundation built on intersection of disabilities and health equity.
3. Maintain the diversity of expertise, interests, actual education, training and specialties of key faculty.
4. Form true collaborations between team members and incorporate collaborative efforts within various programs at each partner institution.
5. Adopt a shared commitment to a balanced partnership.
6. Ensure that complementary, independent, and joint goals and activities are specified in the partnership plan.
7. Capitalize on each individual’s particular strengths.
8. Maintain regular communication with partners.
9. Create effective systems of accountability between the partner universities.
10. Conduct regular review of activities and progress toward meeting partnership goals and objectives.
11. Showcase the desire and devotion to ensuring long-term sustainability.
12. Maintain a can-do mentality at all times.
13. Boast visionary, persistent, dedicated, and hands-on leadership that reminds each person involved how their combined work will benefit the community.
14. Develop coursework with the involvement of an academic department to deepen the possibility of collaboration.
15. Market specifically designed and developed coursework.
16. Use funding to create initiatives that support the minority population in the community and in their educational settings.
17. Commit to making sure that the students at the MSIs not only have the aptitude they need to enter into the healthcare field but also the necessary tools.
18. Provide financial support through projects and minority pipeline grants including multi-year financial support so students do not have to work but can focus entirely on building their research portfolio for graduate school.
19. Support students in writing, navigating graduate school, preparation for GREs, etc.
20. Create opportunities to leverage additional partnerships and funding (e.g. exploring resources from state MCHB funding opportunities).
21. Share resources with other universities not directly involved in the minority partnership.
22. Consider employing faculty and staff of diverse racial, ethnic, and linguistic backgrounds to expand the diversity of the UCEDD network and professionals who specialize in disability.

Additional recommendations that UCEDDs can do now to facilitate innovative partnerships with minority-serving institutions, with or without additional funding, are outlined below in Table 4.

Table 4. What UCEDDs Can Do Now – With or Without Additional Funding

- Obtain outside consultation on current status of partnership building with minority-serving institutions.
- Develop resources that are culturally and linguistically responsive.
- Research state demographics and ensure that UCEDD projects and outreach efforts directly align or respond to the demographics of the state.
- Diversify trainee programs by marketing to diverse populations. Tailor marketing and program materials to be culturally sensitive to language, design, and message¹⁰.
- Develop lines of communication with MSIs by inviting MSI faculty to serve as members on Community Advisory Councils (CACs), other advisory boards, ad hoc work groups, search committees, think tanks, or other natural and respectful ways to establish routine interaction. This provides the opportunity to reach out when funding becomes available for collaborative projects. The wrong time to reach out to establish a relationship is when funding is announced.
- Partner and engage with AUCD's Multicultural Council.
- Feature the respective institution through joint sponsorship of conferences.
- Facilitate scholarly exchanges through lectures or workshops on specific topics.
- Have "home" and "away" sessions for lecture series to put each organization in the position of serving as host.
- Engage in a mutually beneficial activity that requires both parties. Working together towards some tangible measurable outcome for a community or entity will build a true sense of collaboration.
- Take the time to observe, listen, ask questions, and learn from the MSI.
- Recruit pipeline opportunities in the MSI. This offers great benefit to both organizations.
- Spend time on collaborative grant writing that focuses on capacity building in the MSI. While it is labor intensive, if successful, it pays for the initial investment and allows for strengthening the partnership. It's also crucial that both parties contribute to the grant idea and its methodology, but divide up the work by building on each institution's strengths.
- Understand the power dynamics between the two organizations and be careful to establish equitable relationships.
- Encourage the establishment of clearly agreed-upon outcomes and deliverables with clear timelines and benchmarks to support accountability.
- Support joint appointments (with funding) in the respective institutions as such appointments would strengthen identification with the partnership.

Recommendations to AIDD

1. Consider restructuring the sub-award process so as to eliminate inefficient reporting that could potentially have a negative effect on the annual budget cycle.
2. Distribute the grants to the UCEDDs with sub-awards to the MSIs or to a Principal Investigator within an MSI who has developed a clear collaborative work scope with the UCEDD. Specifying how the money should be shared will assist in developing equilibrium.
3. Clearly delineate how each institution will be accountable for their respective scopes of work.
4. Consider employing faculty and experts of diverse racial, ethnic, and linguistic backgrounds within AIDD and AUCD to inform such programs and review proposals such as these.
5. Consider addressing inequities for individuals with DD and their families from underserved racial, ethnic, and linguistically diverse as a priority of Projects of National Significance (PNS).
6. Include on the trainee follow up survey a question that indicates the racial and ethnic demographics of individuals with disabilities they currently serve and in what location.
7. Consider the creation of a five-year follow-up of the Minority Partnership grants to see what the long-term sustainable benefits are.
8. Modify any future FOA of this type to possibly require an identified “champion” in the MSI, who will be supported at or more than 50% FTE for up to five years.
9. Outline a series of specific deliverables in the proposal that would demonstrate the expanding capacity of the MSI.
10. Add an additional objective to the minority partnerships that addresses issues of equity.
11. Focus a large portion of the methodology on evidence-based practices to build a meaningful relationship between the two institutions, not just measurable outcomes. The outcomes will emerge when there is a deep belief within the UCEDD and the MSI that each will be better for working together.
12. Consider a six-month planning period, or separate planning grants, to allow grantees to develop target goals and increase commitment to specific projects and activities between the partners organizations and allow for more time to define common interests and pursuits.
13. Provide flexibility for individuals to make structural changes in the scope of the work, if necessary, for the long-term success of the grant.
14. Establish long-term funding opportunities to allow these partnerships to create a UCEDD-like identity inside the MSI, with partnership goals and activities in all four core function areas.
15. Continue to encourage UCEDDs to facilitate broader institutional collaboration, such as co-sponsorship of programs and lectures.

Ways AUCD Technical Assistance Activities Can Support Minority Partnerships

1. Utilize UCEDD TA contract funds to provide a stipend for individuals from MSIs in partnerships with UCEDDs to attend the UCEDD Leadership Institute, and other leadership opportunities as they become available.
2. Facilitate a series of scheduled calls with AIDD and the partners of the MSIs to ensure that the MSIs feel like an equal partner in the collaboration and for AIDD to learn the perceptions of the partnerships, candidly, from both sides.
3. Facilitate a future joint call between the two grantees to discuss sustainability strategies.
4. Create an archive of resources from the partnership (e.g. materials, webinars) so that all future partnerships can use these materials to help build their own, including sharing syllabi and recommended reading lists on a web portal
5. Make available resources and videos that are currently available and designed for primary care providers working in underserved communities across the country (i.e. www.primarycareforall.org)

6. Ensure MSIs have easy access to AUCD’s Council on Research and Evaluation (CORE) resources.
7. Inform UCEDDs, in order to prepare for partnership building, about the strong history of MSIs and HCBUs, in order to ensure a deep understanding of the need for collaboration.
8. Promote and highlight efforts of the UCEDD network members to support minority partnerships. See <http://www.aucd.org/template/page.cfm?id=851> for additional resources.

Conclusion

In 2009, to promote diversity within the DD Network, as well as address health disparities experienced by minority populations, AIDD awarded three-year partnership grants to two UCEDDs – the Center for Leadership in Disability (CLD) at Georgia State University, and the University of Southern California UCEDD (USC UCEDD) at the Children’s Hospital of Los Angeles.

The foregoing report was developed in order to guide other UCEDDs and MSIs in following the examples of the two grantees by revealing strategies, highlighting accomplishments and outcomes of the projects, and identifying lessons learned as well as recommendations for UCEDDs, AIDD, and AUCD. The expectation is that by informing the network, leadership from all Centers will seek out similar opportunities to create academic and clinical programs for diverse students and the individuals they will go on to serve.

Through this grant, the partnerships have established a positive presence in the respective institutions, created new initiatives, and established new programs that have positively affected the participation of minority populations in disability and healthcare fields. The minority partnerships offered an opportunity to bring people from diverse populations into the disability field as collaborators and colleagues, which offers the potential for them to eventually enter the leadership ranks. UCEDD trainees who benefited from the UCEDDs exposure and additional professional development that resulted from the Minority Partnership grants may also pursue leadership roles. In addition, the partnerships allowed for the UCEDDs to expand the academic content of students and exposed many to career fields they were never aware of. These outcomes could potentially increase the numbers of racially, ethnically and linguistically diverse professionals seeking a graduate career in fields that address the needs of the DD population.

The multitude of accomplishments by the minority partnerships, although not without their challenges, has proven the positive impact such programs have on diversity in the field of developmental disabilities and healthcare now and in the future. However, in order for the program to continue to impact the diversity of the field of developmental disabilities, and eventually have a role in reducing health disparities in minority populations, the minority partnerships need to continue down the path of sustainability and be replicated in other universities and states. A significant number of lessons and recommendations are shared as a resource to the UCEDD network for such replication efforts.

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UCEDD Resource Center

A project of AUCD, in partnership with AIDD, to strengthen and support the network of UCEDDs



The Satcher Health Leadership Institute

