

Department of Development Services
Reduction of Disparities in Purchase of Service
Regional Center Funding Proposals (Fiscal Year 2016-17)

Regional Center(s): North Los Angeles County Regional Center

Regional Center Contact Name/Title: George Stevens, Executive Director

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I. PROPOSAL

Please attach the proposal for Fiscal Year 2016-17. Proposals must meet the criteria outlined in the application guidelines in Attachment 1. Proposals must also be consistent with information derived from public meetings with stakeholders regarding purchase of service (POS) disparity data. Regional centers may partner with other centers to implement strategies to address areas of disparity in POS authorization, utilization and expenditures.

II. BUDGET DETAIL

a. Amount of funding the regional center(s) is requesting: \$1,108,584.00

b. Estimated number of consumers to be impacted by the service(s): 6,000+

III. DIRECTOR'S CERTIFICATION

I certify that the information completed above and attached is true and correct.

Director's Name: George Stevens, Executive Director

Director's Signature:

A handwritten signature in black ink, appearing to read "George Stevens", is written over a horizontal line.

**PROPOSAL TO REQUEST FUNDING TO REDUCE DISPARITIES IN
PURCHASE OF SERVICE FOR FISCAL YEAR 2016-17**

Submitted by North Los Angeles County Regional Center

September 8, 2016

Description of NLACRC's POS disparities

NLACRC's FY 2014-15 POS disparity data for per capita expenses by ethnicity/race for all ages indicates that the top three ethnic groups with the highest rate of per capita expenses for all NLACRC consumers by Ethnicity/Race for All Ages are the White, Asian and Polynesian populations, with Hispanic or Latino being near the lowest for per capita expenses, even though they are one of the largest populations that we serve.

While the variance in the amount spent may appear to be the result of purchase of service disparities, differences in spending might be influenced by many other factors including but not limited to socioeconomic status, language and societal barriers, cultural preferences, educational level, geographic location, living situation, and individual needs and choices of the consumer and family.

Further research is needed to identify the underlying reasons for variances in utilization of regional center-funded services by different ethnic/racial groups.

Target population

Despite the fact that the reasons for POS disparities is unclear, there is evidence in our community that indicate the need to provide more support to the Hispanic or Latino populations which appear to be underserved.

In 2012, a survey was conducted with over 100 Latino mothers who have children with autism, many of whom are Regional Center consumers. While the mothers appreciated Regional Center services, they identified multiple barriers personally encountered in obtaining assistance for their children including psychosocial, economic, political and healthcare factors. Underserved populations often encounter language and societal barriers (immigration, medical, poverty, lack of food and adequate shelter), which prevents them from utilizing services.

NLACRC will provide education, resources, and information primarily to our Hispanic and Latino populations, which are amongst our largest and fastest growing underserved groups.

Brief summary of public forums

Three public meetings were held on August 26th, August 30th and September 1st with executive director George Stevens conducting the meetings. The POS Disparity public forums were combined with our Performance Contract Public Meetings. The end of August or beginning of September is the time of year that NLACRC typically schedules its performance contract

meetings. It was felt that there would be less confusion to schedule to discuss both the Performance Contract and POS funding proposal in one meeting.

The public meetings were promoted via e-mail blasts to consumers, family members, service providers and NLACRC staff that were sent on August 19th, August 24th and August 28th of 2016. Information was also posted on our web site on August 19th.

Cultivar y Crecer Parent Support Group – The first public meeting was held as part of the Cultivar y Crecer parent support group meeting for Spanish-speaking parents on Friday, August 26th at 6:30 p.m. Twenty-eight people attended the meeting.

One parent voiced her concerns about the quality of services being provided and it was explained to her that the rates paid to providers makes it difficult for providers to hire staff at more than minimum wage, which results in high turnover.

The group members responded very positively to the idea of receiving training on how to become effective legislative advocates. They were informed about a Candidates Forum that will take place on October 18th at New Horizons in North Hills where they will have the opportunity to hear the views of legislative candidates who are running for State Senate seats in the November election.

Two additional public meetings were held at our Lancaster office on August 30th and at our Van Nuys office on September 1st from 6:30 to 8:00 p.m. One person attended the Lancaster meeting and four people attended the Van Nuys meeting. One individual expressed her support of the Family Empowerment Team in Action (FETA) as it would involve going out into the community to reach our underserved rather than waiting for people to come to NLACRC to seek help.

For the Education Advocate it was suggested that rather than hiring a staff person we might want to consider working with education advocacy vendors.

One individual who attended the public meeting on September 1st also submitted written comments (to be included with Performance Contract Public Meeting report).

Recommendations to reduce service disparities

NLACRC will utilize several different approaches to help better meet the needs of the underserved Hispanic or Latino populations. We feel that other populations we serve may benefit as well.

NLACRC requests funding for the following projects:

1. Statewide POS Disparities Research Project through Children's University Hospital

2. Family Empowerment Team in Action (“FETA”) in collaboration with California State University Northridge (“CSUN”)
3. Community and Legislative Educator consultant
4. Education Advocate
5. Funding of bilingual pay for bilingual service coordinators
6. Social media outreach

1. STATEWIDE POS DISPARITIES RESEARCH PROJECT

NLACRC is in support of the Statewide POS Disparities Research Project and requests DDS’ consideration for full funding. Please see the document “Understanding Barriers and Implementing Effective Strategies to address Disparities in Service Among Californians with Developmental Disabilities” (Attachment A).

2. FAMILY EMPOWERMENT TEAM IN ACTION (“FETA”)

Plan or service to be delivered

The objective of FETA is to develop a responsive team of two social work master level interns and a supervising faculty member from California State University Northridge (“CSUN”). The FETA will address challenges that prevent families from accessing and utilizing Regional Center services.

How plan or service will be delivered

FETA will address core challenges by helping families meet their basic needs including accessing health care and mental health care for parent, applying for Medi-Cal, securing low-income housing, accessing legal advice for housing issues and family law, obtaining information about family planning, getting employment assistance, locating quality child care for client’s siblings, assisting with immigration problems and assistance, locating food banks and securing food and improving parent/client relationship.

Vendor training - A cultural sensitivity training curriculum will be developed by CSUN faculty members and delivered to Regional Center vendors.

Advocacy training – The empowerment coordinator and three advocates will develop curriculum and set up ongoing training in all valleys to assist with Regional Center consumers’ educational services. Student assistants will assist in developing curriculum, contacting families, and facilitating families attending the training.

Anticipated duration of plan or service

FETA is a three-year program. In the first year, the team will consist of two MA social work

interns, a lead coordinator, a professor in the Department of Social Work, a FETA coordinator and NLACRC personnel. In the second year, the number of interns will double to four and in year three, another supervising faculty member and 4 interns will be added. The social work interns will be fluent in Spanish (written and conversation) and they will work 20 hours per week.

Anticipated costs

The anticipated costs are as follows (See Attachment B for breakdown):

2016-17: \$136,482.00

2017-18: \$141,870.00

2018-19: \$197,823.00

Total request for three years: \$476,174.00

Criteria to be used to evaluate and monitor effectiveness of the plan and/or service(s)

The CSUN Institute for Community Health and Wellbeing (“ICHWB”) will utilize the FETA and some of the families served to develop evaluation criteria. The ICHWB team will be responsible for collecting data. The ICHWB will provide the FETA with program feedback and the NLACRC Executive Team with a yearly program evaluation report.

1. Any criteria that will be used to evaluate and monitor the effectiveness of the plan and/or service(s).

The effectiveness of the FETA program will be evaluated using both qualitative and quantitative methods driven by two sets of research questions:

1) FETA program clients: What are the experiences that FETA program clients have had with the program? How have they benefited from their involvement with FETA case management, resources, and staff? Which of their needs have been addressed? In what ways might FETA work to address unmet needs?

2) FETA case managers, student interns, and other staff: What are the experiences that FETA case managers, students, and other staff have had working with the program? How have they benefited from their involvement with the FETA program? What are the specific challenges that FETA case managers, students, and other staff have encountered in working with FETA?

Research design

I. Sample

To examine these questions, the evaluation will investigate the experiences of two groups of FETA participants: 1) FETA clients; and, 2) FETA staff.

We anticipate that with the cooperation of NLACRC directors and the FETA team that there will be approximately 20 FETA clients included in the evaluation. These clients will be recruited from those served by current FETA case management teams. Additionally, we also expect 7-10 FETA staff to be included in the sample.

II. Data Sources

Evaluation data will be collected using two primary methods: focus-groups and self-administered questionnaires. All data will be collected by trained research staff who have successfully completed human subjects research ethics training.

FETA clients: Evaluation data from FETA clients will be collected using focus group and/or individual interviews, and self-administered questionnaires. The first phase of this process will be to conduct interviews with existing FETA clients. The purpose of the focus groups will be to collect verbatim testimonial data from clients about their experiences with the program, to examine which of their needs are currently being met by FETA services, and where there may be areas for further development. In order to achieve the greatest rate of participation, and to minimize the amount of disruption to client schedules, every effort will be made to conduct these interviews during pre-established group meetings.

Members of the research team will meet with groups of clients during their regularly scheduled group meetings. In order to provide a safe and confidential space for discussion, group facilitators or other FETA and NLACRC staff will not be present during the interview sessions. With permission of the participants, interviews will be audio-recorded and transcribed in order to collect accurate testimonial data from clients. As needed, these interviews will be conducted in both English and Spanish, with Spanish transcripts translated into English for analysis.

The second phase of data collection from clients will be conducted using self-administered questionnaires. The purpose of the questionnaire data will be to collect more refined information about client experiences and needs. Specific emphasis will be placed on the effectiveness of FETA's individual services in areas related to those outlined by the NCI Child Family Survey. These areas include: services and supports received by children and families; information and planning for services and supports; access and support delivery; choice and control in the services and supports received; community connections; satisfaction with the receipt of supports; and, the positive difference made in the lives of families. These questionnaires will be administered in paper form and, as needed online using encrypted Qualtrics software, and in both English and Spanish. The contents of questionnaires will also focus on key areas of interest and concern derived from participant responses during the interviews, and in consultation with NLACRC (e.g., quality of life, family stress, etc.).

FETA Case Managers, Student Interns, and Staff:

Evaluation data from FETA staff will be collected using focus group and individual interviews. The purpose of these interviews will be to collect descriptive data from staff about their experiences and perceptions working with FETA, and to examine the challenges they have encountered as a member of the FETA team. In order to achieve the greatest rate of participation, and to minimize the amount of disruption to FETA staff schedules, members of the research team will meet with the FETA staff during regularly scheduled staff meetings. As with the client interviews, staff interviews will be audio-recorded and transcribed, with permission, in order to collect accurate testimonial data. As needed, interviews will be conducted in both English and Spanish.

Plan or service(s) implementation and contracts to be executed

NLACRC will execute a contract with California State University Northridge ("CSUN") that will be for a three-year period as soon as we know the results of our funding request.

Process for maintaining records, collecting data, and tracking qualitative and quantitative outcomes.

Raw data being collected for this project includes the use of standardized measures, and qualitative testimonials. Quantitative data will be input and analyzed using Statistical Package for the Social Sciences ("SPSS"). Value labels and variable names created in SPSS will be used as the codebook. Qualitative focus groups and interviews will be transcribed and coded for themes.

Approval from the CSUN Institutional Review Board (IRB) for the Protection of Human Subjects will occur prior to beginning the project. Consent for participation will be received prior to data collection or involvement in the research study. IRB approval includes provisions for appropriate protection of voluntary participation, privacy, confidentiality, security, and de-identification of personally identifiable information of human subjects. Specifically, all identifiable data will be stored on password protected computers or cloud servers, or in a locked filing cabinet in the primary investigator's locked faculty office on the CSUN campus. All identifiable information that will be collected will be removed and replaced with a code. Once de-identified, identifiable data will be stored in this way for 2 years after the completion of the research project. A list linking the code and participants' identifiable information will be kept separate from the research data. Only the members of the evaluation team will have access to the codes linking responses to participants' names.

The de-identified data will be stored in a secure location in a filing cabinet or password-protected computer in the primary investigator's locked faculty office on the CSUN campus, and separate from identifiable data. A list linking identifiable data and participant number will be

also stored in a secure location in a filing cabinet in the primary investigator's locked faculty office on the CSUN campus, separate from all other data.

Qualitative Analysis:

The analysis of focus groups and individual interviews will be conducted in the following steps:

- a) Interviews will be translated (if necessary) and transcribed.
- b) Next, transcriptions will be reviewed for common themes using analytic note taking, and "bucketing" of common responses.
- c) Similar responses will be aggregated along common themes.
- d) Excerpt-commentary units will be generated in preparation for analysis and reporting.

Quantitative Statistical Analyses:

Data will be coded, compiled, and analyzed using the software Statistical Package for the Social Sciences, Version 22 (SPSS). Data will be cleaned and missing data treated through missing value analysis and replacement. A de-identified, anonymized data-set will be created and compiled for analysis.

3. COMMUNITY AND LEGISLATIVE EDUCATOR

Plan or service to be delivered

The Community and Legislative Educator will provide training to consumers and families to further empower and engage consumers and their families in the legislative arena.

Workshops will provide extensive training in the art and practice of effective advocacy. As a result, NLACRC will grow an active network of advocates who will be ready, willing, and able to represent the interests of the developmental disability community in public meetings, in print media and in direct meetings with elected officials and policy makers.

Workshops will provide a supportive small group environment where individuals will learn the history of the Lanterman Act movement and recognize that only citizen action can preserve and protect the rights that Californians with developmental disabilities enjoy.

With instruction, guidance and mentoring, participants will develop the knowledge, skills, and confidence to communicate and advocate on behalf of themselves and the larger disability community.

The Educator will provide workshops to underrepresented communities to increase understanding of the regional center system the IFSP/IPP process, how to identify needs, and effective problem solving.

The Educator will work with NLACRC to cultivate and maintain positive working relationships with State and local officials through events such as grassroots activities, Candidates Forums, and routine contacts between executive leadership and local district offices.

How plan or service will be delivered

Two-hour workshops will be offered each quarter providing direct face-to-face education and mentoring for consumers, family members and other community stakeholders who wish to become actively engaged and effective spokespersons for themselves or for their family members.

Potential advocates will be recruited to represent underserved regional center populations. Workshop presentations and materials for Spanish speaking and other non-native English speaking audiences will be developed and existing Spanish speaking advocates will be recruited to participate in presentations.

The instructional topics and overall learning outcomes are similar for both consumers and for family/community members. However, the specific materials and instructional methods are customized to be appropriate and effective for each audience.

Educational workshops will be offered for families in underserved communities to increase understanding of the regional center system, IFSP/IPP process, identifying needs and effective problem solving.

The Educator is also currently working with NLACRC to organize two Candidates Forums that are scheduled for October 6th in the Santa Clarita Valley and October 18th in the San Fernando Valley.

Anticipated duration of plan or service

Duration of the project is for a one-year period from August 2016 through August 2017. The consultant position will be evaluated by NLACRC after one year to determine if there is a desire to continue for a second year.

Anticipated cost

Total projected Annual cost in the amount of \$83,200.00.

Criteria to be used to evaluate and monitor effectiveness of the plan and/or service(s)

1. A minimum of 200 families and or consumers falling within the definition of underserved will receive written information and education addressing their rights to services and supports in Spanish and in “family/consumer friendly language”.

NLACRC will identify families and consumers meeting underserved criteria and will produce and disseminate a “bulletin” providing a basic primer on how to work effectively with the regional

center to receive the services you need. The Bulletin will also announce availability of “hands on” workshops that will teach the tools to be effective advocates.

NLACRC will maintain a documentation record of total families and consumers who receive the published bulletin.

2. A minimum of 60 family members and or consumers falling within the definition of underserved will participate in Advocacy Workshops. The workshops and materials will be provided in Spanish and in family/consumer friendly language.

NLACRC will maintain a documentation record of total number of families and consumers who participate in workshops.

3. As a result of workshop participation a minimum of 45 participants will improve their understanding of the system and indicate an increased level of confidence in advocating for services they believe are important for themselves or their family member.

Plan or service(s) implementation and contracts to be executed

A contract has been executed with Steve Miller and Michelle Heid as the consultants. Service implementation began as of August 10, 2016 and will end August 30, 2017.

Process for maintaining records, collecting data, and tracking qualitative and quantitative outcomes.

All workshop participants will take a pre-test assessing their current level of understanding of their rights under the Lanterman Act and the importance of advocacy within the system and with elected officials. At the conclusion of the workshop participants will retake the test. It is expected that all participants will demonstrate increased knowledge and willingness to utilize the information they have learned.

NLACRC will maintain copies of participant pre and post-tests and statistical summary of results.

4. EDUCATION ADVOCATE

Plan or service to be delivered

One of the greatest challenges for many NLACRC families and especially those who are monolingual in Spanish, is knowing how to advocate for themselves in the education system. NLACRC will hire an Education Advocate who can assist families when they are experiencing difficulty getting services and support that they need from the schools.

How plan or service will be delivered

The Educational Advocate provides consultation and training to case management staff on

consumers' educational issues, educational advocacy services, mediation or hearing management on related service issues. Educates consumers and families on due process rights and participates in due process. This would be an ongoing position as it is essential to families and our growing population.

1. Responds to staff requests for educational advocacy consultation, reviews files and researches applicable laws, statutes, and court decisions, identifies issues, develops advocacy strategies, advises and/or trains staff on effective IEP participation. When appropriate, directly advocates with schools and school districts. Coordinates use of contract educational advocate services, oversees work produced by contractors.
2. Researches assigned cases prior to mediation or hearings. Reviews laws, statutes, legal decisions, reviews case decisions, makes recommendations on actions. May assist witnesses in preparation of testimony, present testimony or conduct the agency's portion of the hearing.
3. Creates and develops working relationship with schools and school districts. Attends SELPA and other education meetings, identifies issues, proposes actions, implements approved plans.
4. Provides group and individual advocacy training for staff, consumers, families, and others.
5. Hires, trains, directs, and evaluates assigned staff. May provide support to committees of the Board of Trustees.
6. Responds to Fair Hearing requests and Welfare and Institutions Code Section 4731 complaints for consumers with low POS expenditure, including educating consumers and families on due process rights, researching/investigating cases and allegations, preparing hearing and due process materials, communicating with outside legal counsel, representing NLACRC at informal meetings, mediations, and hearings, as needed.
7. Responds to other due process requests as needed.

Anticipated duration

This will be an ongoing position contingent upon funding availability.

Anticipated cost

Salary for one Education Advocate for one year is \$107,760.

Criteria to be used to evaluate and monitor effectiveness of the plan and/or service(s)

NLACRC will identify underserved families who are in the most need of assistance and determine the types of educational issues that impact them the most. Desired outcomes will be documented as well as a follow up assessment to monitor if outcomes have been met.

Plan or service(s) implementation and contracts to be executed with vendors

Service implementation will begin contingent upon the availability of funding. NLACRC may want to hire a vendor who provides educational advocacy services depending upon whether or not we are able to find a qualified candidate to fill the Education Advocate position.

Process for maintaining records, collecting data, and tracking qualitative and quantitative outcomes

NLACRC will develop tools to assess pre- and post-competency knowledge of educational advocacy for underserved families. The results from these assessments will be analyzed to determine the effectiveness of the educational advocacy services provided.

5. BILINGUAL PAY

Plan or service to be delivered

In order to provide services and support more effectively to our consumers and families, NLACRC has provided bilingual pay to those job classifications that regularly interact with our community e.g. service coordinators, administrative support, etc. Additional funding would allow NLACRC to redirect the funds we are currently expending to hire additional service coordinators to reduce our caseload ratios, which will allow us to better serve our underserved community.

How plan or service will be delivered

Once NLACRC receives the funding for the OPS funding that we expend on bilingual pay, we will re-direct those monies to hire more service coordinators. The number of service coordinators hired will depend on the funding we received.

Anticipated duration of plan or service

Bilingual pay is provided to designated positions and as such they are regular positions.

Anticipated cost

For FY16/17, NLACRC is projected to expend \$365,400 to fund bilingual pay. If NLACRC receives these additional monies, it will allow NLACRC redirect those funds to hire approximately 5 additional service coordinators.

Criteria to be used to evaluate and monitor effectiveness of the plan and/or service(s)

Hiring additional bilingual service coordinators will allow NLACRC to reduce caseloads and be able to more effectively address the needs of consumers and families. NLACRC is currently researching the possibility of utilizing a phone survey where consumers or family members would receive a phone call shortly after an IPP to ask for feedback after the IPP meeting has taken place.

Plan or service(s) implementation and contracts to be executed

NLACRC would begin the hiring process as soon as funding is available.

Process for maintaining records, collecting data, and tracking qualitative and quantitative outcomes

Data would be collected utilizing the phone survey as mentioned above or a similar method to determine if the consumer's and family's needs are being met as well as to be able to follow up on any concerns that might arise.

6. SOCIAL MEDIA OUTREACH

Plan or service to be delivered

NLACRC has hired a social media consultant, RG Pacific ("RGP"), to help us utilize social media tools such as Facebook in order to reach more diverse audiences by promoting events such as our upcoming Candidates Forums on October 6th and 18th, and to share information and resources.

RGP responded to a Request for Proposal and was selected as NLACRC's social media consultant. RGP has extensive knowledge and experience in social media and marketing, having worked with governmental, nonprofit and private entities. RGP also has the ability to help us post bilingual announcements in Spanish on social media.

How plan or service will be delivered

RGP has created a Facebook page for NLACRC that we are just beginning to use to post events and information. RGP is assisting us with developing a monthly posting plan and providing us with guidance on the most effective types of posts to attract followers.

Other services to be delivered include integrating social media with the NLACRC web site and e-mail marketing. By incorporating Google Analytics on the NLACRC web site, they can help us determine who visits the web site and content that interests people the most.

RGP will soon begin to provide a monthly report that includes a campaign overview, performance, costs and Return on Investment, e-mail open rates and clicks. Reports will demonstrate progress and how marketing efforts affect web site traffic.

Data will be analyzed each month to find new sources of traffic and RGP will modify their strategy accordingly. The reports can also help determine if the audience responds better to posts in their native language. RGP's team is equipped to provide posts in Spanish to reach the Latino and Hispanic individuals that NLACRC served.

Anticipated duration of plan or service

Duration of the service is for one year which began on June 1, 2016 and will end on June 30, 2017. NLACRC will evaluate the performance after one year to determine if services will be retained in 2017-18.

Anticipated cost

The projected annual cost of the contract is in the amount of \$76,050.00.

Criteria to be used to evaluate and monitor effectiveness of the plan and/or service(s)

If the consultant's services are effective, we should see an increase each month in Facebook followers and web site visitors, and an increase in attendance at our events.

Plan or service(s) implementation and contracts to be executed

A contract was executed with RGP in June 2016.

Process for maintaining records, collecting data, and tracking qualitative and quantitative outcomes.

RGP will be responsible for maintaining records and collecting data utilizing analytic tools related to visitorship and other trends on our Facebook page. NLACRC will work closely with RGP to track qualitative and quantitative outcomes as they relate to Facebook activity, web site visitors, e-mail marketing, etc.

SUMMARY OF FUNDING REQUEST

PROJECT	DURATION	AMOUNT REQUESTED
Family Empowerment Team In Action (FETA) with CSUN	Three-year project	\$ 476,174.00
Community & Legislative Educator Consultant	One year	\$ 83,200.00
Education Advocate	One year	\$ 107,760.00
Bilingual Pay for Service Coordinators	Ongoing	\$ 365,400.00
Social media outreach	One year	\$ 76,050.00
TOTAL AMOUNT REQUESTED		\$1,108,584.00

If you have questions about this proposal, please feel free to contact George Stevens, NLACRC Executive Director, at (818) 756-6200.

**Understanding Barriers and Implementing Effective Strategies to Address Disparities
in Service among Californians with Developmental Disabilities**

California is both the most populous state in the nation and the most ethnically, racially, and culturally diverse. Ensuring all Californians can access services to which they are entitled, in sensitive and responsive settings, is both current policy and an ethical imperative. In spite of investment in addressing, and prominent attention paid to, racial and ethnic health care disparities, differences still exist across multiple domains in the United States, including access to care, use of services, health status, and quality of care. Data from the Centers for Disease Control continue to show national disparities in early diagnosis of autism and treatment by race and ethnicity. California is no exception.

The purpose of this three year grant is to identify and understand the barriers to service access and utilization, tailor effective strategies to address those barriers, and implement strategies that optimize access to, and utilization of, regional center services across racial and ethnic groups.

Statewide Disparities

Using existing data, regional centers' services to individuals from diverse communities can be examined by exploring three distinct sets of statistics: 1) Access to Care, by comparison of the ethnicity of individuals served by regional centers and the population as a whole; 2) Funding Disparities, by an assessment of the amount of money regional centers spend on individuals in different ethnic groups; and, 3) Service Use Rates, by an examination of the percentage of individuals, by ethnicity, who receive no funded services.

Access to Care

The following is a chart comparing estimates from the United States Census Bureau's breakdown of California ethnic groups as of July 2015 and the ethnic breakdown of Lanterman Act-eligible individuals supported by regional centers as of June 30, 2015.^{i, ii}

Ethnicity	US Census Bureau Estimate	CDER Data
Asian (including Filipino)	14.7%	8.97%
Black/African American	6.5%	9.76%
Hispanic	38.8%	36.15%
Native American	1.7%	0.37%
Polynesian/Pacific Islander	0.4%	0.23%
White	38.0%	35.55%
Other/ Multi-Cultural		8.97%

While not a perfect comparison, because the Census data sorts all populations into six categories, while approximately 9% of individuals supported by regional centers have an ethnicity classified as "other," important conclusions can be drawn. Most notably, individuals from Asian and Native American communities are underrepresented in active regional center cases.

Funding Disparities

According to DDS data, in Fiscal Year 2014-15 the average amount spent statewide per individual with a developmental disability on regional center-funded services was approximately \$12,500. For Caucasians, per person spending was \$18,412, compared to \$8,452 for Hispanics, \$14,479 for African Americans, and \$10,711 for Asians. For this time period, all regional centers reported that fewer funds were expended per capita on Hispanic individuals than Caucasian individuals, and fourteen also reported spending more on Caucasians than Asians.ⁱⁱⁱ

A closer examination of the statewide data reveals that expenditure patterns by ethnicity change with age. For instance, while per capita spending for all groups increased between school-age and adulthood, the rate of increases for different ethnicities is not uniform. These trends suggest a complex interrelationship between age, ethnicity, utilization of paid regional center supports, and other factors.

Service Use Rates

Approximately 20% of individuals statewide who have an active case with a regional center do not access regional center funded services in any given year. For Fiscal Year 2014-15, this percentage ranged from a low of 16% for Other ethnicities to a high of 26% for Polynesians.^{iv} A quick examination of regional center POS data suggests these broad percentages are not consistent across age groups. More detailed analysis could determine whether this is the product of unmet needs for certain age groups or is more reflective of needs being met through other sources (*i.e.*, school).

Target Populations

All twenty-one regional centers support the funding of this grant to better understand and implement effective strategies to address barriers to access and service utilization. The target population is individuals statewide who are members of ethnic and racial groups with unmet needs related to their own or their family members' developmental disabilities. DDS data suggests that statewide, individuals who are not Caucasian access, on average, fewer paid supports through regional centers. Unanswered questions related to this include:

- Is family income, ethnicity, or limited English proficiency (also known as “linguistic isolation”)^v the better predictor of the level of regional center-funded services that an individual will access?
- Are there differences in care-seeking behavior due to differing cultural beliefs and preferences?
- Does personal or family choice drive the level of regional center funded services that are accessed?
- Are there inequities prevalent in the developmental disabilities services system based on a lack of culturally competent services, linguistic barriers, socioeconomic, access to other community resources, or other factors that in some way limit access to services and negatively impact utilization of services?
- Why are expenditure patterns different between different ethnic groups when examining them by age group?

Even when controlling for other factors, ethnic disparities exist in the utilization of healthcare and social services. Regional centers have been grappling with the issue of access and utilization of purchased services for more than twenty-five years. In that time, it has become apparent that the issue is an incredibly complex one, influenced by ethnicity, race and culture, socioeconomic status, language barriers, and education levels. Literature and studies indicate the complex nature of the issue:

- A study in 2002 found that differences in service delivery were attributable to age, individual characteristics, and residential setting.^{vi} This sentiment was echoed in a report from the Department of Developmental Services (DDS) to the Legislature in 2003^{vii}.
- Several analyses of the issue have pointed to challenges associated with poverty as well as limited English proficiency and literacy as larger determinants of access to services.
- A 2014 national study examining healthcare disparities in adults with intellectual and developmental disabilities noted that “[even] when income, health insurance, and access to care are accounted for, disparities remain.” A limitation of that study was the inability to draw causal conclusions between ethnicity and health care utilization.^{viii}
- A 2016 study examining differences in regional center expenditures for individuals diagnosed with Autism Spectrum Disorder across demographic categories notes the state’s lack of comprehensive information on family income and other public or private benefits individuals receive.^{ix}

Summary of Public Forums

SG/PRC held its public forum on this topic on Tuesday, August 23, 2016. Approximately 15 people were in attendance. At that meeting Carol Tomblin, SG/PRC’s Director of Compliance and Outreach, presented participants with a description of the proposed project, in addition to other ideas for addressing differences in utilization at the local level.

Additionally, thirteen other regional centers presented the concept to their respective communities at a variety of stakeholder meetings held throughout the state between August 22, 2016, and September 8, 2016.

Separately, the premise of the study was presented at all four DDS-hosted meetings throughout the state in August 2016. At these meetings, DDS noted that a predominant strategy identified by regional centers over time at meetings on similar topics was the need to “create focus groups within specified ethnic communities to learn more about individual challenges they face in accessing services.”

Particularly at the meeting held in Los Angeles on August 26, 2016, audience members reiterated support for the concept of a research study to better inform future strategies. In addition, the need to better understand the reasons for underutilization of regional center services and the need for a study were raised at the three additional DDS stakeholder meetings.

Recommendations to Reduce Service Disparities

SG/PRC is requesting funding from DDS for a three-year project that will identify the underlying reasons for variances in utilization of regional center-funded services by different ethnic/racial groups and recommend systemic solutions for ameliorating this. Additionally, using information garnered from the data, each regional center will work through its staff and Cultural Specialist to implement effective strategies at the local level.

As noted above, there are several unanswered questions related to the impact of ethnicity and other factors on utilization of regional center-funded services. SG/PRC recommends conducting an intensive three year research project while simultaneously funding support for local regional centers' staff and Cultural Specialists. On a flow basis, as data becomes available, it will be used to immediately inform the work of the regional center and the Cultural Specialists as they seek to ensure equal access to needed services by diverse communities.

SG/PRC intends to contract with the Association of Regional Center Agencies (ARCA) to carry out this work. ARCA represents the network of all twenty-one non-profit regional centers that coordinate services for, and advocate on behalf of, California's nearly 300,000 people with developmental disabilities.

Strategy for Implementation

Regional centers throughout the state implement practices encouraged by the National Standards for Culturally and Linguistically Appropriate Services (CLAS), including:

- Ensuring that the workforce and governing board is representative of the community;
- Training the workforce and governing board on cultural and linguistic competence;
- Providing language assistance to non-English-speaking individuals and families, including ensuring that information is communicated with as little jargon as possible; and,
- Partnering with community organizations to ensure cultural and linguistic competency. ^{x, xi}

Some regional centers have done additional innovative work in this area for some time, such as the *Promotora* project through Frank D. Lanterman Regional Center, and the Stanford Design School projects completed by both Golden Gate and San Andreas Regional Centers.

In Fiscal Year 2016-17 each regional center was provided with funding for a Cultural Specialist to work within their area to enhance the services for individuals and families from diverse communities. Under the guidance of a steering committee, ARCA will provide staff and research support to the twenty-one regional centers' staff and Cultural Specialists in this area. For the research and data analysis components of the three-year project, ARCA will subcontract with Children's Hospital Los Angeles (CHLA). CHLA staff have been identified as well-suited to this work (see attachments).

Cultural Specialists will utilize the information provided through these various avenues to inform their efforts to make the services provided at the local level more responsive to the needs of individuals from diverse communities. One example of the type of local change that can be made comes from a listening

project that was undertaken at SG/PRC last year. Families explained that they only felt comfortable with respite workers from their same ethnic background, who are in limited supply and often reserved in advance. As respite was authorized in monthly increments, scheduling time with the preferred worker was difficult and available services were not utilized. In response to understanding the specific barrier to service, SG/PRC was able to successfully address this barrier at the local level by shifting to quarterly respite authorizations.

YEAR 1

In the first year of the project, CHLA will develop twenty-one individual community profiles to assist the regional centers' work while an in-depth systemic examination of this issue is undertaken. Profile creation will be based on existing data, but also informed by each center's locally-known issues, obtained via one-on-one interviews with the directors of each regional center and key personnel.

With these community profiles, cultural specialists will be immediately able to better reach specific unserved and underserved populations in their areas. For example, one regional center noted underrepresentation of Native Americans in its Early Start program. In an effort to better serve this population, the regional center identified tribal leaders in its catchment area and began work with them and Public Health Nurses to increase participation of this population in Early Start.

These profiles will be created from regional center service data and publicly-available information. Service data includes services provided, demographics of individuals with developmental disabilities (including primary language), National Core Indicators data, available indicators regarding family income (*i.e.*, Medi-Cal Aid Codes), and other related data. Publicly-available information includes the US Census, the California Health Interview Survey (CHIS), and other relevant sources.

The community profiles developed by CHLA will categorize regional centers based on community characteristics (*e.g.*, ethnic composition, housing, socioeconomic status (SES), available health services, insurance coverage rates, immigrant populations, urban/rural communities). This will also inform second-year work, which will include more in-depth data collection.

These profiles have immediate benefits to the community. In one case, where a center began a semi-formal examination of detailed data, they found that the utilization of authorized respite services by monolingual Spanish speaking families was lower than for other populations in their catchment area. During a meeting with parents, the regional center representatives were informed that many families are not comfortable receiving these types of services within the home setting. The development of community profiles will allow for the more systemic identification of similar issues that can then be targeted in a more timely way by individual regional centers.

The twenty-one community profiles will not only provide regional centers a clear focus for their individual outreach efforts but will serve as the source of data used to identify a sample of 8-10 regional centers that are representative of the state. Given that each regional center operates as a unique non-profit organization, CHLA will ensure it focuses on the range of organizational structures and cultures in the overall study. When selecting sites for in depth examination, CHLA will consider: 1) regional center

organizational cultural differences and structure and, 2) community characteristics (*e.g.*, ethnicity, immigration status, SES, rural/urban).

Simultaneously, ARCA staff will develop supports to enhance the work of Cultural Specialists and other key staff at regional centers as they focus on enhancing services to diverse communities. Specifically, this will include:

- Convening regular teleconferences among the Cultural Specialists statewide to provide a forum for networking and the sharing of best and promising practices;
- Providing Cultural Specialists with information about research in the field of healthcare and social service disparities, including the impact of structural barriers such as healthcare literacy.^{xii}
- Supplying Cultural Specialists with information regarding research-based techniques for performing outreach to diverse communities.
- Alerting Cultural Specialists to training opportunities regarding outreach and service to diverse communities.
- Arranging two direct trainings identified as needful based on a survey of Cultural Specialists regarding practices for outreach and service to individuals and families from diverse communities.

YEAR 2

In the second year of the project, the above supports for regional center Cultural Specialists will continue. As the project progresses, the topics of discussion will evolve. For instance, during Year 2 it is expected that Cultural Specialists will explore together the ways that information from each center's community profile is beginning to change practices.

From a data analysis perspective, the second year will move from aggregate and regional data to highly targeted understandings of micro-community needs. This will allow Cultural Specialists to continue to focus on catchment-wide issues while also better addressing smaller, sub-regional disparities in service.

For these purposes, work will focus on surveys of community stakeholders (*e.g.*, community organizations, family resource centers and key leaders), as well as vendored service providers from the 8-10 regional centers selected at the conclusion of Year 1. In collaboration with the regional centers, CHLA will also organize in-person focus groups with individuals with developmental disabilities and family members, as well as service coordinators, at the selected regional centers.

Using the community profiles developed in Year 1 to appropriately target their work, and using a "community-engaged" approach CHLA, will recruit individuals with developmental disabilities and family members. Key to this effort are the regional centers and accessing their surrounding communities by attending meetings, working with community partners such as the SCDD (as well as non-disability specific organizations), sending out informational letters, and other means to identify an appropriate number of participants. Each focus group will include 8-10 participants and be linguistically accessible to the groups being targeted. CHLA will convene two or three focus groups of individuals with developmental disabilities and family members at each site as well as two or three groups of service

coordinators at each site. The purpose of the focus groups will be to better understand the barriers to service access leading to recommendations to address the barriers. Gaining a better understanding of the reasons why regional center consumers are not accessing purchased services is an example of a particular area of focus. Throughout this process, CHLA will engage the advisory group on the interpretation and implications of the findings with respect to policy and intervention development.

YEAR 3

The third year will consist of the implementation of a self-sustaining ongoing support protocol for Cultural Specialists. ARCA staff will continue to support the Cultural Specialists through ongoing meetings and forums for the sharing of individual regional center work. It is also anticipated that sustainable informal relationships will develop between Cultural Specialists who are targeting their work to similar populations.

As CHLA's initial analysis of quantitative and qualitative data is completed, ARCA staff will also provide Cultural Specialists with information regarding identified barriers to service delivery and additional regional center-specific strategies to address them.

Year 3 will also provide an opportunity for regional centers to identify communities or sub-communities that they continue to see as underrepresented in their eligibility or expenditure data. CHLA will conduct focus groups in those areas to better understand the unique dynamics that are driving the identified issues.

During Year 3 there will be an exploration of systemic structural barriers that exist in California's developmental services system that prevent specific populations from accessing needed services or supports statewide. These could include legal limitations on service delivery that have an unintended disproportionate impact on specific populations. ARCA staff will document these findings with the assistance of the regional center Cultural Specialists in order to provide recommendations for additional work in this area.

Plan Delivery and Duration

As noted above, SG/PRC will contract with ARCA to carry out the three-year project as well as to provide support to the state's twenty-one regional centers' staff and Cultural Specialists. The chart below provides additional information regarding the timeframes for each of these activities.

Activities/Deliverables	Timeframe (Beginning and End Dates)	Agency Responsible
1. Staff meetings of key RC personnel and Cultural Specialists	Jan 2017 – June 2019	ARCA
2. Research effective practices for serving diverse communities and providing information to key RC personnel and Cultural Specialists	Jan 2017 – June 2019	ARCA
3. Establish and provide staff support to a project	Jan 2017 – Dec 2018	ARCA

advisory committee		
4. Analyze regional center purchase of service data and examine the correlation between paid supports and other factors such as ethnicity, primary language, and socioeconomic status	Jan 2017 – June 2017	CHLA
5. Analyze available information to begin to develop community profiles and data analyses for each regional center area	Jan 2017 – June 2017	CHLA
6. Survey key RC personnel and Cultural Specialists to identify needed areas for training	February 2017	ARCA
7. Conduct one-on-one interviews with each regional center Executive Director/key personnel	March 2017 – June 2017	CHLA
8. Arrange for and conduct two trainings on identified topics via webinar for key RC personnel and Cultural Specialists that will be retained for future regional center staff training purposes	March 2017-June 2017	ARCA
9. Provide each regional center with a community profile based on its POS data as well as demographic information from its catchment area	June 2017	CHLA
10. Survey key RC personnel and Cultural Specialists to identify additional needed areas for training	July 2017	ARCA
11. Conduct surveys of service providers and community members in the selected regional center catchment areas	Sept 2017 – Dec 2017	CHLA
12. Work with selected regional centers and communities to identify focus group participants	Sept 2017 – Dec 2017	CHLA
13. Arrange for and conduct two additional trainings on identified topics via webinar for key RC personnel and Cultural Specialists that will be retained for future regional center staff training purposes	Sept 2017-June 2018	ARCA
14. Analyze data from the focus groups in the selected regional center catchment areas	Jan 2018 – June 2018	CHLA
15. Disseminate research results and recommended strategies to key RC personnel and Cultural Specialists	July 2018 – June 2019	ARCA

16. Identification of additional needed focus groups	July 2018 - June 2019	CHLA
17. Conduct additional requested focus groups	July 2018 - June 2019	CHLA
18. Identify systemic barriers to service delivery	July 2018 - June 2019	ARCA/CHLA

Anticipated Cost and Monitoring of Effectiveness

It is anticipated that the proposed project will run from January 2017 through June 2019. It is expected that the funds for the project will be encumbered during Fiscal Year 2016-17 and expended over three fiscal years as follows:

- Fiscal Year 2016-17: \$220,360;
- Fiscal Year 2017-18: \$368,970; and,
- Fiscal Year 2018-19: \$310,370.

Service effectiveness will be evaluated by tracking the progress in achieving the deliverables described above, by recording the number of individuals (professionals, self-advocates, and family members) involved in the research study, and monitoring the policy changes at the local and statewide level that results from these efforts.

Timeframe and Contracts

SG/PRC anticipates beginning this project upon approval of the requested funding. No later than January 2017, SG/PRC will have entered into the necessary contract with ARCA. Subsequently, ARCA will enter into the required contract with CHLA.

Qualitative and Quantitative Outcomes

It is expected that as a result of funding this proposal, the following data will be collected during Year 1:

- Research-based effective practices for serving diverse communities;
- Third-party analysis of regional center purchase-of-service data;
- Analysis of each regional center's catchment area (i.e., demographics);
- Survey results of key regional center personnel related to training needs; and,
- Qualitative data from one-on-one interviews with key regional center staff.

Quantitative data from the regional centers (i.e., demographic information, POS data), Census Bureau and the California Health Interview Study will be summarized and reviewed to construct community profiles and data analyses for each of the twenty-one regional centers. ARCA will maintain information about the number of key regional center staff and Cultural Specialists who participate in meetings, webinars, and other training opportunities.

Based upon the foundational data collected during Year 1 that culminates in the development of twenty-one individual community profiles, the focus of the data collection during Years 2 and 3 becomes primarily qualitative. Focus groups and one-on-one interviews will be recorded and transcribed, yielding

qualitative data that CHLA will analyze in a consistent and measurable manner. CHLA will complete simultaneous data collection, analysis, and theory construction. As the data are collected, they are immediately analyzed for patterns and themes, taken back to the field for more study, and analyzed further. This will allow CHLA to determine at what point it has reached theoretical saturation, which is the point when a concept has been sufficiently developed and further observations are unnecessary. Additionally, beginning in Year 2, further quantitative data describing the characteristics of participants involved in the focus groups will also be summarized to aid in understanding the populations involved.

The following records will be maintained throughout the life of the grant:

- Agendas and minutes for meetings of regional center Cultural Specialists;
- Copies of information disseminated to Cultural Specialists regarding best practices and the results of the research study;
- Information regarding local practices that have changed in response to the study or other best practice data;
- Training materials and attendance data from the four webinars that are conducted on the topics identified;
- Field notes from focus groups and one-on-one interviews; and,
- Agendas, minutes, and attendance data for the grant advisory committee.

It is expected that as a result of funding this proposal, no fewer than the following number of individuals will be reached throughout the grant period:

- 150 professionals (including regional center staff members and others) and 200 family members or individuals supported by the regional center will participate in interviews and focus groups.
- 50 regional center employees will participate in each of four webinars on topics related to service to diverse communities.
- It is estimated that 1,000 individuals with developmental disabilities and/or their family members who are unserved or underserved will access or increase utilization of regional center services.

SG/PRC anticipates that the results of this project of community analysis, further study, and staff support will inform local and statewide efforts to serve individuals from diverse communities and their families for years to come. If systemic barriers are identified, these findings will serve as the basis to recommend needed policy reforms.

ⁱ <http://www.census.gov/quickfacts/table/PST045twenty-one5/06>

ⁱⁱ http://www.dds.ca.gov/FactsStats/docs/QR/Jun2015_Quarterly.pdf

ⁱⁱⁱ California, Department of Developmental Services, Purchase of Services (POS) Disparity Data: Welfare and Institutions Code Section 4519.5-4519.6 (Sacramento 2016) 19.

^{iv} California, Department of Developmental Services, Purchase of Services (POS) Disparity Data: Welfare and Institutions Code Section 4519.5-4519.6 (Sacramento 2016) 25.

^v http://www.norcalunitedway.org/sites/norcalunitedway.org/files/Struggling_to_Get_By_3.pdf#page=53

^{vi} California, Department of Developmental Services, A Statewide Descriptive Statistical Analysis of Variation in Purchase of Services Categories for 1995-1996 and 1999-2000: Volume 1(Sacramento, 2002) 1.

^{vii} California, Department of Developmental Services, Purchase of Services Study II: Report #1: Modeling the Variation in Per Capita Purchase of Services Across Regional Centers (Sacramento 2003) xi.

^{viii} Scott HM, Haverkamp SM (2014) Race and Health Disparities in Adults with Intellectual and Developmental Disabilities Living in the United States. *Intellectual and Developmental Disabilities* 52(6): pp 409-418. doi:10.1352/1934-9556.52.6.409

^{ix} Leigh JP, Grosse SD, Cassady D, Melnikow J, Hertz-Picciotto I (2016) Spending by California's Department of Developmental Services for Persons with Autism across Demographic and Expenditure Categories. *PLOS ONE* 11(3): e0151970. doi:10.1371/journal.pone.0151970

^x <https://www.thinkculturalhealth.hhs.gov/Content/clas.asp>

^{xi} <http://www.cdc.gov/healthliteracy/culture.html>

^{xii} https://www.adrc-tae.acl.gov/tiki-download_file.php?fileId=29294

BIOGRAPHICAL SKETCH			
NAME Smith, Kathryn A. Navarette		POSITION TITLE Co- Investigator	
eRA COMMONS USER NAME KATSMITH			
EDUCATION/TRAINING			
INSTITUTION AND LOCATION	DEGREE	YEAR(s)	FIELD OF STUDY
University of California Los Angeles, School of Public Health	Dr.P.H	2011	Health Services
University of California Los Angeles (UCLA)	M.N.	1978	Nursing
California State University Long Beach	B.S.N.	1977	Nursing

A. POSITIONS

Academic Appointments

2014-Present Associate Professor of Clinical Pediatrics, Keck School of Medicine, University of Southern California (USC)
2006-2014 Assistant Professor of Clinical Pediatrics, Keck School of Medicine, University of Southern California (USC)
1986-Present Assistant Clinical Professor, University of California, Los Angeles (UCLA), School of Nursing, Los Angeles, CA

Professional Experience and Appointments

1979-1988 Clinical Nurse Specialist, Pediatrics – Orthopaedic Hospital, Los Angeles, CA
1988-1990 Public Health Nurse Specialist/Community Care Coordinator – Los Angeles County, California Children Services, Automated Case Management System/Community Based Care Coordination Project, Los Angeles, CA
1990-1992 Project Director – Early Intervention Management Information Systems Development Project, Los Angeles, CA
1990-1993 Co-Director, National Center for Case Management and Automation
1993-1998 Co-Director, ACCESS-MCH: Automation and Care Coordination Enhancing Services Systems in MCH
1996-2001 Director, Establishing a Community Based Interagency Services System for Children with Special Health Care Needs in Los Angeles County
1998-Present Associate Nursing Director, University of Southern California, University Center of Excellence in Developmental Disabilities, Children’s Hospital Los Angeles
1998-2004 Director, An Integrated Medical Home Training Program for Providers and Families of Children with Special Health Care Needs
2000-2003 Director, Building Medical Homes for Children with Special Health Care Needs
2001-2004 Director, The California Medical Home Project
2004-Present Assistant Director, MCH Training Program, UCLA Center for Healthier Children, Families and Communities
2006-Present Associate Director for Administration, University of Southern California, University Center of Excellence in Developmental Disabilities, Children’s Hospital Los Angeles
2008-Present Director, Rett Clinic, University Center of Excellence in Developmental Disabilities, CHLA
2008-Present Nurse Care Manager, Boone Fetter Autism Clinic, Children’s Hospital Los Angeles
2009-Present Co-Director, Spina Bifida Center, Children’s Hospital Los Angeles
2010-Present Senior Site Coordinator, Autism Treatment Network, Children’s Hospital Los Angeles

Other Experience and Professional Memberships

1994-Present March of Dimes Birth Defects Foundation, Southern California Chapter. Education Committee, 1994-1997; Board of Directors 1997-1998; Executive Committee 1997-1998; Chair 1997-1998; Professional Education Committee 1997-2002; Chair, Professional Education Committee 1998-2002; Program Services Committee 1998-Present; Chair, Program Services Committee 2002-2004
2000-Present Chair, Los Angeles County California Children Services Workgroup

B. PUBLICATIONS

- Betz, CL, Smith, K, and Macias, K. Testing the Transition Preparation Training Program: A Randomized Controlled Trial. International Journal of Child and Adolescent Health: Special Issue on: Youth Health Care Transition, 2010; 3(4).
- Smith, K. Health promotion through community care. In: Children and their Families: The Continuum of Care (2nd edition, Bowden, V. and Greenberg, C. [editors]). Wolters Kluwer Health/ Lippincott Williams and Wilkins, Philadelphia, PA, pp 62-74, 2010.
- Smith, K. and Savage, T.A.: Policies, legislation and ethical/legal issues. In: Nursing Care for Individuals with Intellectual and Developmental Disabilities: An Integrated Approach (1st edition, Betz, C.L. and Nehring, W.M., [editors].) Brookes Publishing, Baltimore, MD, pp 355-370, 2010.
- Betz, C.L., Smith, K.N., & Macias, K. Testing the transition preparation training program: A randomized controlled trial. International Journal of Child and Adolescent Health, 2010, 595-608, 201.
- Freeman, K.A., Smith, K., Adams, E., Mizokawa, S. and Neville-Jan, A. Is continence status associated with quality of life in young children. Accepted for publication by the Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach, 2014.
- Betz, C.L., Smith, K.N., Macias, K., & Bui, K. Internet Use by Adolescents with Spina Bifida, Pediatric Nursing, in press, 2014.

C. ONGOING RESEARCH SUPPORT

- CDC, National Spina Bifida Patient Registry, PI/Project Director, 9/1/2014 – 8/31/2019; 1 U01 DD001069.
- CDC, National Spina Bifida Urological/Renal Protocol- Urologic Management to Preserve Renal Function Protocol for Young Children with Spina Bifida, 0-5 Years, PI/ Project Director, 9/1/2014 – 8/31/2019; 1 U01 DD001068.

BIOGRAPHICAL SKETCH

NAME Kubicek, Katrina			
POSITION TITLE Assistant Director			
EDUCATION/TRAINING			
INSTITUTION AND LOCATION	DEGREE	YEAR(s)	FIELD OF STUDY
University of Texas, Austin	B.A.	1996	Anthropology
Tulane University, New Orleans, LA	M.A.	1998	Cultural Anthropology
University of Southern California,	PH.D student	current	Health Behavior Research

A. Positions and Honors

2000-2001	Project Coordinator, University of Texas, San Antonio, TX
2001-2005	Senior Research Associate, Lodestar Management/Research, Los Angeles, CA
2005-2012	Lecturer, California State University of Los Angeles, Los Angeles, CA
2008-2010	Senior Research Manager, Children's Hospital Los Angeles, Los Angeles, CA
2010-present	Program Manager, Children's Hospital Los Angeles Assistant Director of Community Engagement program, SC CTSI, Los Angeles, CA

B. Selected Peer-reviewed Publications

1. Kipke MD, **Kubicek K**, Weiss G, Wong C, Lopez D, Iverson E, Ford W. The health and health behaviors of young men who have sex with men. *Journal of Adolescent Health*, 40, 342-350. *Journal of Adolescent Health*, 2007; 40(4): 342-350. PMC2955360.
2. **Kubicek K**, Weiss G, Iverson, E., Kipke MD. Deconstructing the complexity of substance use among young men who have sex with men (YMSM) by optimizing the role of qualitative strategies in a mixed methods study. *Substance Use and Misuse*, 45, 754-776. *Substance Use and Misuse*, 2010; 45: 754-776.
3. **Kubicek, K**, Weiss G, Beyer W, Kipke MD. Using Photovoice as a tool to adapt an HIV prevention intervention for African American young men. *Health Promotion Practice*, 2012; 13(4): 535-543.
4. **Kubicek, K.**, Robles, M., Chen, C., Valino, H., & Richman, N. A community-based participatory research project to adapt asthma education for after-school programs. *Journal of Primary Prevention*. In press.
5. Burner, E., Menchine, M., **Kubicek, K.**, Robles, M. & Arora, S. Perceptions of successful cues to action and opportunities to augment behavioral triggers in diabetes self-management: Qualitative analysis of a mobile intervention for low-income Latinos with diabetes. *Journal of Medical Internet Research*, 2014; 16(1): e25. PMC3936269.

C. Research Support

Ongoing Research Support

8UL1TR000130 (Buchanan) 03/31/2015 (Kipke – Sub award PI) USC/NIH (NCRR) Los Angeles Basin Clinical and Translational Science Institute. Role: Assistant Director of Community Engagement Program	07/01/2010–
D10-CHLA-048 8/31/2014 (No Cost Extension) California HIV/AIDS Research Program Young Men's Relationships: Opportunities for HIV Prevention Role: Principal Investigator	9/01/2011 -

A Proposal for the North Los Angeles Regional Center	Attachment B		
California State University Northridge	Maximum External Rate 8% on \$85K salary		
Family Empowerment Team in Action (FETA)	2016-2017	2017-2018	2018-2019
	2 Interns	4 Interns	8 interns
	4 assistants	6 assistants	8 assistants
Personnel			
Program Manager, Family Focus Resource Center Coordination Pay	2,000	2,000	2,000
Supervising Faculty Member's Release Time (fall and spring semesters - three units per semester)	21,250	21,250	42,500
Supervising Faculty Member's Release Time (summer pay)	3,400	3,400	6,800
MA Social Work Intern \$2,000 "Participant Support"	4,000	8,000	16,000
Student Social Work Assistants @ \$1,000 "Participant Support"	4,000	6,000	8,000
Empowerment Coordinator, Educational Advocacy for Families / Sensitivity Training for Vendors	26,000	26,000	26,000
Three Advocates	16,640	16,640	16,640
Total Personnel	77,290	83,290	117,940
Personnel Benefits			
Program Manager, Family Focus Resource Center Benefits @ 41%	820	820	820
Supervising Faculty Member Release Time (fall and spring) Benefits @ 45%	9,563	9,563	19,125
Supervising Faculty Member Summer Pay Benefits @ 45%	1,530	1,530	3,060
MA Social Work Interns @ 10.6%	424	848	2,176
Student Social Work Assistants @ 10.6%	424	636	848
Coordinator, Educational Advocacy @ 29.1%	7,566	7,566	7,566
Three Advocates @ 29.1%	4,842	4,842	4,842
Total Benefits	25,169	25,805	38,437
Operating Expenses			
Advocacy training materials	1,500	1,500	1,500
Copies and Supplies	250	500	500
Cell phones with voicemail \$150 per month	1,800	3,600	5,000
Laptops	3,000	-	-
Printer	200	-	-
Secure filing cabinet	150	-	-
Pre-placement clearances for the interns (i.e., Live Scan)	450	750	1,200
Travel (mileage reimbursement and bus tokens for families)	3,000	3,000	3,500
Total Operating Expenses	10,350	9,350	11,700
Contract Services			

Evaluation and Yearly Report - Institute for Community Health and Wellbeing	9,050	8,225	8,550
Subtotal Request	121,859	126,670	176,627
Indirect @ 12%	14,623	15,200	21,195
	136,482	141,870	197,823
Total Request			
\$476,174.41			
Budget to be reviewed and approved by Office of Research and Sponsored Projects			