LEGISLATION AND PUBLIC POLICY COMMITTEE (LPPC)
MEETING NOTICE/AGENDA
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THE PUBLIC MAY LISTEN IN BY CALLING:	**1-800-839-9416**
PARTICIPANT CODE:	**8610332**

DATE: May 24, 2016

TIME: 12:00 p.m. - to 4:00 p.m.

LOCATION: State Council on Developmental Disabilities
1507 21st Street, Suite 210
Sacramento, CA 95811
(916) 322-8481

TELECONFERENCE SITE(S):

Pursuant to Government Code Sections 11123.1 and 11125(f), individuals with disabilities who require accessible alternative formats of the agenda and related meeting materials and/or auxiliary aids/services to participate in the meeting, should contact Michael Brett at 916/322-8481 or michael.brett@scdd.ca.gov. Requests must be received by 5:00 pm on May 18, 2016.

AGENDA

		PAGE
1.	**CALL TO ORDER**	J. Lewis
2.	**ESTABLISH QUORUM**	J. Lewis
3.	**WELCOME/INTRODUCTIONS**	J. Lewis

For additional information regarding this agenda, please contact Michael Brett, 1507 21st Street, Ste. 210 Sacramento, CA 95811, (916) 322-8481. Documents for an agenda item should be turned into SCDD no later than 12:00 p.m. the day before the meeting to give members time to review the material. The fax number is (916) 443-4957.

4. **MEMBER REPORTS** Members

This item is for committee members to provide a report on their legislative and/or public policy activities related to the agency or group they represent. Each person will be afforded up to three minutes to speak.

5. **APPROVAL OF MARCH 17, 2016 MINUTES** J. Lewis 4

6. **PUBLIC COMMENTS**

*This item is for members of the public only to provide comments and/or present information to the Council on matters **not** on the agenda. Each person will be afforded up to three minutes to speak. Written requests, if any, will be considered first.*

7. **OLD BUSINESS (Standing Items)**

a. Budget Update B. Giovati

b. IHSS/CMS Updates/Overtime Discussion/DC Closures C. Lapin/DRC/ All

c. Federal & State Legislation Updates/Council Update on LPPC Bill Package & Other Bills B. Giovati/ N. Nieblas

1) AB 1553 (Irwin) Qualified ABLE program
2) AB 2091 (Lopez) IEP Translation Services
3) SB 1221 (Hertzberg) Firefighters Interaction
4) SB 1252 (Stone) Patient Notification
5) SB 1072 (Mendoza) School Bus Alarms

d. Self-Determination J. Lewis/A. Lopez/C. Lapin/All

i) Statewide SDP Committee

e. Disparity Issues All 13

8. **NEW BUSINESS**

a. Detail Sheets/Bill Review	B. Giovati/ N. Nieblas/All	158

1) AB 1715 (Holden) Behavior Analysis
2) AB 1821 (Maienschein) Sex Offenses
3) AB 1824 (Chang) Service Animals
4) AB 2212 (Harper) Bullying
5) AB 2231 (Calderon) Care Facilities
6) SB 982 (McGuire) Developmental Centers
7) SB 1034 (Mitchell) Health Care: Autism

b. Muscular Dystrophy Proclamation	J. Lewis/All	276
c. Discussion of Council Legislative Platform	J. Lewis/All	280

9. **ADJOURN** J. Lewis

5. APPROVAL OF MARCH 17, 2016 MINUTES

CALIFORNIA SCDD

DRAFT

LPPC Committee Meeting Minutes
DATE: March 17, 2016

Attending Members	Members Absent	Others Attending
Janelle Lewis (FA)		Bob Giovati
April Lopez (FA)		Michael Brett
David Forderer (SA)		Wayne Glusker
Sandra Aldana (SA)		Eric Rodriguez
Jennifer Allen (SA)		Michael Garcia
Lisa Davidson (FA)		Dana Dorsey
Connie Lapin (FA)		
Evelyn Abouhassan		

1. **CALL TO ORDER**

   Chairperson Janelle Lewis (FA) called the meeting to order at 1:13 p.m.

2. **ESTABLISH QUORUM**

   A quorum was established.

3. **WELCOME/INTRODUCTIONS**

   Members and others introduced themselves as indicated.

4. **MEMBER REPORTS**

   Connie Lapin (FA): The following reports were given:

   - *In a Different Key*, a story on autism, is receiving much publicity.
   - Discussed how the new Executive Director was hired for the Westside Regional Center. Two candidates were in the running with one being chosen internally. Part of the interview process was for both candidates to appear before the community and answer questions.
   - Attended the Arch Conference that went into the CMS Rules.

Legend:
SA = Self-Advocate
FA = Family Advocate

- Next DS Taskforce is taking place April 13, 2016 with State Council representation.

- Briefed the committee on the New Day Conference which dealt with public policy, CMS rules, and Self Determination. Mrs. Lapin (FA) stated that the conference went great.

- During the Self Determination Now conference, a campaign was being promoted on the importance of NOW.

- Through Person Centered Advocacy, there will be a conference taking place April 6, 2016.

- Mentioned the testimony from Judy Mark. For more details on this, please click on the below link which is located on the SCDD Website:

  http://www.scdd.ca.gov/res/docs/pdf/LPPC/2016/LPPC%20Handout%20for%203%2017%2016%20APPROVAL%20The%20Story%20of%20the%20CA%20SD.pdf

Lisa Davidson (FA): The Los Angeles Regional office held their RAC on February 22, 2016, thanking Dr. Sandra Aldana (SA) (Councilmember/fellow committee member) for her attendance/interest. Ms. Davidson (F) also stated that the next RAC will take place March 28, 2016.

Jennifer Allen (SA): No report.

Dr. April Lopez (FA): Dr. Lopez (FA) discussed the following:

- The Statewide Self-Determination meeting was a fabulous success. with positive feedback from the participants. It was also appreciated that it was open to the general public and had representation from all Regional Centers.

  Aaron Carruthers (Executive Director), Bob Giovati (Deputy Director of Policy and Planning), and herself attended five or six meetings at the State Capitol with various legislators to discuss/explain issues of significance to the Council.

Evelyn Abouhassan: The following reports were given:

- DRC is sponsoring two bills: AB 488 (Gonzales) and AB 2873 (Thurmond)
- DRC would like the State Council to get more involved with access – related bills.
- Committee/Staff discussed that this committee would like to have a spot on the DRC Legislative committee. Ms. Abouhassan is going to check with DRC staff.

Chairperson Lewis (FA): No report.

Dr. Sandra Aldana (SA): No report.

David Forderer (SA): No report.

5. **APPROVAL OF THE February 8, 2016 MEETING MINUTES**

It was moved/seconded (Lapin)(FA), (Davidson)(FA) and carried to approve the February 8, 2016 meeting minutes with corrections. There were no abstentions.

(See attendance list for voting members)

Corrections made to the LPPC Packet Meeting Minutes:

- Change Chairperson Lewis' (FA) last sentence to read: "BHT Services are being disrupted." This is from her member report located on page 4.
- Remove and change Ms. Lapin's (FA) last sentence to read: "The book can be purchased on Amazon.com." This is from her member report located on page 5.
- Remove 4th statement from Mrs. Lapin's (FA) discussion on Self-Determination located on page 11.

6. **PUBLIC COMMENTS**

There were no public comments.

7. OLD BUSINESS (Standing Items)

a. Budget Update/Special Session/Lanterman Coalition

The above was recapped with the following highlights:

- Lanterman Coalition: Staff met with the coalition on the Brown Administration's developmental services funding proposal/proposed Managed Care Organization (MCO) Tax.
- CMS Rules.
- With regards to the budget update/special session/Lanterman Coalition, committee would like to remain updated on these subjects.

b. IHSS/CMS Updates/Overtime Discussion/DC Closures

Mrs. Lapin (FA)/committee updated the committee on the following items:

- A budget hearing was held regarding overtime.
- DRC Testimony on maintaining a safety net from Catherine Blakemore, Executive Director from Disability Rights California. (See motion below)
- Crisis homes.
- To have Debra Doctor at the next LPPC meeting on IHSS/CMS updates.
- Sharing resources on DC Closures

It was moved/seconded (Forderer (SA), (Lopez (FA) to take the support recommendations/letter to the Executive Committee on maintaining the safety net. All were in favor with no abstentions.

(See attendance list for voting members).

For more information on this testimony, it can be found in the LPPC Packet on page 20. Please click on the below link which is located on the SCDD Website:

http://www.scdd.ca.gov/res/docs/pdf/LPPC/2016/LPPC%20Packet%20Approved%203.17.16.pdf

Legend:
SA = Self-Advocate
FA = Family Advocate

c. **Federal and State Legislation Updates/Council Update on LPPC Bill Package and Other Bills.**

The above was recapped with the following highlights on housing. It was also mentioned that housing is part of the Council's State Plan.

d. **Self-Determination**

Ms. Lapin (FA)/committee gave an update on the Self-Determination conference and Statewide SDP Committee.

See Dr. Lopez' member report.

i. **Update on Person Centered Planning**

Chairperson Lewis (FA) mentioned that the Self-Determination conference gave a presentation on Person Centered Planning.

Discussed Self-Determination/CMS Waivers

Discussed different ways of presenting Person Centered Planning

ii. **HCBS**

See agenda item 7b for inputs.

e. **Disparity Issues**

This item was not discussed

8. **NEW BUSINESS**

a. **Detail Sheets/Bill Review**

Committee would like to have the bill language included in the LPPC Packet along with an updated watch list.

Deputy Director Giovati briefed the committee that the State Council has approximately 157 bills on its watch list.

Staff and the committee then went on to discuss/vote on the following bills:

Supported Bills:

- **AB 1553**
  It was moved/seconded (Davidson (FA), Allen (SA) to support AB 1553 with one abstention from Evelyn Abouhassan .

  (See attendance list for voting members).

- **AB 2091**
  It was moved/seconded (Davidson (FA), Lapin (FA) to support AB 2091 with one abstention from Evelyn Abouhassan.

  (See attendance list for voting members).

  Committee asked to have staff check and see who is sponsoring this bill.

  For more details on this bill, please click on the below link which is located on the SCDD Website:

  http://www.scdd.ca.gov/res/docs/pdf/LPPC/2016/LPPC%20Handout%20for%203%2017%2016%20APPROVAL%20AB%202091%20Detail%20Sheet.pdf

- **SB 1221**
  It was moved/seconded (Aldana) (SA), (Davidson) (FA) to support SB 1221 with one abstention from Evelyn Abouhassan.

  (See attendance list for voting members).

- **SB 1252**
  It was moved/seconded (Lapin) (FA), (Lopez) (FA) to support SB 1252 with one abstention from Evelyn Abouhassan.

  (See attendance list for voting members).

- **Driverless Cars**
  It was moved/seconded (Lapin) (FA), (Lopez) (FA) to support Driverless Cars with no abstentions.

  (See attendance list for voting members).

Bills to Watch:

- **AB 1821**
  After staff/committee discussion, the LPPC decided to watch this bill. No action was taken.

  At the next LPPC Meeting, the committee would like to discuss/receive an update on this bill.

  Committee would like this bill placed on the next agenda for update.

- **AB 1824**
  After staff/committee discussion, the LPPC decided to watch this bill. No action was taken. More information on this bill is to come.

  Committee would like this bill placed on the next agenda for update

- **AB 2231**
  After staff/committee discussion, the LPPC decided to watch this bill. No action was taken.

  Committee would like this bill placed on the next agenda for update.

- **AB 2383**
  After staff/committee discussion, the LPPC decided to watch this bill. No action was taken.

  Committee would like this bill placed on the next agenda for update.

- **SB 982**
  After staff/committee discussion, the LPPC decided to watch this bill. DRC also has a watch. No action was taken.

  Committee would like this bill placed on the next agenda for update.

- **SB 1034**
  After staff/committee discussion, the LPPC decided to watch this bill. No action was taken.

  Committee would like more clarification on this bill.

  Committee would like this bill placed on the next agenda for update.

With the exception AB 2091, the full description/detail sheets of the above bills can be found in the LPPC Packet on pages 46 to 79. Please click on the below link which is located on the SCDD Website:

http://www.scdd.ca.gov/res/docs/pdf/LPPC/2016/LPPC%20Packet%20Approved%203.17.16.pdf

Additional Bills Discussed:

- **AB 488**
  State Council is co-sponsoring this bill

- **SB 1024**
  State Council is co-sponsoring this bill.

- **SB 1072**
  The State Council is sponsoring this bill with Senator Tony Mendoza's office which deals with school transportation safety.

  For informational purposes, staff/committee briefed the following:

  Deputy Director Giovati, Chairperson Lewis met Senator Mendoza's staff on March 16, 2016. In addition, Executive Director Aaron Carruthers and Council Chair Dr. Lopez also met with Senator Mendoza's staff.

  LPPC Staff/Council will be participating in upcoming SB 1072 hearings.

  While sponsoring this bill, the State Council has been asked to provide the following:

  - Personal stories.
  - Author statements.
  - Witnesses.

  For more details on this bill, please click on the below link which is located on the SCDD Website:

  http://www.scdd.ca.gov/res/docs/pdf/LPPC/2016/LPPC%20Handout%203.17.16.pdf

- **SB 1427**
  Chairperson Lewis mentioned that the Council is watching this bill.

  Committee/staff held a final discussion on attending budget hearings. The next hearing for the senate takes place April 7, 2016.

b. **Press Outreach**

This item was not discussed.

9. **ADJOURN**

Meeting adjourned at 4:41 p.m. Next meeting is planned for May 2016.

Chairperson Lewis (FA) mentioned to the committee that at the last Council meeting it was voted for this committee to meet six times a year. However, Dr. Lopez (FA), Council Chair, stated that if more meetings are needed, she can call additional meetings.

Legend:
SA = Self-Advocate
FA = Family Advocate

7e. DISPARITY ISSUES

A RECOMMENDATION REPORT FROM THE HHS ADVISORY COMMITTEE ON MINORITY HEALTH (ACMH)

Assuring Health Equity for Minority Persons with Disabilities

A Statement of Principles and Recommendations

Submitted to

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office of Minority Health

Assuring Health Equity for Minority Persons with Disabilities

A STATEMENT OF PRINCIPLES AND RECOMMENDATIONS U.S. Department of Health and Human Services Advisory Committee on Minority Health (ACMH)

Submitted

Through
Garth Graham, MD, MPH,
Deputy Assistant Secretary for Minority Health
To
Kathleen Sebelius, Secretary,
U.S. Department of Health and Human Services

July 2011

Advisory Committee on Minority Health: Section 1707 of the Public Health Service Act, as amended, by the Minority Health and Health Disparities Research and Education Act of 2000 (P. L. 106-525) authorizes the establishment of an Advisory Committee on Minority Health. The Committee also is governed by provisions of Public Law 92-463, as amended (5 U.S.C. Appendix 2), which sets forth standards for the formation and use of advisory committees. The Act directs the Advisory Committee on Minority Health to advise the Department of Health and Human Services, through the Deputy Assistant Secretary for Minority Health, on improving the health of racial and ethnic minorities and on the development of the program activities of the Office of Minority Health.

COMMITTEE MEMBERS:

Chairperson

Rubens J. Pamies, MD, FACP (deceased)
Vice Chancellor for Academics Affairs,
Dean for Graduate Studies, Professor of Medicine, University of Nebraska Medical Center
Omaha, NE
Term. Date: 02/23/2011

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Diana M. Bonta, RN, DrPH
Kaiser Permanente, Vice President, Public Affairs, Southern California Region
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Term. Date: 11/01/2011

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Table of Contents

Introduction and Context for the Report on Minorities with Disabilities 7

Health Inequities for Persons with Disabilities 7

Lack of Provider Competency in Disabilities as a Barrier to Care 10

Minorities with Disabilities: Marginalized, Vulnerable, and Forgotten Populations 11

Limited Data and Research on Health Inequities among People with Disabilities . 12

Minorities with Disabilities: Conclusions and Recommendations 12

1. Raise awareness about minorities with disabilities. 13

2. Recognize disability as a fundamental component of cultural competency... 13

3. Require competency for all health care providers and professionals. 13

4. Improve research and practice on disabilities in minority populations. 14

5. Strengthen the health care workforce to ensure high quality care for people with disabilities. 15

Concluding Comments 15

Endnotes 15

Assuring Health Equity for Minority Persons with Disabilities

Introduction and Context for the Report on Minorities with Disabilities

The charge of the Advisory Committee on Minority Health (ACMH) is to advise the Secretary of the Department of Health and Human Services on ways to improve the health of racial and ethnic minority populations and on the development of goals and program activities within the Department. The Committee now faces a major new responsibility: It will have a critical role in ensuring that health care reform, as embodied in H.R. 3950, The Patient Care and Affordable Care Act of 2010 (P. L.111-148), is implemented equitably. This process should be monitored to guarantee that the provisions of the bill adequately respond to the needs of vulnerable populations and propel the nation toward achieving health equity.

With these responsibilities in mind, ACMH's first 2009 report, Ensuring that Health Care Reform Will Meet the Health Care Needs of Minority Communities and Eliminate Health Disparities: A Statement of Principles and Recommendations, proposed 14 Principles for Minority Health Equity in Health Care Reform to ensure that health policy reform will meet the health care needs of minority communities.[1] Recognizing our country's history of health inequities and the need for systematic vigilance, oversight, and corrective action, ACMH proposed the development and establishment of a Federal Health Equity Commission, which would provide oversight and monitoring of health care reform implementation in a manner designed to eliminate health inequities for minority and vulnerable populations.[2] ACMH's second 2009 report, *A Federal Health Equity Commission will Promote the Public's Health and Ensure Health Equity in Health Care Reform: A Statement of Principles and Recommendations*, which is in the clearance process, describes the ACMH's proposal for this Commission.

Next in its series of reports, ACMH focuses on an especially underserved and vulnerable population: minorities with disabilities. ***By every measure, persons with disabilities disproportionately and inequitably experience morbidity and mortality associated with unmet health care needs in every sphere. Minorities with disabilities are doubly burdened by their minority status.*** As health care reform proceeds, ACMH believes that the circumstances and needs of this population should be specifically addressed to ensure that the benefits of health care reform are available to all, which is the focus of the current report.

Health Inequities for Persons with Disabilities

On September 30, 2009, the National Council on Disability (NCD) issued *The Current State of Health Care for People with Disabilities*, a lengthy and extensively documented (i.e., 227 pages, 600 endnotes) report.[3] According to the U.S. Census Bureau, of the 291.1 million people in the U.S. population in 2005, 54.4 million (18.7%) had a disability, and 35.0 million (12.0%) had a severe disability (e.g., used a wheelchair, walker, or cane; were unable to or needed help to perform functional activities, activities of daily living (ADLs), or instrumental activities of daily living (IADLs); had a learning disability or other mental or emotional condition; or had any other mental, emotional, or physical condition that affected their everyday life).[a] Physical disabilities

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[a]In the American Community Survey, disability is measured by several concepts related to an individual's functional limitations and ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Functional activities include seeing, hearing, speaking, lifting, carrying, using stairs,

tend to be more common than are sensory or mental health disabilities. African Americans and Hispanics/Latinos typically experience disability at a higher rate than do Whites/Caucasians.[4] People with disabilities are a large and important group of health consumers in the United States. However, despite the demographic increase in the disability population and the implications for people with disabilities and the broader society, according to the Institute of Medicine, the federal government, legislators, and health care systems have yet to respond.[5]

According to the NCD report, people with disabilities have poorer health and use health care at a significantly higher rate than do people without disabilities. People with disabilities also experience a higher prevalence of secondary conditions (e.g., obesity) and use preventive services at a lower rate than do persons without disabilities. People with disabilities frequently lack health insurance or coverage for necessary services such as specialty care, long-term care, care coordination, prescription medications, durable medical equipment, and assistive technologies. Persons with disabilities often receive care from multiple providers without adequate coordination of services as well. Along with poorer health and higher use of health care, the NCD report documents that barriers to preventive services disproportionately affect people with disabilities: for example, persons with disabilities are less likely to receive counseling for smoking cessation than are persons without disabilities. Other barriers include health care provider stereotypes about disabilities; lack of appropriate provider training; and a lack of accessible medical facilities and examination equipment, sign language interpreters, and individualized accommodation. People with disabilities also experience inequitable treatment in health care settings, racial and ethnic disparities, limited access to health information, and exclusion from health-related research.[6]

Numerous prior reports have described the particular challenges to health and well-being faced by persons with disabilities. Asserting the principle that good health is necessary for people with disabilities to work, learn, and engage with their families and communities, these reports have placed the health of people with disabilities among the public health issues that should be at the forefront of health care policy research, financing of health care delivery, and training/education of health care providers.[7] The health and wellness of people with disabilities are public policy concerns that should drive the acquisition and use of new knowledge and technologies.

Specific examples of health disparities and unique problems in accessing health care services for people with disabilities include the following:[8]

- Women with disabilities have fewer Papanicolaou smears (Pap tests) and mammograms than do women without disabilities. Compared to women without disabilities, women with disabilities are less knowledgeable about and aware of risk factors for cardiovascular disease and are less likely to participate preventive screening.

- Adults who are deaf or hearing impaired are three times as likely to report fair or poor health as compared to those who do not have hearing impairments. American Sign Language (ASL) is the primary language for many people who are deaf; however, interpreters often are not provided during medical visits.

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walking, or grasping small objects. ADLs include getting around inside the home, getting into or out of bed or a chair, bathing, dressing, eating, and toileting. IADLs include going outside the home, keeping track of money and bills, preparing meals, doing light housework, taking prescription medicines, using the telephone, and maintaining employment.

- Adults with developmental disabilities are at increased risk for hearing and vision difficulties, cardiovascular disease, obesity, seizures, mental health and behavioral problems, poor oral health, and poor general fitness. Young adults with developmental disabilities often have difficulty transitioning from coordinated childhood medical care to adult medical services because some providers are not trained to provide needed care and are not adequately reimbursed by insurance companies for care coordination.

- Compared to the general population, people with significant vision loss are more likely to have heart disease and hypertension, to be overweight or obese, and to smoke. Printed health care instructions, educational materials, and information such as directions for taking prescription medications are not always provided in formats accessible to the visually impaired. People with vision impairments often do not receive high-quality diabetes education.

- Persons with intellectual or developmental disabilities (ID or DD) experience disparities in oral health outcomes. According to the Surgeon General's *Report on Oral Health in America* (2000), oral health is a key factor in the quality of life and life expectancy of people with disabilities.[9]

Disparities in health and health care for people with disabilities often are influenced by social determinants such as education, income and poverty, and the local environment. Policy makers and the current administration have acknowledged the health disparities that people with disabilities experience and the critical need for health care reform to better address the needs of this population. The Patient Protection and Affordable Care Act includes language and/or specific provisions or amendments that:

(1) prohibit discrimination against people with disabilities;
(2) seek input from disability organizations on home- and community-based care and treatment;
(3) collect state level data on community- and home-based care by type of disability; (4) expand state aging and disability centers and increase availability of community based care services;
(5) reduce the incidence of preventable illness and disability;
(6) engage Disability Resource Centers to improve access to and use of health risk assessments;
(7) provide preventive services to reduce physical and mental disability and restore functioning;
(8) evaluate community intervention programs for Medicaid populations designed to reduce disability;
(9) develop a national health promotion strategy that includes a focus on disability;
(10) identify standards for measurement of disability status and ensure collection of data on disability status for all federally funded health care of public health program, activity or survey;
(11) assess access to care and treatment including the number of providers trained in serving this population;
(12) increase the disability cultural competency of providers;
(13) prohibit the practice of reducing the value of the life of persons with disabilities in determining cost effective health care; and
(14) set standards for determining eligibility for Social Security benefits due to disability.[10]

In addition, the health care reform bill calls for the creation of a committee to review and update the criteria and methodology for defining Medically Underserved Populations (MUP) and Primary Care Health Professions Shortage Areas. According to Section 5602, the Negotiated Rulemaking Committee will assess the availability and appropriateness of data used to determine the MUP designation, the impact of this methodology and the designation process on communities and providers, and the extent to which the current methodology accurately reflects barriers to access and care faced by certain populations[11]. This component of the legislation also represents a unique opportunity to facilitate dialogue regarding applying the MUP and Primary Care Health Professions Shortage Areas designations to individuals with disabilities, thereby increasing access to resources to address disparities within this population (M.H., personal communication, June 1, 2010).

Lack of Provider Competency in Disabilities as a Barrier to Care

The pervasive absence of professional training and the lack of disability competency and awareness among health care providers are among the most significant and fundamental barriers preventing people with disabilities from receiving quality health care.[12]

Without appropriate training and awareness, health care providers often hold incorrect assumptions and stereotypes about people with various disabilities—assumptions that may result in inadequate care. Research has revealed, for example, that some providers incorrectly assume that people with physical or developmental disabilities (1) do not have a good quality of life; (2) do not feel pain thus do not require anesthesia; (3) have cognitive deficits simply because they may not be fluent in standard English; and (4) do not require reproductive counseling and care because they are not sexually active. In addition to undermining quality of care, interactions that involve these assumptions can damage patient-provider trust and discourage people with disabilities from seeking care.[13]

The ACMH 2008 report *Reducing Health Disparities by Promoting Patient-Centered Culturally and Linguistically Sensitive/Competent Health Care* outlines the critical role that cultural competency can play in eliminating health inequities.[14] The report states that disability should be a basic and critical component of cultural competency training and education for health care providers.[15,16] The ACMH insists that cultural competency be understood as an overarching approach to access and service delivery that benefits all citizens. One objective of *Healthy People 2020* is that graduate students in public health receive training related to persons with disabilities.[17] It recommends that cultural competency that includes disability be required teaching and licensing components of curricula for all medical school and health professional training programs.

The consequences of the absence of disability competency among health care providers are dire.[18] It is possible to become a board-certified physician without having hands-on experience with patients with disabilities. Furthermore, many physicians are reluctant, or aversive, to treating patients with complex disabilities, who may also be limited in their ability to communicate their health history or needs.[19] As there is no clear line between where disability ends and medical conditions begin, physicians should be able to determine the extent to which a patient's condition is a component, consequence, or coincidence of his or her disability.

Minorities with Disabilities: Marginalized, Vulnerable, and Forgotten Populations

While there is a substantial need for increased public awareness about disabilities in general, there is a specific need for data regarding health disparities among minorities with disabilities. It is particularly important to raise awareness about the burden of disability and race/ethnicity vis-à-vis health disparities and inequities.[20] Aside from the public health issues that most racial/ethnic minorities face, minorities with disabilities experience additional disparities in health, prejudice, discrimination, economic barriers, and difficulties accessing care as a result of their disability—in effect, they face a "double burden." For example, Blacks/African Americans with Down syndrome are more than seven times as likely as are Whites/Caucasians to die by age 20. The life expectancy for Whites/Caucasians with Down syndrome is about 55 years compared to 25 years for Blacks/African Americans.[21] Further research is needed to explore health disparities in other racial/ethnic communities (e.g., Asian Americans and Pacific Islanders, Hispanics/Latinos, Native Americans /Alaskan Natives) and other minority groups within the disabled community (e.g., immigrants/refugees, women).[22]

Similar to the concept of double burden, *simultaneous oppression* is defined as "areas in which the experiences of Blacks/African Americans with disabilities result in a distinct form of oppression that entails limited or no individuality and disability identity, resource discrimination, and isolation within the Black/African American community and family."[23] Resources typically are not allocated to devalued individuals. Simultaneous oppression adds "insult to injury" as a result of stereotyping, stigma, psychological discomfort, paternalism, and pity.[24] Whereas simultaneous oppression has often been associated with Blacks/African Americans in the literature, the idea can be applied to the experiences of other minorities with disabilities.[25]

Cultural perceptions of disabilities not only affect the type of treatment that a family seeks or receives but also interact with important and unaddressed aspects of cultural competency.[26,27] Widespread discrimination against the disabled population, including minorities, has resulted in lack of appropriate health care. Disabilities are often misdiagnosed or overlooked among minority populations. The following examples highlight the intersection of health disparities, minority disability, access to care, and the need for more culturally competent services:

- In 2008, Minnesota public health officials launched a study to investigate autism among Somali children. Findings revealed that rates of Somali children ages three and four participating in autism disorder services through the public school system was significantly higher than were those of any other racial or ethnic group. Given the stigma surrounding autism in the Somali community and reported reluctance to accept the diagnosis of autism or seek care, it is possible that these findings underestimate the problem. Language barriers also present challenges for some Somali parents/families wanting to access services, whereas others opt to seek treatment from traditional healers.[28]

- In general, people who are deaf or hearing impaired face barriers in accessing high- quality care, including difficulty communicating with providers and accessing information. These barriers can lead to misdiagnosis, medical errors, and patient distrust and fear. Such challenges are exacerbated for individuals who are not fluent in English (e.g., immigrants and refugees) or use ASL.[29]

Testimony, presentations, and discussions at an ACMH meeting on January 5, 2010, highlighted several issues that are particularly important for minorities with disabilities: (1) challenges associated with being dually diagnosed (i.e., having a disability as well as a chronic disease); (2) the potential for and risks of polypharmacy[b]; (3) lack of provider expertise when children with disabilities are transitioning to adulthood; (4) lack of adequate behavioral services for persons with ID/DD; (5) lack of provider expertise with assistive technologies to ensure responsiveness to the evolving needs of persons with disabilities; and (6) inability/failure of health care providers to promote healthy behaviors, active living, and the value of wellness among persons with disabilities. Despite the abundance of recommendations, there are limited federal directed resources and collaborative leadership to implement these recommendations.[30]

Limited Data and Research on Health Inequities among People with Disabilities

People with disabilities experience significant health disparities compared with people who do not have disabilities,[31] and the consequences of disability vary across the life span. A study of the health status of athletes participating in the Special Olympics provides a clear-cut example: two-thirds of these individuals were overweight or obese; nearly one-half had untreated tooth decay or gait abnormalities; one-third was missing teeth; and one-quarter failed hearing tests.[32] Furthermore, it is critical to understand the unique needs and resources of children with special healthcare needs (i.e., children at increased risk for physical, developmental, behavioral, or emotional conditions who require services beyond that required by children generally)[33] and the impact of disabilities on the children and their families. Despite these disparities, people with disabilities are not included in major federal health disparities research. As a consequence, federally funded health disparities research does not recognize people with disabilities as a population that experiences disparities. This lack of recognition makes it extremely difficult to obtain population-based data related to minorities and disabilities.[34]

Federal policy does not identify people with disabilities or subgroups of people with disabilities, as MUPs.[35] As a result, medical students and residents who are interested in working with these populations are not eligible for federal loan repayment programs. In addition, incentives for research and database development are not readily available.

The NCD report finds that federally conducted or supported disability and health research is poorly integrated into overall health disparities and health promotion research. Two specific structural problems impede the development of a unified, coherent plan for disability and health research and program development: (1) the level of funding is inadequate to establish a clear research strategy that will inform policy and planning; and (2) disability health disparities and health promotion research at the federal level is weak and uncoordinated.[36]

Minorities with Disabilities: Conclusions and Recommendations

The ACMH recognizes and understands the consequences of federal and state policymakers as well as other public officials' limited awareness of vulnerable and marginalized population of minorities with disabilities. The charge of the ACMH is to improve the health of racial and ethnic minority populations and raise awareness about issues affecting persons within its constituent communities, who are vulnerable and underserved.[37] To address and overcome the lack of data, knowledge, and culturally competent care specific to minorities with disabilities, the ACMH recommends the following:

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[b] If a person is taking several medications, the risk for drug interactions and side effects increases.

1. Raise awareness about minorities with disabilities.

Multiple strategies should be implemented at the federal, state, and local levels to raise awareness of the health inequities that persons with disabilities experience, especially minorities. The Department of Health and Human Services' (DHHS) Office of Minority Health (OMH) and the Department's Office on Disability (OD) should collaborate to leverage resources for this campaign. DHHS OMH and DHHS OD should widely communicate their support for the NCD 2009 report, *The Current State of Health Care for People with Disabilities,* and use this report to raise awareness about the needs of minorities with disabilities. Furthermore, it is important for agencies to collaborate to develop and operate a platform for the exchange of promising or best practices to eliminate health disparities.

Increased funding is needed to develop strategies that would engage minority communities by providing education on disabilities and resources for advocacy (e.g., providing all families with tools and knowledge that empower them to advocate on behalf of their relatives with disabilities). Strengthening funding and leadership roles of federal groups such as the Interagency Committee on Disability Research (ICDR) of the National Institute on Disability and Rehabilitation Research, as well as funding research on minorities with disabilities that emphasizes a patient-centered approach could further this mission.

2. Recognize disability as a fundamental component of cultural competency.

Health disparities within the disabled community have been attributed in part to a lack of cultural competency among providers.[38] Consideration of culturally specific differences among people with disabilities, and among subgroups of that population, is essential to the provision of effective care and treatment. The lack of understanding of, or limited sensitivity to, the experiences, beliefs, values, and practices of persons with disabilities can have a profound impact on their access to quality care. An individual's cultural identity as both a disabled person and a minority can influence self-perceptions of health and care-seeking behaviors. Providers' misperceptions of patients with disabilities can have a negative impact their ability to provide culturally sensitive and appropriate care. Therefore, in accordance with mandates of health care reform, disability should be considered a fundamental component of cultural competency education for health professionals.[39] Failure to include disability in cultural competency education can result in poor patient-provider communication, mistrust of the provider, inappropriate treatment, and reluctance to seek care.

3. Require competency for all health care providers and professionals.

The Association of American Medical Colleges and the Liaison Committee on Medical Education should establish specific disability competencies required of health care professionals before graduation from medical and residency training programs. They should translate these competencies into specific course recommendations that physician, nursing, pharmacy, and other health profession training programs can adopt.

Disability competency should be a core curriculum component or licensing requirement for (1) accreditation or receipt of federal funding for most medical and dental schools and other professional health care training institutions, (2) hospital participation in federally funded medical student internship and residency programs, (3) applicants who seek a medical or another health care professional license or certification, and (4) continuing education programs. Cultural and linguistic competency training should include mechanisms to address provider challenges such as bias or low expectations and to implement best practices into policy to ensure access to quality healthcare services. Such requirements would ensure that health profession institutions are properly equipped to train future health professionals and health organizations and institutions have protocols in place to provide care and services to patients with disabilities. Teaching, research, and practice organizations should collaborate to develop cultural competency practice guidelines that account for the range of disabilities and diversity of ethnicities.

4. Improve research and practice on disabilities in minority populations.

Congress should increase funding for the ICDR of the National Institute on Disability and Rehabilitation Research to (1) vest it with sufficient resources and authority to fulfill its mandated research coordination role and (2) expand its role to include collaboration with other agencies such as the Centers for Disease Control and Prevention (CDC), the Agency for Healthcare Research and Quality (AHRQ), and DHHS OD, to identify areas for joint health and health disparities research. More funding should be allocated for improved data collection design to support data-based reporting and analyses on inequities regarding morbidity and mortality among minorities with disabilities. For instance, federal support can help states, counties, and cities collect local health data and connect their data to other public databases.

DHHS OMH and OD should review and synthesize the above-referenced major reports on minorities with disabilities and the health disparities and inequities they experience. DHHS OMH and OD should provide leadership by highlighting the need for action based on the recommendations from these reports. This work also will provide DHHS OMH and OD leaders an opportunity to advocate for increased funding for (1) research focused on disabilities in minority populations, and (2) improved data collection on minorities with disabilities throughout relevant federal agencies.

The Federal Collaboration on Health Disparities Research (FCHDR), a collaboration of federal agencies working to find solutions to eliminate health disparities through research, began operations in 2006 to explore, coordinate, and support innovative health disparities research and identify priorities for cross-agency collaboration. Because the research on health and health disparities that government agencies conduct is not coordinated, it is unclear how much research is currently aimed at addressing health disparities and promoting health and wellness for the people with disabilities. ACMH urges continued FCHDR leadership with strong support from DHHS OMH and OD to (1), synthesize and coordinate federal data collection and research; (2) identify or create opportunities for joint health and healthcare disparities research, particularly on minorities with disabilities; (3) promote community based participatory research to strengthen the impact of healthcare delivery systems on healthcare disparities, and (4) support research evaluating the implementation of evidence-based clinical practices.

5. Strengthen the health care workforce to ensure high quality care for people with disabilities.

ACMH urges HRSA, the Centers for Medicare & Medicaid Services (CMS), and other agencies with influence on health care providers to examine strategies that ensure a workforce that provides appropriate, high quality, culturally competent care for people with disabilities. These strategies may include, but are not limited to, applying a Health Professional Shortage Area (HPSA) designation based upon the availability of providers for the disabled population, especially minorities with disabilities. Such a designation would enable physicians, physician assistants, advanced practice nurses, and dentists who choose to provide health care services for a significant number of patients with disabilities to be eligible for the National Health Service Corps (NHSC). The NHSC provides loan repayment in exchange for a service commitment to designated underserved populations. HRSA and other agencies such as CMS and DHHS OD should identify and implement strategies that will encourage providers to serve the people with disabilities.

Concluding Comments

As people with disabilities and people of racial/ethnic minority status face health and healthcare disparities that put them at disadvantage in their quality of life compared to their counterparts, the health and wellness of these populations are public policy concerns that warrant increased attention and action. It is particularly important to raise awareness about the dual burden of inequities that minorities with disabilities face. To improve knowledge, understanding, and care for people with disabilities in general and minorities with disabilities in particular, increased federal support and resources are needed to raise awareness; improve research, practice, and data; and prepare the health care workforce to provide equitable and quality care. Addressing the aforementioned issues and recommended strategies will further movement toward health equity for vulnerable populations and ultimately all people.

Endnotes

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[1] US Department of Health and Human Services Advisory Committee on Minority Health. Ensuring that Health Care Reform Will Meet the Health Care Needs of Minority Communities and Eliminate Health Disparities. A Statement of Principles and Recommendations. July 2009. Available at http://minorityhealth.hhs.gov/Assets/pdf/Checked/1/ACMH_HealthcareAccessReport.pdf

[2] US Department of Health and Human Services Advisory Committee on Minority Health. A Federal Health Equity Commission Will Promote the Public's Health and Ensure Health Equity in Health Care Reform. A Statement of Principles and Recommendations. Submitted to US DHHS OMH, Washington, DC, December 2009.

[3] National Council on Disability. *The Current State of Health Care for People with Disabilities.* September 30, 2009. Available at http://www.ncd.gov/publications/2009/Sept302009

[4] Ibid., Note 3.

[5] Institute of Medicine. *The Future of Disability in America* (Washington, DC: National Academies Press, 2007); Institute of Medicine. *Disability in America: Toward a National Agenda for Prevention* (Washington, DC: National Academies Press, 1991); Surgeon General of the United States. *Call to Action to Improve the Health and Wellness of People with Disabilities* (Washington, DC: Government Printing Office, 2005); DHHS Office on Disability. *Breaking Down Barriers to Health Care for Women with Disabilities: A White Paper from a National Summit* (Washington, DC: Department of Health and Human Services, Office of Women's Health, 2004).

[6] Ibid., Note 3

[7] National Council on Disability. Meeting the Unique Needs of Minorities with Disabilities: A Report to the President and the Congress, April 26, 1993; DHHS Office of Minority Health. Improving the Quality of Life for Minorities with Disabilities, Closing the Gap, October/November 1999; DHHS Office of Minority Health. Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation, 2002; US Department of Health and Human Services, *Report of the Surgeon General's Conference on Health Disparities and Mental Retardation*, US Department of Health and Human Services, 2002; First National Child Health and Child Welfare Conference. *Closing the* Disparity Gap for Racial and Ethnic Minority Children: An Investment in Our Future, October 2004; Advisory Committee on Training in Primary Care Medicine and Dentistry. The Role of Title VII Section 747 in Preparing Primary Care Practitioners to Care for the Underserved and Other High-Risk Groups and Vulnerable Populations, November 2005.

[8] Ibid., Note 3.

[9] Surgeon General of the United States. *Oral Health in America: A Report of the Surgeon General.* May 2000 (Washington, DC: US Department of Health and Human Services); Discussion and presentations at ACMH Meeting January 5-6, 2010.

[10] Surgeon General of the United States. *Oral Health in America: A Report of the Surgeon General.* May 2000 (Washington, DC: US Department of Health and Human Services); Discussion and presentations at ACMH Meeting January 5-6, 2010.

[11] Ibid. Note 10

[12] Ibid., Note 3.

[13] Ibid., Note 3.

[14] US Department of Health and Human Services Advisory Committee on Minority Health. *Reducing Health Disparities by Promoting Patient-Centered Culturally and Linguistically Sensitive/Competent Health Care,* submitted to US DHHS OMH, Washington, DC, September 8, 2008.

[15] Lewis, Allen. Disability disparities: A beginning model. (2009). *Disability & Rehabilitation* 31(14):1136-1143. Available at http://www.ingentaconnect.com/content/apl/tids/2009/00000031/00000014/art00004.

[16] Eddey, G.E, and K.L. Robey. (2005). Considering the culture of disability in cultural competence education. Academic Medicine 80(7):706-712.

[17] U.S. Department of Health and Human Services. Healthy People 2020 Public Meetings: 2009 Draft Objectives. Available at: http://www.healthypeople.gov/HP2020/Objectives/files/Draft2009Objectives.pdf. Accessed 5/6/10.

[18] Ibid. Note 3

[19] Ibid., Note 3.

[20] Rader, Rick. "Add This to the Pile: The Simultaneous Oppression of Minorities with Disabilities Seeking Health

Care Justice." Presentation to the Advisory Committee on Minority Health, January 5, 2010.

[21] Ibid., Note 20.

[22] Ibid., Note 20.

[23] Ibid., Note 20.

[24] Ibid., Note 20.

[25] Vernon, Ayesha. (1997). Fighting two different battles: Unity is preferable to enmity. In L. Barton & M. Oliver (Eds.), Disability studies : Past, present, and future (pp. 255-262). Leeds: The Disability Press.

[26] Corbin, Stephen B. "To Live Well with a Disability – A Report Card of 'Ds' Won't Pass." Presentation to the Advisory Committee on Minority Health, January 5, 2010.

[27] Ibid., Note 20.

[28] Minnesota Department of Health. March 2009. Autism Spectrum Disorders among Preschool Children Participating in the Minneapolis Public Schools Early Childhood Special Education Programs. St. Paul, MN.

[29] Iezzoni, L., B.L. O'Day, M. Kileen, and H. Harker (2004). Communicating about health care: Observations from persons who are deaf or hard of hearing. *Annals of Internal Medicine* 140;356-362.

[30] Correa-de-Araujo, Rosaly. "US DHHS Office on Disabilities Overview." Presentation to Advisory Committee on Minority Health, January 5, 2010.

[31] Ibid., Note 3. NCD urges that Congress amend the Minority Health and Health Disparities Research and Education Act of 2000 to broaden the definition of "health disparity population" found in 42 U.S.C. § 287c-31(d) to encompass "populations for which there is a significant disparity in the quality, outcomes, cost, or use of health care services or access to or satisfaction with such services as compared to the general population," as specified in 42 U.S.C. § 299a-1(d). This would enable people with disabilities to be included in the health and health care disparities research, program development, professional training, health promotion, and clinical interventions conducted and supported by the National Center on Minority Health and Health Disparities, as well as by other federal agencies engaged in health disparities research and activities on behalf of racial and ethnic minorities and other geographic and population groups.

[32] Ibid., Note 20.

[33] McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102(1, pt 1):137-140.

[34] Ibid., Note 14.

[35] Ibid., Note 20.

[36] Ibid., Note 3.

[37] Ibid., Note 8.

[38] Ibid., Note 14.

[39] Ibid., Note 14

THE SENATE SELECT COMMITTEE ON AUTISM & RELATED DISORDERS

Chair, President pro Tempore
Darrell Steinberg

"A Report by the Taskforce on Equity and Diversity for Regional Center Autism Services"

Submitted by Taskforce Staff:
Lou Vismara, MD
Bob Giovati
Concepción Tadeo

2013-2014 Legislative Session

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Contents

Executive Summary 1

Chapter 1 Overview of the Taskforce on Equity and Diversity for Regional Center Autism Services 5

Chapter 2 Existing Statutes and Regulations That Promote Equity, Diversity and Cultural Competence 13

Chapter 3 Regional Centers Must Provide Information in a Linguistically and Culturally Competent Manner 27

Chapter 4 Demographic Analysis of Purchase of Service Expenditures by the Regional Centers 39

Chapter 5 Performance & Outcome Measures on Issues of Equity, Diversity and Cultural Competency 49

Chapter 6 Guidelines & Best Practices on Issues of Equity, Diversity and Cultural Competency 65

Appendices 80

References 117

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The Taskforce on Equity and Diversity for Regional Center Autism Services

Executive Summary

Autism Spectrum Disorders and Issues of Cultural Competency

Autism spectrum disorders (ASD) are complex neurological disorders that have an onset in infancy and can cause mild to severe difficulties in childhood development, including language delays, communication problems, limited social skills, and repetitive and other unusual behaviors. Nationally, ASD now affects an estimated one in every 88 children across all racial, ethnic, and socioeconomic backgrounds. Although the etiology of ASD is unknown, experts believe there is more than one cause for ASD. Genetic factors appear to play a role, and there is growing scientific evidence about the role of environmental influences. Research is underway to investigate the extent genetic and environmental factors contribute to ASD.

The significance of socioeconomic, psychosocial, and cultural factors in the evaluation and treatment of ASD are considered to be very important, but unresolved, issues. According to data from the National Survey of Children's Health being black, Latino, or poor was associated with decreased access to services (http://www.cdc.gov/nchs/data/series/sr_10/sr10_254.pdf).

The National Institute on Minority Health and Health Disparities (NIMHD) has also stated that disparate socioeconomic differences, which can be attributed to a complex interaction among multiple factors, are largely responsible for the widening differences in health status among racial and ethnic lines. Furthermore, these demographic considerations may further influence health disparities for under-served individuals by impacting other health-related dynamics such as genetics, environment, and racial bias, fragmented organization of services, and the patients' fear and mistrust of the healthcare system. It appears likely that many of these same issues, related to equity, diversity, and cultural competency, are important determinants and influences within the regional center system of care. Therefore, careful attention to the assessments and recommendations that are being implemented by healthcare systems for these issues may provide significant and innovative solutions for regional center consumers and providers.

Taskforce and Workgroups on Equity and Diversity for Regional Center Autism Services

On April 30, 2012, the Senate Select Committee on Autism and Related Disorders (Committee) held an informational hearing at the State Capitol in Sacramento, California. The purpose of the hearing was to examine questions of fair and equal access to regional center services for families and consumers with autism spectrum disorders (ASD). As a result of the information and testimonies presented at this hearing, Senator Steinberg convened the Taskforce on Equity and Diversity for Regional Center Autism Services (Taskforce). This multidisciplinary group, established under the auspices of the Committee, was charged with providing findings and recommendations to ensure that all Californians who are currently regional center consumers, regardless of their race, ethnicity, educational background, or other socio-economic factors, receive appropriate interventions and supports for autism spectrum disorders in a timely, equitable, and fair manner. Furthermore, that the regional centers provide these state-funded programs and services impartially and without bias.

The work of the Taskforce was assisted and supported by five workgroups that were established to carefully scrutinize various aspects of regional center operations with a view to identifying legitimate problems of equity and diversity and improving service distribution. Subsequently, the five workgroups, based on expertise and reviewing extensive data and information, concluded that various shortcomings existed within some of the regional centers as to how services were being delivered to disadvantaged consumers. It was further noted that a variety of reasons existed for these disparities. Based on the extensive list of findings and recommendations submitted by the Taskforce and workgroup members, the staff has compiled a preliminary synopsis of these proposals that are being presented in this initial draft report.

Summary by the Taskforce Staff of the Initial Findings and Policy Recommendations by the Taskforce and Workgroups

The staff of the Taskforce carefully and extensively reviewed all of the findings, conclusions, and comments that were submitted by the Taskforce and affiliated Workgroups. Based on these initial findings and reports the staff has proposed the following recommendations that were summarized as follows:

1) The Individual Program Plan (IPP), which is the cornerstone of the Lanterman Act, must be culturally and linguistically competent (Chapter 2, pages 14-17).

2) Culturally and linguistically competent services must offer flexibility and creativity (Chapter 2, pages 17-20).

3) All regional centers must establish a strategic plan to achieve equity and cultural competency (Chapter 2, pages 20-22).

4) Cultural and linguistic competency require partnerships with community-based organizations and generic resources (Chapter 2, pages 22-24).

5) Regional centers must receive appropriate funding and resources in order to provide culturally and linguistically competent services (Chapter 2, pages 24-26).

6) There must be availability of statewide resources (Chapter 3, page 31-32).

7) The Individual Program Plan (IPP) should comply with national standards on equity and cultural and linguistic competency (Chapter 3, pages 33-34).

8) There must be a commitment by the Department of Developmental Services (DDS) and regional centers to continuous quality improvements in providing services that promote equity and cultural and linguistic competency (Chapter 3, pages 34-36).

9) Regional centers should establish a partnership with consumers, and their families, to promote equity, diversity and cultural and linguistic competency (Chapter 3, pages 36-38).

10) There must be effective implementation of Welfare & Institutions Code (WIC) Section 4519.5, which includes uniform data collection, analysis, evaluation, transparency, and oversight (Chapter 4, pages 41-45).

11) DDS should establish effective accountability to the legislature that is consistent with existing laws and regulations (Chapter 5, pages 50-53).

12) DDS should provide leadership to establish a culture that promotes equity, fairness, and diversity within the regional center system of care (Chapter 5, pages 54-55).

13) DDS should provide standards, guidelines, and outcome measures, consistent with current healthcare standards that regional centers can utilize as self-assessment tools in promoting equity and diversity for autism services (Chapter 5, pages 56-57).

14) DDS should collaborate with existing resources to provide guidance and oversight on issues of equity and diversity (Chapter 5, pages 57-60).

15) DDS should establish performance measures and indicators that are consistent with current healthcare standards (Chapter 5, pages 60-62)

16) DDS should establish performance contract outcome measures to provide oversight on issues of equity and diversity (Chapter 5, pages 62-64).

17) Cultural competency best practices and community outreach should utilize specific examples of effective regional center programs (Chapter 6, pages 67-74).

18) Regional centers must establish new public-private partnerships and implement innovative approaches to obtain non-state resources (Chapter 6, pages 75-77).

19) Additional strategies to implement best practices on cultural and linguistic competency should be evaluated regularly (Chapter 6, pages 77-79).

Conclusions and Next Steps

In these difficult financial times, some of the recommendations will have to wait until additional funding is available. Many of the suggestions offered cannot be accomplished in a revenue neutral setting. Furthermore, this draft report, which is based on the initial findings and recommendations of the Taskforce and Workgroups, is submitted by the staff as a preliminary document. The staff recommends that, following a careful review and input by the Taskforce members, this report should be distributed to the public for their comments and as part of a comprehensive and thorough evaluation process. Following the completion of this vetting process, the staff recommends that a final report should be submitted to the members of the Senate Select Committee on Autism and Related Disorders for their review, consideration of another public hearing on this issue, and possible final approval.

CHAPTER ONE:

The Taskforce on Equity and Diversity for Regional Center Autism Services

Recent and emerging evidence in the number of children diagnosed with Autism Spectrum Disorders (ASD) in California and the United States indicates that ASD have reached a a level of public health crisis that must be addressed (1-3). ASD, which consist of complex neurological disorders of development that onset in early childhood, include full spectrum autism and related disorders such as Asperger's Syndrome, Pervasive Developmental Disorder (PDD), and PDD-Not Otherwise Specified. These disorders affect the functioning of the brain to cause mild to severe difficulties, including language delays, communication problems, limited social skills, and repetitive and other unusual behaviors.

Nationally, ASD now affects an estimated one in every 88 children across all racial, ethnic, and socioeconomic backgrounds (4). ASD is more prevalent in males and affects one in every 54 boys. The spectrum of ASD represents the fastest growing serious developmental disability in California and the nation. ASD is more common than childhood cancer, juvenile diabetes, and pediatric AIDS combined.

California's Services for Individuals with Autism Spectrum Disorders

In many respects California is well positioned, compared to other states, to meet the service needs of individuals with ASD and their families. In 1971, autism was added to the state's Lanterman Developmental Disabilities Services Act (Lanterman Act), and under that law California provides more services to persons with ASD and their families than any other state.

No other state has such an extensive infrastructure of community-based programs and services across multiple systems of care available to individuals with ASD and their families. The state developmental services system provides treatment, habilitation, and other services to Californians with developmental disabilities so that they may lead more independent, productive, and integrated lives. Persons with full spectrum autism are eligible for services. Individuals with other forms of ASD are not eligible for state-funded services unless they are determined by the regional center staff to have

impairments that constitute a substantial disability. The California Department of Developmental Services (DDS) contracts with 21 regional centers across the state. These regional centers, which are organized as separate 501C3 non-profit corporations, are the entities that coordinate, purchase, and provide community-based services for eligible consumers with developmental disabilities.

Nearly 60,000 Californians with autism are now served through the regional center services system. The number of individuals with autism in the system has more than tripled since 1998 and increased more than twelvefold since 1987. During the past five years, the system experienced an annual net increase of about 3,200 persons with autism. These 3,200 persons added each year represent about 50 % of all persons added to the system statewide. Approximately 85 % of the consumers with ASD are under age 22, indicating that a large wave of persons with autism will enter adulthood beginning in a few years.

California's Early Start Program provides service coordination and screening, diagnostic, assessment, and various early intervention services to children from birth up to 36 months of age who have a developmental delay or are at risk of delayed development or a developmental disability and their families. The program is implemented in the community by the regional centers under contract with the California Department of Developmental Services. More than 40,000 California children, about 2.5 % of children under age three, are served through the program annually. It is unknown how many children served have the symptoms or diagnosis of ASD since many children do not have an official diagnosis by age three.

Table 1 shows the funded regional centers that provide services to consumers and families in California.

Table 1. Directory of Regional Centers in California

Regional Center	County	Counties Serve
1. Alta California Regional Center	Sacramento	Alpine, Colusa, El Dorado, Nevada, Placer, Sacramento, Sierra, Sutter, Yolo, Yuba
2. Central Valley Regional Center	Fresno	Fresno, Kings, Madera, Mariposa, Merced, Tulare
3. East Los Angeles Regional Center	Los Angeles	Eastern Los Angeles (including Alhambra, Whittier)
4. Far Northern Regional Center	Shasta	Butte, Glenn, Lassen, Modoc, Plumas, Shasta,

		Siskiyou, Tehema, Trinity
5. Frank D. Lanterman Regional Center	Los Angeles	Central Los Angeles (including Burbank, Glendale, Pasadena)
6. Golden Gate Regional Center	San Francisco	Marin, San Francisco, San Mateo
7. Harbor Regional Center	Los Angeles	Southern Los Angeles (including Bellflower, Harbor City, Long Beach, Torrance)
8. Inland Regional Center	San Bernardino	Riverside, San Bernardino
9. Kern Regional Center	Kern	Inyo, Kern, Mono
10. North Bay Regional Center	Napa	Napa, Solano, Sonoma
11. North Los Angeles County Regional Center	Los Angeles	Northern Los Angeles (including San Fernando, Antelope Valley)
12. Redwood Coast Regional Center	Del Norte	Del Norte, Humboldt, Mendocino, Lake
13. Regional Center of the East Bay	Alameda	Alameda, Contra Costa
14. Regional Center of Orange County	Orange County	Orange County
15. San Andreas Regional Center	Santa Clara	Monterey, San Benito, Santa Clara, Santa Cruz
16. San Diego Regional Center	San Diego	Imperial, San Diego
17. San Gabriel/Pomona Regional Center	Los Angeles	Eastern Los Angeles (including El Monte, Monrovia, Pomona, Glendora)
18. South Central Los Angeles Regional Center	Los Angeles	Southern Los Angeles (including Compton, Gardena)
19. Tri-Counties Regional Center	Santa Barbara	San Luis Obispo, Santa Barbara, Ventura
20. Valley Mountain Regional Center	San Joaquin	Amador, Calaveras, San Joaquin, Stanislaus, Tuolumne
21. Westside Regional Center	Los Angeles	Western Los Angeles (including Culver City, Inglewood, Santa Monica)

California's public education system is responsible for the education of children with ASD beginning at age three. Local education agencies, primarily school districts, educate many children with high-functioning ASD through regular education programs. During the six years between 2001 and 2007, the number of children with ASD in California's special education system increased by 183 %, representing an average increase of more than 4,000 children each year. The growth in the special education population with ASD far outpaced the 3.9 % rate of growth in K-12 enrollment from 2000-01 to 2006-07.

A variety of physicians, behavioral providers, speech and language therapists and other care professionals in California have an important role to provide interventions and supports for individuals with ASD and their families. Low-income Californians who are eligible for health care may access services for the diagnosis and medically necessary treatment of ASD through the state's Medi-Cal Program. California's mental health parity law, Assembly Bill 88 (Thomson), Chapter 534, Statutes of 1999, requires the majority of private health plans and insurers in California to provide covered individuals with coverage of health care and mental health care services for the diagnosis and medically necessary treatment of ASD. Furthermore, SB 946, which was authored by Senator Steinberg and signed into law in 2011, mandated that private health plans and insurance companies provide coverage for applied behavioral analysis (ABA), and other forms of validated behavioral health treatments, for individuals with ASD.

The Challenges of Equity, Diversity and Cultural and Linguistic Competency

For decades, health disparities have been an ongoing public health problem in the U.S. and California, especially for racial and ethnic minorities as well as for other underserved populations. Such disparities can result in severe health, social and economic consequences including increased mortality. The challenges are even greater for Latino and African-American children (5). The Institute of Medicine's landmark report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* provides extensive evidence that racial and ethnic minorities have less access to health care and are more likely to receive lower quality health services than white Americans (7). Additionally, these disparities and inequities are associated with adverse outcomes, increased costs and expenditures, overutilization of inappropriate resources, and potentially catastrophic medical errors (6-7). In order to effectively address healthcare disparities, health systems overall must be committed to change – and not just by frontline providers, but by leaders and planners, administrators and support staff – the whole system.

For more than a decade, cultural and linguistic competency has been an emerging issue in health care delivery to potentially achieving health equity. This premise is supported by research from Magaña and colleagues (8) who contend that improving providers cultural sensitivity and behavior during their interactions with a child with

ASD may reduce disparities in the health care utilization, particularly among Latino children. The U.S. Census Bureau recently announced that for the first time, white infants no longer comprised a majority of births. Hispanic, Black, Asian and other non-white infants accounted for 50.4% of U.S. births in the 12-month period that ended last July. The number of people in the U.S. who don't speak English as their native language has grown 140% over the past three decades, according to the Census Bureau (9).

California, which has been a "majority minority" state since the late 1990s, has been leading the way on issues related to equity, diversity and cultural and linguistic competency. In California, diverse communities account for about 60% of the population. Officials estimate about 40% of Californians speak a language other than English at home and that the number of individuals whose first language is Spanish, Chinese, Tagalog, Korean, Vietnamese or another of the 100 languages spoken in the state, is rapidly proliferating.

Issues of equity, diversity, and cultural and linguistic competency have been noted with regards to regional center services. In December, 2011, Los Angeles Times staff writer Alan Zarembo and his colleagues (10) authored a four part series on autism that provided a multifaceted and interesting view of ASD. These articles provided data and information with regards to potential inequities in ASD services by regional centers.

Informational Hearing by the Senate Select Committee on Autism and Related Disorders

In response to the articles from Zarembo and colleagues, and subsequent concerns that were expressed by some consumers, families, and advocates, Senator Darrell Steinberg, on April 30, 2012, convened an informational hearing on these issues by the Senate Select Committee on Autism and Related Disorders (Committee). A full video recording of this hearing, as well as transcripts and other background information, are on the Committee's website: http://autism.senate.ca.gov/informationalhearings .

The overall information that was presented at that hearing provided disturbing details of apparent disparate public spending by some regional centers to diverse and underserved communities. In response to these findings and apparent inequalities,

Senator Steinberg established the Taskforce on Equity and Diversity for Regional Center Autism Services (Taskforce) to work under the auspices of the Committee. The list of Taskforce members is provided in Appendix A. This group of multidisciplinary experts, which included consumers, families, advocates, regional center staff, autism specialists, researchers, and public policy experts, was charged with providing a thorough and immediate scrutiny of these issues. Furthermore, the Taskforce was requested to furnish specific findings and recommendations to ensure that all eligible consumes, and their families, receive services and interventions that are provided in an appropriate, timely, and effective manner. Senator Steinberg also stressed that, *"In achieving this objective, we must also consider the underlying causes and contributing factors that have resulted in these inequities."*

Taskforce on Equity and Diversity for Regional Center Autism Services

In establishing the Taskforce, Senator Steinberg instructed its members to provide findings and recommendations with regards to the following five topic areas: 1) existing statutes, regulations, and compliance requirements; 2) regional center methodologies in providing information in a culturally and linguistically competent manner; 3) assessment and oversight on the demographic analysis (WIC 4519.5) of the purchase of services expenditures by regional centers; 4) performance and outcome measures related to equity/diversity; and, 5) best practices related to cultural and linguistic competency for regional center services.

The Taskforce, co-chaired by Dr. Sergio Aguilar-Gaxiola and Ms. Areva Martin, determined that each Taskforce member would focus primarily on one of the five topic areas noted above. Equally, the Taskforce and co-chairs recognized the importance of additional experts to achieve the objectives of each of these five workgroups. This cadre of additional experts were nominated and appointed by the Taskforce and designated as Workgroup members. Thus, the Taskforce was subdivided into a total of five Workgroups. Each group would consist of four Taskforce members and six Workgroup individuals and focused specifically on one of the topic areas (regulations; effective communication; WIC 4519.5; outcome measures; best practices) noted above.

Recommendations and Next Steps

The Taskforce had several virtual meetings that were achieved by either webinars or conference calls. Key findings and recommendations included in this draft report emerged from the work of the five workgroups. Specifically, members of each of the five workgroups conducted and participated in numerous conference calls and discussions. Subsequently, the staff prepared a draft of the findings and recommendations from each group. In some cases, contrasting and dissimilar findings were submitted by the same group. Therefore, the Taskforce staff conducted an extensive review of these initial Workgroup recommendations and combined those that were similar while at the same time organizing recommendations into categories. Finally, the staff prepared and submitted this preliminary draft report based on the following considerations:

- Conclusions that appeared to be consistent with a majority opinion of the Taskforce and Workgroup members.
- Results that either could be implemented in the foreseeable future or at a time when additional funding and resources might be available.
- Findings and recommendations that are congruent with the regional centers' infrastructure and existing systems of care.
- Proposals that were consistent with established best practices and could promote effective "systems changes" to improve regional center services.
- Strategies that were measurable and could be linked to specific outcome measures.

The staff is submitting this preliminary report to Senator Darrell Steinberg, Chairperson of the Senate Select Committee on Autism and Related Disorders. The staff assumes full responsibilities for these initial findings and recommendations, and emphasizes that this report is still in its draft form. The staff recommends the following actions and next steps:

- Distribution of this draft to all of the Taskforce members for their input with potential revisions based on comments from Taskforce members.

- Distribution to all of the Committee members for their review and revisions.
- Following the approval of a preliminary draft report by Committee, the release of the preliminary draft report for public comment.
- Public hearing by the Senate Select Committee on Autism and Related Disorders.
- Approval of final report by the Senate Select Committee on Autism and Related Disorders.

CHAPTER TWO:
Existing Statutes and Regulations That Promote Equity, Diversity and Cultural Competency

Testimony and discussions during the April 30, 2012 hearing by the Senate Select Committee on Autism and Related Disorders (Committee) questioned whether existing laws and regulations within the Lanterman Developmental Disabilities Act were being appropriately enforced to ensure the fair and equitable allocation of regional center services. Although there were no indications of any intentional or premeditated improprieties, a lack of knowledge or information, inadequate resources, or the absence of an appropriate infrastructure, could result in the lack of implementation and oversight of existing regulatory requirements.

Therefore, pursuant to the instructions provided by Senator Steinberg and the Committee, the Taskforce on Equity and Diversity for Regional Center Autism Services (Taskforce) established a Workgroup on Existing Laws and Regulations (Workgroup #1) in order to identify and review existing statutes, regulations, and prerequisites, as well as the oversight and compliance procedures, which are related to regional center services for ASD and are intended to ensure that these services are provided to consumers and their families in a timely, fair and equitable manner.

Workgroup #1 was led by Ms. Catherine Blakemore (Executive Director, Disability Rights California, Inc.) and Mr. George Stevens (Executive Director, North Los Angeles County Regional Center) and included representatives of consumers, providers, academia, advocacy, and healthcare. A complete list of Workgroup #1 members and their affiliations is provided in Appendix B.

California is facing significant fiscal constraints now and in the foreseeable future. Therefore, Workgroup #1 approached its work by balancing the necessity to close the most urgent gaps related to equity and diversity, with the reality of limited resources in the immediate years ahead. Workgroup #1 embraced three key strategies in providing its recommendations that included the following:

- That the recommendations reflect the most pressing issues and gaps, related to inequalities, identified by regional center consumers and their families.

- That the recommendations promote the development of successful models in order to achieve equity, diversity, and cultural competence.
- That the recommendations promote greater awareness, monitoring, and accountability on issues related to equity, diversity, and cultural competence.

The Individual Program Plan (IPP) – A Cornerstone of the Lanterman Act – Must be Culturally and Linguistically Competent

The Lanterman Act requires that a person who receives services from a regional center must have programs, services and supports that are "person-centered" and that are based on the specific assessment and needs of each consumer. This planning effort is not a single event or meeting, but a series of discussions or interactions among a team of people including the person with a developmental disability, their family (when appropriate), regional center representative(s) and others.

The description of these services, which is referred to as a "preferred future" by some regional centers, is based on the individual's strengths, capabilities, preferences, lifestyle and cultural background. Thus, the planning team decides what needs to be done, by whom, when, and how, if the individual is to begin (or continue) working toward the preferred future. The document known as the Individual Program Plan (IPP) is a record of the decisions made by the planning team.

In 1992, amendments to the Lanterman Act provided significant details and specificity as to the manner in which the IPP must be implemented by the Department of Developmental Services (DDS) as well as the regional centers. These regulations, which are posted on the DDS website https://dds.ca.gov/Statutes/LawsRegs_Home.cfm are contained in the Welfare & Institutions Code Sections: 4500 et. seq.; 4646(a) & (c); 4502(j); 4502.1; 4646.5(a)(1); 4646(d) & (g); 4646.5(a)(4) & (c)(3); 4648.1.

It is important to note that these regulations require the following:

- DDS will prepare a standard format for IPPs, with instructions. The format and instructions will embody an approach centered on the consumer and family.
- DDS will prepare training materials to implement the person-centered approach to IPPs.

- To insure a person-centered approach to IPPs, each regional center shall use the standard format, instructions, and training materials prepared by DDS.
- All public or private agencies receiving state funds for providing the services and supports selected through the IPP process shall respect the choices made by consumers including, but not limited to, where and with whom they live, their relationships, the way they spend their time, the pursuit of their personal future, and program planning and implementation.
- The activities of employees of the regional centers and service providers related to person-centered IPPs, shall reflect awareness of, and sensitivity to, the lifestyle and cultural background of the consumer and family.

Infants and toddlers from birth to 36 months of age may be eligible for early intervention services provided by the Early Start Program (also administered by DDS) if they have a developmental delay in either cognitive, communication, social or emotional, adaptive, or physical and motor development or have an established risk condition of known etiology, with a high probability of resulting in delayed development. Eligibility criteria for this program are detailed in California Government Code Section 95014(a) and services for these infants or toddlers are established, using a process that is similar to the IPP, through an Individual Family Service Plan (IFSP) that is developed to address the strengths, needs of the infant or toddler, parental concerns, and early intervention services.

The existing provisions of the Lanterman Act clearly require that issues of equity, diversity, and cultural and linguistic competence must be considered as decisive and essential components of every IPP and IFSP. Not only are these issues crucial to the very concept of person centered planning, but the efficacy and outcomes of programs and services are also directly related to providing interventions that delivered in a culturally and linguistically competent manner.

I. Recommendations By Taskforce Staff

A. DDS and regional centers should ensure that all consumers, and their families, receive information including written document(s) about the IPP/IFSP process and procedure and regional center services and supports that is culturally and

linguistically appropriate. This information should be provided at these three junctures:

a. Before the IPP/IFSP meeting: Information in the consumer/family's preferred language should be provided about: 1) the IPP/IFSP process and timelines, 2) required content of the IPP/IFSP (i.e., goals/objectives, timelines, etc.), 3) consumer rights with respect to the denial of services (i.e., due process, complaint procedures), and 4) services and supports that can be purchased by regional centers and the responsibility of regional centers to assist in obtaining generic resources.

b. At the IPP/IFSP meeting: IPP/IFSP meetings should be conducted in the consumer/family's preferred language. Within an appropriate and timely manner, following the conclusion of the IPP/IFSP process, consumers and families should be provided, as additional resources and funding are available, with a document (in the consumer/family's preferred language) that provides information about services that have been agreed to at the IPP/IFSP meeting (including the amount, frequency, duration, location, start date, and provider of the services and other requirements of Welfare and Institutions Code 4646.5).

c. After the IPP/IFSP meeting: Consumer and family should receive the IPP/IFSP document in the consumer's and family's preferred language no later than 30 days after the IPP/IFSP meeting. Moreover, all informational documents should be delivered using simple methods recognizable to the consumer and their family.

B. DDS and regional centers should ensure that all consumers, and their families, receive information that is culturally and linguistically appropriate on "consumer rights". This information must indicate the steps a consumer or family can take if they disagree with the IPP outcomes; including procedures such as the IPP appeals and complaint process, and the additional resources that are available as part of the appeals course of action.

C. DDS and regional centers, as additional resources and funding are available, should ensure that all consumers, and their families, receive information that is culturally and linguistically appropriate on the services that are available and provided by the regional center, including service coordination responsibility and advocacy assistance, to assist the consumer and family in accessing services available through generic resources and private entities including health insurance.

D. The final IPP document should include proposed dates by which these services shall be implemented.

E. DDS shall require, as additional resources and funding are available, that all consumer information that is obtained, including but not limited to any intake, assessment, evaluation, IPP, and monitoring forms, includes data that is required in Trailer Bill Language 4519.5.

F. DDS and regional centers, as additional resources and funding are available, should post all of the findings and information contained in this section on their respective websites.

Culturally and Linguistically Competent Services Demand Flexibility and Creativity

The complex issues and challenges related to equity and diversity that are currently facing regional centers, and their providers, demand imagination, creativity, and ingenuity. While the concept and the importance of "person-centered planning," which is underscored in the Lanterman Act, would seem to encourage flexibility, other regulatory requirements appear to provide challenges and barriers to addressing issues of equity and diversity. For example, the following issues have been noted as possible IPP/IFSP necessities in order to overcome potential barriers in providing culturally competent regional center services to diverse and underserved communities that are culturally and linguistically appropriate:

- Non-traditional service hours.

- Unique cultural supports and services that may be necessary in the implementation of effective evidence-based therapies for individuals with ASD.
- Cultural preferences that may require the use of "center-based" interventions rather than services which are provided in the natural environment such as the family home.
- Flexibility in adult consumers choosing to live with families/relatives and still be able to obtain appropriate services to enhance the independence, skills and capabilities of the consumer.
- Access to bi-lingual staff who are able to communicate in the consumer's or family's preferred language.
- Access to documents and information in the consumer's or family's preferred language.

Flexibility is also required with regards to certain requirements that may be related to parent or family participation. Parents are currently required to be physically present for many of the services and interventions that are provided to consumers with ASD. However, issues related to equity and diversity may require that the IPP team during the IPP process to determine the appropriate amount of parental participation in programs and services provided to consumers. This approach will provide the planning team with the flexibility and discretion to establish the appropriate criteria and determinations regarding service delivery.

The IPP planning must consider the provision of training to primary caregivers, as well as to family members, in the primary language required by the consumer in order to achieve the goals and objectives of the IPP. Further, the regional centers, as additional resources and funding are available, should be directed to consider parent training alternatives, such as: 1) training that occurs outside of work hours, 2) access to training online, and 3) training using telehealth/telemedicine. These trainings should be delivered in a culturally and linguistically appropriate manner using simple methods and consistent with the consumer's and family's education and health literacy level. Additionally, statutory language should be added to clarify that the requirements for parent training are not intended to act as barriers to treatment or to hinder, decrease, or

delay services provisions for the consumer.

Providing appropriate access to "Participant Directed Services and Fiscal Management Services" is another factor of potential importance to diverse and underserved communities. Previously, consumers and families were able to obtain direct funding from regional centers through a "voucher" system where the consumer or family could hire individuals to provide the following services: day care, nursing services, respite services, community-based training services, and transportation. As a result of changes in federal law, vouchered services are no longer available. Instead, consumers must use participant directed services in conjunction with a fiscal intermediary.

II. *Recommendations By Taskforce Staff*

A. The IPP team must consider the consumer and/or family's needs for the following in determining culturally and linguistically appropriate services that may include, but are not limited to, the following:
   a. Allow for non-traditional service hours (weekends/evenings).
   b. Allow flexibility with requirements, including parental participation requirements.
   c. Allow flexibility regarding the scope of services available for adult consumers who choose to live with families/relatives to obtain appropriate services to enhance independence skills.

B. DDS, in partnership with the regional centers and as additional funding and resources become available, must ensure access to bilingual/bicultural staff and providers by implementing the following:
   a. Develop rate differentials for services and supports which are provided by bilingual staff.
   b. Access to trainings for the regional center staff that are provided by organizations and providers that are culturally/linguistically competent, to trainings that serve cultural/language needs of diverse communities (i.e., *Congreso Familiar*, *Fiesta Educativa*, etc.).
   c. Require new RFPs to address issue of equity/diversity.

d. Partner with community/faith-based organizations that may assist in providing assistance, resources, and supports on issues related to equity and cultural competency.

C. DDS, in partnership with regional centers, and as additional resources and funds are available, should ensure that consumers and their family have appropriate access to participant directed services, including Fiscal Management Services (FMS)/Employer Agent or FMS Co-Employer, and that regional centers, to the extent that is possible, have sufficient choices of vendors for the above services who are capable of delivering services that are culturally and linguistically appropriate to the consumer and his/her family.

All Regional Centers Must Establish a Strategic Plan to Achieve Equity and Cultural and Linguistic Competency

Each regional center is faced with its own unique challenges, gaps, and barriers in achieving equity, diversity and cultural competency for its consumers. Therefore, the members of the Taskforce and Workgroups acknowledged and emphasized that there is not a "one size fits all" single answer; rather specific solutions and strategies to resolve these issues must be developed individually by each of the 21 regional centers. Although specific solutions may vary from one regional center to another, current regulations require that "DDS will prepare a standard format for IPPs, with instructions. The format and instructions will embody an approach centered on the consumer and family." Thus, DDS should establish a basic framework, with accompanying guidelines and regulations, related to issues of cultural and linguistic competence, to serve as a standard for all 21 regional centers.

Issues of equity and diversity were not prominently featured or discussed during the initial planning and implementation of the Lanterman Act. However, California's current demographics indicate that the white, non-Latino population has become a minority within the state and issues of equity and cultural and linguistic competency must be considered as an urgent priority that demands the immediate attention of DDS and of all the regional centers.

Therefore, the members of the Taskforce and Workgroup #1 strongly endorsed the concept that DDS should partner with and provide appropriate supports so that each of the regional centers will develop their own self-assessment, as well as a concurrent strategic plan, to evaluate and address issues related to equity, diversity, and cultural and linguistic competency. These evaluations and plans should be periodically updated on an ongoing basis and should include policies and procedures to provide adequate, appropriate, and ongoing training to all staff members on issues of cultural and linguistic competence, equity, and diversity. Furthermore, regional centers should see to establish contracts with entities who have demonstrated abilities and capabilities to meet the cultural and linguistic needs of the consumers and their families. Regional centers should also seek to develop creative, cost-effective solutions to overcome the disparity that occurs when traditional service formats fall short of meeting the needs of low-income and culturally-diverse consumers. Alternative strategies, which might be considered, could include interventions such as center-based therapy, home, community, or clinic-based therapy, or telehealth/telemedicine services, when the consumer and/or his/her family prefers such alternatives.

III. Recommendations By Taskforce Staff

A. DDS shall require all regional centers to develop a Regional Center Strategic Plan for Equity and Cultural and Linguistic Competency (RESPECT) which shall address issues, outcomes, and monitoring related to culturally and linguistically competent services and other factors that promote equity, fairness, and diversity.

B. The findings and recommendations contained in the RESPECT shall be updated, at a minimum of every two years and all include, but not be limited, to the following:

   a) Cultural and linguistic competency staff training.

   b) Culturally competent providers and services: Amend Title 17 California Code of Regulations Section 54310: Vendor Application Requirements, to add language that will require providers to include information about language abilities of their staff and their abilities to

provide services in a culturally and linguistically competent manner.

c) Culturally competent data and information.

Cultural and Linguistic Competency Requires Partnerships with Community-Based Organizations and Generic Resources

In view of the rapidly increasing diversity of California and the complexities that are associated with these services, DDS and regional centers must seek effective community-based partnerships in order to address these issues. Many of these grass-roots organizations are not only focused on early child development, but also provide supports for underserved families and have also established an important infrastructure to improve healthcare outcomes among underserved and diverse communities. Partnerships by the regional centers with community-based organizations may also enhance and facilitate access to generic resources. For example, mentoring and supports by neighborhood advocates could provide assistance to regional center consumers through the following activities:

- Promote the dissemination of culturally and linguistically appropriate information, supports, and resources by community-based organizations, medical clinics, and health centers to regional center consumers and families.
- Assist regional center consumers obtaining ABA services from their private insurance companies, as currently mandated by the recent passage of SB 946, authored by Senator Steinberg.
- Establish collaborative partnerships between the regional center and organizations that promote and reflect the demographics (racial, ethnic, language and cultural representation) of the region and community.
- Overcome the stigma that is associated, in some communities, with the evaluation, diagnosis and treatment of developmental disabilities.

Entities that provide services to diverse and underserved consumers have often established a partnership with community-based organizations (including faith-based

groups) that are a highly effective and offer multiple opportunities to achieve equity, diversity and cultural and linguistic competency. These grass-roots associations are not only highly regarded, but usually possess a high "social standing/acceptance and credibility" within various culturally diverse groups, and may serve as important conduits of important information and supports for their members. Furthermore, these organizations are instrumental for sustainability efforts and may also potentially provide resources and supports that could be utilized to leverage and assist the regional center services. Therefore, support that could be provided by these community-based organizations includes the following:

- Dissemination of regional center information and services.
- Provide assistance, and mentoring to regional center consumers and families.
- Assist consumers and families in navigating the regional center system.
- Assist consumers and families in accessing community-based resources and supports such as a *promotora* (community health worker) model.
- Social and emotional supports for regional center consumers and their families

Effective partnerships among regional centers, consumers, and grass-roots associations will require additional budgetary allocations in order to provide administrative supports, effective outreach and engagement, consumer information and assistance, and measurable outcomes. Additional funding would also be required if DDS were to undertake a statewide review of such factors such as the need for regional center assistance in accessing generic resources from public or private entities or the need for the regional center to purchase a needed service, as determined through the individual program planning process, when the generic resource fails to provide the required service.

IV. Recommendations By Taskforce Staff

A. DDS, as additional resources and funding become available, and in partnership with regional centers and other community-based organizations, should furnish consumers with a resource guide that provides information and assistance with

regards to culturally and linguistically appropriate services available to consumers and families in the regional center catchment area.

B. All new "Requests for Proposals" (RFPs) that are associated with consumer programs, supports, or other services that are relevant to issues of equity, diversity, and cultural and linguistic competence shall include a section to evaluate the applicant's ability to partner with community-based organizations on issues of equity and diversity.

C. All regional centers shall establish an Advisory Board for Leadership and Equity (ABLE) that shall promote partnerships between regional centers and community-based organizations and shall seek to accomplish the following:

   a. Meet at least quarterly.

   b. Provide annual findings and recommendations to the regional center Board of Directors on regional center policies and procedures that will promote equity, diversity and cultural and linguistic competency for consumers and their families.

   c. Review and provide input on the Regional Center Strategic Plan for Equity and Cultural Competency (RESPECT)

Regional Centers Must Receive Appropriate Funding and Resources in Order to Provide Culturally Competent Services

Currently there are about 252,000 consumers that are receiving services through the regional center system with a total budget of approximately $4.4 billion annually. The vast majority (73 %) of these consumers live at home, while another 10 % live independently; 15 % live in community care facilities; and less than 1 % reside in state-operated developmental centers. There are about 58,000 regional center consumers with the diagnosis of ASD, and this condition now accounts for almost two-thirds of all new consumers who are entering the regional center system.

DDS contracts with the 21 regional centers, which are private non-profit agencies, to provide a wide array of services including early intervention, behavioral services, respite, residential, supported living, day and work programs. DDS allocates funds,

42 % of which are from federal sources, to regional for either, staffing and administration (operational funding), or for the purchase of services (POS) for consumers. Operational funding, which is based on a state-employee formula developed over 20 years ago, has diminished during recent budgetary reductions. POS funds have been distributed on an historical basis that is predicated on the prior annual expenditure by each regional center.

Recently, DDS has received concerns with regards to disparities between regional center funding and the average amounts spent by various regional centers on their consumers. Therefore, DDS has entered into discussion with the regional centers to develop a new, and more equitable, funding formula that would be driven specifically by the characteristics and the needs of the individual consumers. At the Committee hearing on April 30, 2012, Director Delgadillo explained that DDS is exploring a "bridge formula" that will provide resources and funding to regional centers in a more equitable manner than the prior "historical formula." Ms. Delgadillo further stated that, *"We are on track in terms of developing a new formula that is based on client characteristics that will help address the concerns of today's hearing."* She further explained that the goals of this new funding formula would be *"blind to ethnicity"* since it would be completely based on the individual's characteristics and individual service needs. However, DDS has been unable to furnish additional information on this newly proposed budget allocation formula and the process and timelines for this project were not clearly defined.

V. ***Recommendations By Taskforce Staff***

A. By Dec. 31, 2013, DDS shall report to the offices of the President pro Tempore, Speaker of the Assembly, appropriate policy and budget committees of the Legislature, and the Senate Select Committee on Autism & Related Disorders, the following:

a) Status of budget process to provide funding to regional centers.

b) How this process is consistent with the Lanterman Act.

c) How DDS is monitoring efficacy of its budget allocation process.

d) How DDS is ensuring that rates between regional centers and providers are cost effective.

B. Require that DDS include families, consumers and stakeholders from underserved and diverse communities in the process of establishing any new budget methodology and that DDS establishes a process that is fully transparent, provides ample and appropriate opportunities for public input, and complies with all the requirements for changes in California's statutes and regulations.

CHAPTER THREE:
Regional Centers Must Provide Information in a Culturally and Linguistically Competent Manner

Providing information in a clear, linguistically competent and culturally appropriate manner has the potential not only to achieve health equity and improve health outcomes, but also to create social and physical environments that ensure greater consumer satisfaction, ultimately increasing the efficiency and effectiveness of regional center and support staff. Consumers and families who are seeking regional center services are entitled to a thorough explanation and understanding of: 1) the underlying conditions and diagnosis, 2) the services that are available, 3) the administrative process, and 4) the legal rights to appeal any adverse findings or decisions. Thus, it is vital that all of this information, such as written materials, oral directives, discussions, instructional and informational presentations, be delivered in a way that is accessible and easily understood. It is especially critical that all documents requiring signatures are understood by the consumers and their families.

Health literacy plays a central role in promoting quality of life, healthy development, and healthy behaviors across all groups and life stages. Health literacy is defined as "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (HHS 2000 and Institute of Medicine 2004). According to the US Department of Education's report entitled *The Healthy Literacy of America's Adults – Results from the 2003 National Assessment of Adult Literacy* (13), only 12 % of adults were considered capable to read and comprehend complex medical information because they could comb through complex material to locate information required to define a medical term. It seems then that for individuals with intellectual disabilities, low education levels or a lack of proficiency in English challenges remain. Therefore, literature and information that is provided to consumers, and their families, must be disseminated using methods, venues, and approaches that are accessibly to diverse populations. Existing state law also requires government agencies to write each document that it produces in plain, straightforward language, avoiding technical terms as much as possible and using a coherent and easily readable style. This applies to any written

communication that is necessary to carry out the agency's responsibilities under the law.

Workgroup #2 was led by Ms. Rocio de Mateo Smith (State Council on Developmental Disabilities, Area Board 5) and Ms. Anna Wang (Friends of Children with Special Needs) and included representatives of consumers, providers, academia, advocacy, and healthcare. A complete list of Workgroup #2 members and their affiliations is provided in Appendix C.

Workgroup #2 reviewed a variety of informational materials provided by various regional centers. Workgroup #2 members commented that the development of these materials was irregular at best and ranged from ill-designed and translated materials, which were not easy to read or understand, to excellent educational and informative pieces. Some workgroup members expressed the opinion that the substandard materials were, for the most part, "at least better than nothing" illustrating the lack and unsatisfactory nature of these materials and stressing the need to improve them.

Materials that were deemed to be effective and innovative often reflected knowledge of the issues and an awareness of the characteristics of regional center consumers in specific service areas. Examples of three successful methods included: 1) inclusion and implementation of the "promotora model" (see Chapter 6, page 73); 2) a conversationally written "fotonovela" or media booklet used in Marin County; and 3) information available in various languages on the DDS website: http://www.dds.ca.gov/Publications/docs/DDSBrochure_English.pdf. However, Workgroup #2 noted that many of the regional center websites were not current and as user friendly for consumers and often lacked relevant information pertinent and language-appropriate to consumers and their families.

The Individual Program Plan (IPP)

The IPP Process – a cornerstone of the Lanterman Act – is a "person-centered" approach that under the guidance of a service coordinator establishes that the services and supports a consumer and his/her family receive through the regional center, its providers and vendors, and/or the generic services available in the community are the

ones they need. Even after a family has already established a history with the regional center, a lack of clarity and language barriers can create unnecessary problems for consumers and families already taxed. A story that was reported to workgroup #2 illustrates this point:

> *A Filipino family with an autistic son receiving services from one of the regional centers included a military father that spoke and read English and a mother that spoke primarily Tagalog and had limited English capacity. During the father's military deployment, which lasted nine months, the case worker asked the mother if her son was tired and wanted to reduce services. The mother understood tired and agreed he was tired after a long day of school and therapy but did not understand that she was perceived as in agreement with reducing service hours for her son. She received a letter from the regional center informing her of the service change but, not reading English, she did not understand. By the time she was able to scan it to her husband, who was deployed on a ship at sea, the time to respond formally had expired and the family lost a significant amount of treatment hours for their son. The family was distraught, the son started to regress, and undue additional stress was created but there was nothing that could be done to change what had already happened.*

It is crucial that, at a minimum, the IPP process and services be delivered in an appropriate manner including using language that is understood by the consumer/family so that they are able to provide informed consent for treatment and services, realize the process taking place and can "actively participate in the development of the plan", an existing requirement in current law. All written correspondence must be in the consumer/family's primary language so they know what to expect, what is included in the IPP plan, and what steps they need to take if they are not in agreement.

I. ***Recommendations By Taskforce Staff:***

A. Incorporate primary language and cultural background considerations into existing law governing the IPP process, as follows (recommended statutory changes are noted in **"bold and underlined":**

a. Institutions Code 4646. (a) It is the intent of the Legislature to ensure that the individual program plan and provision of services and supports by the regional center system is centered on the individual and the family of the individual with developmental disabilities and takes into account the needs, ~~and~~ preferences, **preferred language and cultural background** of the individual and the family, where appropriate, as well as promoting community integration, independent, productive, and normal lives, and stable and healthy environments. It is the further intent of the Legislature to ensure that the provision of services to consumers and their families be effective in meeting the goals stated in the individual program plan, reflect the preferences and choices of the consumer, and reflect the cost-effective use of public resources.

b. Welfare and Institutions Code 4646. (c) An individual program plan shall be developed for any person who, following intake and assessment, is found to be eligible for regional center services. These plans shall be completed within 60 days of the completion of the assessment. At the time of intake, the regional center shall inform the consumer and, where appropriate, his or her parents, legal guardian or conservator, or authorized representative, **in their preferred language** of the services available through the local area board and the protection and advocacy agency designated by the Governor pursuant to federal law, and shall provide the address and telephone numbers of those agencies.

c. Welfare and Institutions Code 4646. (e) Regional centers shall comply with the request of a consumer, or where appropriate, the request of his or her parents, legal guardian, conservator, or authorized representative, that a designated representative receive written notice, **in their preferred language,** of all meetings to develop or revise his or her individual program plan and of all notices sent to the consumer pursuant to Section 4710. The designated representative may be a parent or family member.

d. Welfare and Institutions Code 4646. (g) An authorized representative of the regional center and the consumer or, where appropriate, his or her parents, legal guardian, conservator, or authorized representative shall sign the individual program plan**, drafted in their preferred language**, prior to its implementation. If the consumer or, where appropriate, his or her parents, legal guardian, conservator, or authorized representative,

does not agree with all components of the plan, he or she may indicate that disagreement on the plan. Disagreement with specific plan components shall not prohibit the implementation of services and supports agreed to by the consumer or, where appropriate, his or her parents, legal guardian, conservator, or authorized representative. If the consumer or, where appropriate, his or her parents, legal guardian, conservator, or authorized representative, does not agree with the plan in whole or in part, he or she shall be sent written notice**, in their preferred language,** of the fair hearing rights, as required by Section 4701.

e. Add section: **4639.76 (a) The State Department of Developmental Services, in consultation with regional centers, shall provide clear, culturally and linguistically appropriate and easily understood versions of documents referred to in section 4646 and make them available on its website.**

The Availability of Statewide Resources and Supports

The Taskforce and Workgroups noted that regional centers often face daunting challenges, which have been severely exacerbated by recent budgetary reductions, in meeting the needs of California's increasingly diverse populations. For example, one regional center reported the challenges of addressing the over 50 languages and dialects spoken within their catchment area. Another regional center reported that there were an increasing number of consumers of Asian-Pacific Islander ethnicity, but only a few individuals represented some racial and ethnic groups. Thus, identifying culturally and linguistically appropriate information for these few individuals may be both problematic and cost-prohibitive.

As additional funding and resources become available, these problems could be potentially mitigated and improved by implementing the following strategies and approaches:

- DDS should identify performance measures and outcomes related to equity and diversity issues (see Workgroup # 4 report; Chapter 5.)
- DDS should identify those programs and services within the regional center system throughout the state that are most effective in promoting equity and cultural competency (see Workgroup # 5 report; Chapter 6.)

- DDS should promote strategies and best practices by which effective programs and services that promote equity and cultural and linguistic competency could be shared among all of the regional centers.

Thus, regional centers would benefit from assistance in the development of culturally and linguistically appropriate informational and educational materials, the ability to share relevant already existing materials and practices and training of regional center staff, service providers and vendors in culturally and linguistically appropriate service delivery.

II. Recommendations By Taskforce Staff:

A. DDS should serve as a clearinghouse for regional centers to share existing materials, and, as resources become available, to provide assistance to in the development of materials, and training.

B. Amend Welfare and Institutions Code 4639.76 by adding the following sections:

a. 4639.76 (b): DDS, on an ongoing basis and in consultation with regional centers, should select various linguistically appropriate informational and educational materials currently available within the regional center system and make them available for statewide distribution on its website.

b. 4639.76 (c): DDS should, as resources become available, develop, distribute, and make available on its website, multicultural and easily understood consumer and family-related materials in the languages of the commonly encountered groups and/or groups represented in regional center consumer and service area populations. These materials shall be developed in consultation with regional centers to ensure that consumers and their families are receiving vital information in a method that reflects awareness of, and sensitivity to, the lifestyle and cultural background of the consumer and the family, as well as language and literacy levels.

c. 4639.76 (d) DDS, in consultation with regional centers, and as resources become available, should undertake a needs assessment with regards to issues related to cultural and linguistic competency and, contingent upon these results, should develop a plan for the training of regional

center staff, service providers, and vendors in culturally and linguistically appropriate service delivery.

Standardize and Coordinate the IPP/IFSP with Nationally Recognized Standards on Equity and Cultural Competency

A number of healthcare providers and organizations, as well as state and federal agencies, have established nationally recognized standards that are directly related to issues of equity and diversity (see Workgroup #4 report, Chapter Five.)

These guidelines and standards include findings and implementation strategies that result in a diverse staff and leadership that is representative of the demographic characteristics of the service area; ongoing education and training in culturally and linguistically appropriate service delivery; and consumer care that is obtained respectfully and in a manner compatible with cultural health beliefs, practices and preferred language. These standards also provide a framework by which organizations are able to self-evaluate their proficiency in providing linguistic competency supports such as language assistance and interpreter services; bilingual/bicultural staff, verbal offers and written notices, competence of language assistance, patient-related materials and signage. Furthermore, guidelines such as the Culturally and Linguistically Appropriate Services (CLAS) Standards (Appendix D) also encourage organizational supports for cultural and linguistic competency by advancing a systematic and ongoing assessment of topics such as the following: written strategic plans; oversight mechanisms to provide culturally and linguistically appropriate services; ongoing organizational self-assessments consumer data; demographic, cultural, and epidemiological profile of the community; cultural and linguistic competency needs assessment; collaborative partnerships; conflict and grievance resolution processes; public information; successful innovations related to equity and diversity.

Thus, as additional resources and funding become available, it is crucial that the findings and recommendations provided by national recognized models, such as the CLAS Standards, not only be disseminated, but that these principles and outcomes also

be integrated and embedded with the essential fiber of the IPP/IFSP process.

III. Recommendations By Taskforce Staff:

A. Require DDS, as additional resources become available, to establish standards and outcome measures, based on an adaptation of nationally recognized assessment tool on equity and diversity such as the CLAS standards, by which the IPP/IFSP can be evaluated with regards to equity, diversity and cultural competency.

B. Require DDS, as additional resources become available, to promulgate regulations and provide oversight to assure compliance with the requirements in the provision III(B) noted above.

A Commitment by DDS and Regional Centers to Continuous Quality Improvements in Providing Services that Promote Equity and Cultural and Linguistic Competency

During the past several years DDS and the regional center system have incurred cumulative budget cuts and fiscal reductions that total over one billion dollars, which have also resulted in loss of additional federal resources. Therefore, in view of these ongoing fiscal pressures, most regional centers have been hard pressed, if not completely constrained, from attempting to implement new and innovative programs.

Nevertheless, the Taskforce and Workgroup members received information from some regional centers that were successful in implementing self-assessment programs related to equity and diversity. Furthermore, these regional centers reported that conducting a self-assessment program was an important and effective first step in not only achieving cultural and linguistic competency but that these strategies often improved programs and outcomes for all of their consumers.

For example, the Central Valley Regional Center (CVRC) provides ongoing instructions for their case managers that outline specific best practices on issues related to cultural competency, equity, and diversity. A summary of this training is provided in Appendix E.

Some regional centers have utilized a Cultural Competence Organizational Assessment (CCOA) tool that is designed to obtain information and input on issues related to equity and cultural competency. The goals and objectives of the CCOA tool are to provide an objective assessment of an organization's resources, capabilities, and methods to provide culturally and linguistically appropriate services. The CCOA includes 43 questions divided into four major categories that measure participant information (6 questions), valuing culture and diversity (16 questions), human resources (16 questions), and resources and linkages (5 questions). The CCOA 2012 assessment tool is provided in Appendix F

The CCOA has proven to have sound evidence-based qualities and can be an effective, straightforward, time and resource sensitive tool for regional centers to get a snapshot of where they are in terms of cultural and linguistic competency. It can be used to establish a baseline and/or document improvements. Already in use in part of the regional center system it can serve as a practical model, within current budget constraints, for regional centers to administer and identify not only what they may need to improve, but to recognize strengths and develop steps to transform the disparities that exist in the system.

IV. Recommendation By Taskforce Staff

A. Consider future legislation requiring DDS, in partnership with the regional centers, to provide technical assistance and supports to all regional centers that will enable them to implement annual self-assessment evaluations on issues of equity, diversity and cultural and linguistic competency.

   a. DDS, in partnership with the regional centers and as funding and resources are available, should establish a uniform system that will enable a statewide comparison among the regional centers on issues of equity, diversity, and cultural competency.

   b. The regional center self-assessment on cultural and linguistic competency shall include data and information that includes, but is not limited to, access to services, case management, staff training, and provision of services.

c. DDS should consider the information from the regional center cultural competency self-assessment as part of the department's ongoing evaluation of each regional center.

B. DDS should consider the information from the regional center cultural and linguistic competency self-assessment to design future contractual objectives that will result in the ability for regional centers to provide information in clear, culturally and linguistically appropriate manner and enhance and improve these services.

Establishing a Partnership with Consumers, and Their Families, to Promote Equity, Diversity and Cultural Competency

Some regional centers have established strong bonds with consumers, and their families, which have been successful in establishing innovative programs and supports that are responsive to the unique needs of each individual. Promoting an open and effective dialogue between the regional centers and their consumers has been a key component to this strategy. Some regional centers have found through the use of data from a "consumer satisfaction survey" that they are in a better position to determine their effectiveness in delivering services and information in a clear, culturally and linguistically appropriate manner. An example of such a survey is provided in Appendix G.

Consumer satisfaction surveys are being used extensively by a wide array of health care providers. For example, Dignity Healthcare Systems in Sacramento, routinely queries patients shortly after they undergo a surgical procedure at one of their facilities measuring and tracking staff professionalism and courtesy, facilities and services, and patient's health outcomes. Kaiser Permanente Healthcare also requests consumer input using a simple, user-friendly survey method shortly after a medical visit.

Important information is also obtained through community-participatory evaluation, which is a process controlled by the stakeholders in the program or community in that it is something they undertake as a process for their own development and empowerment (Patton, 2002). Community-participatory evaluation is a community

engagement approach in which stakeholders (e.g., program staff, consumers, family members, etc.) actively engage in developing evaluation measures and the implementation of those measures. It establishes a partnership infrastructure that promotes: (1) community endorsement, (2) shared expectations, (3) investment from program staff, consumer, and family, (4) a deeper understanding of the targeted population, and (5) relevancy of data and findings. This form of evaluation is consistent both with the Lanterman Act and the IPP/IFSP process, which calls for consumer and family involvement in the development and all phases of its implementation.

The potential advantages and benefits of these consumer and community-participatory surveys include the following:

- Empower consumers and patients by validating their opinions and input.
- Promote improved communication.
- Facilitate ease of implementation.
- Disseminate effective models and examples.
- Identify issues and problems in an appropriate and timely manner.
- Create an opportunity to correct errors and mistakes and, if needed, to implement corrective system changes.
- Provide accountability through effective outcome measurement.

The findings of Workgroup #2 indicated that the methods to provide information vary extensively among the 21 regional centers, as do efforts to improve them and a "one-size-fits-all" approach is not the solution. A significant number of regional centers do not appear to have any practices in place to successfully provide information in clear, culturally and linguistically appropriate manner to their consumers. Although some regional centers appear to be making an effort at being culturally and linguistically competent, overall the regional center system face staffing and funding limitations as well as other challenges.

V. ***Recommendations By Taskforce Staff:***

A. Require DDS, as resources become available and in collaboration with regional centers, to establish a uniform, statewide, consumer satisfaction survey that includes questions regarding the methods by which information, both oral and

written are perceived through a cultural and linguistic lens.

B. Require DDS, as resources become available and in collaboration with regional centers, to establish community-participatory surveys.

C. Require DDS, as resources become available and in collaboration with regional centers, to distribute and collect these surveys in a manner that promotes collaboration with the consumers and their families.

CHAPTER FOUR:

Demographic Analysis of Purchase of Service Expenditures by the Regional Centers

In writing this chapter, the staff drew on the knowledge of the Taskforce and Workgroup members and the collective experience of their consumers and families about issues of equity and diversity related to Autism Spectrum Disorders (ASD). These experiences combined with anecdotal and subjective information, which were addressed in Chapter 3, suggest several underlying recommendations that can assist regional centers and staff in their strategic planning, designing, implementing, and evaluating purchase services expenditures.

During the past year, the Department of Developmental Services (DDS) not only identified the importance of improved data collection on issues of equity and diversity, but undertook a series of meetings with legislative staff, policy consultants and other stakeholders to determine an ongoing and strategic approach on these issues. DDS, the Association of Regional Center Administrators, Disability Rights California, and various legislative offices were involved in drafting the actual language. Though consumers themselves were not directly a part of these later discussions, legislative staff spoke on their behalf and took their various concerns into account.

Significant challenges were noted in the implementation of this project, which included the following factors: 1) an obsolete computer system (established in 1985) that is used by the regional centers and DDS; 2) difficulty in the programing of this old computer system due to outdated technology; 3) lack of personnel who are experienced and capable of working with this existing computer system; 4) lack of consistency in standard data collection by regional centers and by DDS; 5) variability in coding criteria among regional centers; 6) large numbers in various coding criteria; and 7) consumers potentially assigned to multiple coding criteria.

Therefore, as part of California's Budget Act of 2012 (SB 1020, Committee on Budget and Fiscal Review), DDS is required to work with the regional centers in compiling data and information to ensure that the spirit and intent of the Lanterman Act was being fully implemented for all Californians without regards to ethnicity, racial background, socio-economic status and/or other demographic factors.

SB 1012, which added section 4519.5 to the Welfare and Institutions Code, contained language requiring DDS and the regional centers to annually compile and post specified data on their respective websites. Furthermore, SB 1012 required that the stakeholder meetings held locally by the regional centers – as specified in the trailer bill language - would play a key role in interpreting the data and determining what corrective actions, if any, would be taken in relation to the data. It was further recognized that the trailer bill language should be viewed as a work in progress, and that additional modifications would be required in accordance with the evaluation and results of the initial findings.

The relevant trailer bill language from SB 1012 is noted as follows:

Section 4519.5 is added to the Welfare and Institutions Code, to read:

4519.5. (a) The department and the regional centers shall annually collaborate to compile data relating to purchase of service authorization, utilization, and expenditure by each regional center with respect to all of the following:

(1) The age of consumer, categorized by the following:

(A) Birth to age two, inclusive.

(B) Three to 21, inclusive.

(C) Twenty-two and older.

(2) Race or ethnicity of the consumer.

(3) Primary language spoken by the consumer, and other related details, as feasible.

(4) Disability detail, in accordance with the categories established by subdivision (a) of Section 4512, and, if applicable, a category specifying that the disability is unknown.

(b) The data reported pursuant to subdivision (a) shall also include the number and percentage of individuals, categorized by age, race or ethnicity, and disability, who have been determined to be eligible for regional center services but are not receiving purchase of service funds.

(c) By March 31, 2013, each regional center shall post the data described in this section that is specific to the regional center on its Internet Web site. Commencing on December 31, 2013, each regional center shall annually post this data by December 31.

(d) By March 31, 2013, the department shall post the information described in this section on a statewide basis on its Internet Web site. Commencing December 31, 2013, the department shall annually post this information by December 31.

(e) Within three months of compiling the data with the department, and annually thereafter, each regional center shall meet with stakeholders in a public meeting regarding the data.

Workgroup #3 was led by Ms. Areva Martin (Martin & Martin; Special Needs Network) and Mr. Rick Rollens (The MIND Institute; Rollens Consulting) and included representatives of consumers, providers, academia, advocacy, and healthcare. Workgroup #3 was requested to provide recommendations for the assessment and oversight with regards to the provisions of WIC 4519.5, which required the demographic analysis of the purchase of services expenditures by regional centers. A complete list of Workgroup #3 members and their affiliations is provided in Appendix H.

Implementation of Welfare and Institutions Code (WIC) Section 4519.5

The Taskforce and Workgroup #3 applaud the work of DDS, the regional centers, legislative committees and stakeholders who have contributed to establishing the requirements and outcomes noted in the provisions of this code section. Furthermore, the Taskforce and Workgroup #3 acknowledge the iterative and ongoing nature of this process. Although WIC Section 4519.5 indicates the type of data that will be collected, a significant number of factors and outcomes remain undefined. For example, the section does not designate the manner by which these data will be analyzed, nor are there criteria by which potential factors related to disparities and inequities in the provision of services can be identified and analyzed. Thus, the manner by which these data will be utilized to identify inequities in regional center services, as well as to highlight those regional centers that are successfully implementing appropriate best practices that are culturally and linguistically appropriate, remain to be determined.

There is also a lack of specificity by which regional center outcomes on equity and diversity can be compared on a statewide basis and methodologies by which these data can be linked to future corrective actions. Similarly, WIC Section 4519.5 is also silent as to what, if any, oversight responsibility is within the purview of DDS and what corrective actions should be taken by DDS to ensure that disparities are corrected in a timely and appropriate manner. Broadly speaking, efforts to engage DDS need to be clear as to oversight responsibilities and whether they will seek data to identify and address gaps in regional center services.

It is equally important to be clear about who is to be engaged. Therefore, the members of the Taskforce and Workgroups believe that consumers, families, advocates, and policymakers must remain fully informed and completely engaged in the implementation of this section. It is crucial that these data be utilized in an efficient and effective manner to ensure that regional center services are provided in a timely, fair, culturally and linguistically appropriate, and equitable manner.

I. ***Recommendations By Taskforce Staff:***

A. DDS shall provide offices of the President pro Tempore, the Speaker of the Assembly, the appropriate policy committees and budget committees of the Legislature, and the Senate Select Committee on Autism and Related Disorders with quarterly updates regarding their progress in meeting the provisions of W & I Code Section 4519.5

Data Collection Must Be Uniform

Although regional centers and DDS are constrained by an outdated computer system, the members of the Taskforce and Workgroup #3 emphasized that all regional centers should collect and analyze data on equity and diversity in a manner that is uniform and consistent throughout the state. The importance of this approach is further underscored by the U.S. Department of Health & Human Services' web site (www.childwelfare.org) statement that: *"Analyzing data to verify and measure the effectiveness of services helps organizations make informed policy and practice decisions, with the ultimate goal of improving outcomes for the families they serve."*

In Chapter Two, the review of existing statutes, regulations, and prerequisites, as well as the oversight and compliance procedures was observed as vital to achieving equity. In the same way, Chapter Three emphasized common core standards and outcome measures, which may suggest that achieving equity, diversity and cultural and linguistic competency involves consistency, a conclusion that is also supported by WIC Section 4519.5. Therefore, DDS should continue to explore other opportunities that ensure consistent methods of seeking and obtaining information related to equity and diversity performance (i.e. racial/ethnic demographics and purchase of services,

services received or not received, translation and linguistic cultural supports, consumer and family satisfaction, etc.) as additional funding resources become available.

The regional centers and DDS must implement methods, measures and procedures throughout the state that produce effective and meaningful data. In order to obtain significant information and reports that permit valid and reliable comparisons among the regional centers and describe statewide trends over time, the data required in WIC Section 4519.5 should be collected, analyzed, and reported on using standardized procedures.

II. ***Recommendations By Taskforce Staff:***

A. In order to provide reports which allow reliable and valid comparisons across regional centers and describe statewide trends over time, the data required by trailer bill language 4519.5 should be collected, analyzed, and reported on using uniform methodology, measures and procedures.

B. Furthermore, it is acknowledged that the regional centers are currently using an extremely antiquated computer and software system which makes WIC Section 4519.5 data collection cumbersome at best. Therefore, this outdated computer system, as additional resources and funding become available, should be updated or replaced as soon as possible.

Analysis and Evaluation of WIC Section 4519.5 Data

The intent of obtaining data and information as specified within this section is to promote equity and diversity among all of the regional centers. However, the manner by which this data will be evaluated and analyzed has not been specified. It appears that any type of assessment by regional centers or issues of equity and diversity will be contingent on future public meetings and public discussions with stakeholders.

Although this process is a step in the right direction, the following factors do not appear to be addressed:

- The manner by which regional centers will collect and utilize data that is uniform, effective and meaningful to identify strengths and/or deficiencies on issues of equity and diversity.

- The manner by which these data will be utilized by regional centers to design solutions that address gaps in services and improve outcomes related to equity and diversity.
- The manner by which these data will be utilized to compare performance and outcomes among the various regional centers throughout the state.
- The manner by which these data will be utilized by the regional centers to implement corrective actions and sustain successful gains.
- The manner by which these data will be utilized by DDS.
- The manner by which DDS will provide appropriate monitoring, oversight and accountability to ensure that regional centers are providing culturally and linguistically appropriate services related to issues of equity and diversity.

III. Recommendations By Taskforce Staff:

A. DDS should establish guidelines, policies, and procedures by which regional centers can utilize the data and information obtained from WIC Section 4519.5 to promote and achieve improvement on issues of equity and diversity.

B. DDS should require an annual report by each regional center on the findings and recommendations related to WIC Section 4519.5, which will become a public document and posted on the web site of the regional center and DDS.

C. The annual report noted above in recommendation III(B) at a minimum should include an analysis of WIC Section 4519.5 (a) and (b) to review the following:

   a. The proportionality of services provided in comparison to the catchment area and to the consumer population for each regional center.

   b. The identification of specific categories or demographics that may be either under- served and/or over-represented; discussions as to the methodologies involved in their identification; explanations as to possible causes of these findings.

c. Self-assessment by each regional center on issues of equity and diversity.

d. Findings and recommendations based on these data on issues of equity and diversity.

D. DDS should ensure that policies, procedures, and oversights to insure that all 4519.5 data made available to the public shall be reported in ways that protect the privacy and confidentiality of individual consumers as required by law.

Funding of Consumer Services

In most cases, services are rendered to consumers by outside vendors on behalf of the regional centers through a Purchase of Services system. Each regional center is compelled by law to provide services and supports that meet the needs of the consumer (or to arrange to have those required services provided through another entity). The primary vehicle for doing so is the Individual Program Plan (IPP). Current law provides a variety of mandated check and balances to assist the regional centers in fulfilling their obligations to consumers.

All consumers should feel they are getting fair treatment from the regional centers. For their part, regional center staff members should always be focused on doing as much as they can to help every consumer they serve.

IV. Recommendations By Taskforce Staff:

A. Each regional center shall determine whether service allocation differences based on WIC Section 4519.5 criteria are statistically significant. Regional center methodology for determining this must be posted on their web site.

Oversight and Monitoring of Regional Centers by DDS

Existing law requires the state to enter into contracts with the regional centers. These contracts are subject to the legislature's annual appropriation of funds. Each regional center is required by the contract to offer services in full compliance with all applicable state laws and regulations. DDS is already authorized by law to specify in the performance contract any areas where the department feels the regional center needs

to upgrade their services and supports. In addition, if the methods of correction prescribed in the Lanterman Act prove unsuccessful, DDS is required to terminate the contract of any regional center that is not fulfilling its contractual obligations.

V. ***Recommendations By Taskforce Staff:***

A. Annual performance contracts should include one or more performance outcome measures related to the WIC Section 4519.5 data.

B. The annual self-assessment plan of each regional center should include an assessment that evaluates WIC Section 4519.5 data. At a minimum, this section should include whether there are disparities apparent within the data, how these disparities are defined and measured, and a plan of corrective action to ensure that disparities are corrected in a timely and culturally and linguistically appropriate manner.

Transparency on the Process and Outcomes

It has been noted that transparency is fundamental to promoting efficiency and effectiveness in government and strengthening the democratic process by giving citizens enough information to reach their own conclusions about the expenditure of public resources and tax dollars. Since the regional centers are local private non-profits, they are not subject to the Brown Act (Government Code Section 54950-54963), which governs the conduct of open meetings for local government bodies in California. However, the need for ongoing transparency on the process and outcomes related to equity and diversity cannot be overstated.

VI. ***Recommendations By Taskforce Staff:***

A. DDS should provide guidelines and oversight to the regional centers to ensure that the stakeholder meetings required by WIC Section 4519.5 (e) are conducted in a manner that reflects, and provides appropriate access to, the diverse population that is representative of the regional centers' catchment area.

B. DDS and the regional centers shall establish policies and procedures to ensure that the input and recommendations provided by stakeholders during public meetings are appropriately noted and duly considered as part of the process to address disparities in WIC Section 4519.5 data.

C. Each regional center should provide a methodology of evaluation for WIC Section 4519.5 data which shall be included in the regional center's cultural and linguistic competency plan.

D. All meetings and actions related to WIC Section 4519.5 shall be subject to the California Public Records Act, the Brown Act, and the Dymally-Alatorre Bilingual Services Act - or the equivalent provisions of the Acts.

CHAPTER FIVE:
Performance and Outcome Measures on Issues of Equity, Diversity and Cultural and Linguistic Competency

This chapter highlights the value of performance outcomes, including ongoing monitoring of indicators, benchmarks, outcomes, and performance measurements. This concept was further emphasized during the April 30, 2012 hearing on equity and diversity by Senator Darrell Steinberg who stated that, *"This system of Regional Centers must be outcome-based and outcome-focused. If we're ever going to reduce disparities, if we're ever going to make a dent, we need to hold the centers and the state accountable for making progress. Make this system outcome-driven, and that will drive change. It will drive cultural change. It will drive a reduction in these disparities and it will lead to better outcomes."*

During that hearing, Senator Steinberg further underscored the benefits of outcome measures as exemplified by his legislation (AB 636), which was enacted in 2001, and established a new data-driven and objective process within the Department of Social Services of reviewing child and family services programs in each county. This bill not only aligned county performance measures with federal guidelines, but also enabled counties to engage in ongoing self-improvement measures that resulted in significantly fewer children and youths being placed in foster care."

To determine the performance measures and indicators and the extent to which regional centers are using metrics/indicators related to issues of equity and diversity to self-assessing, the Taskforce established Workgroup #4. The charge for this workgroup was to develop a process utilizing these metrics/indicators to improve performance and outcomes where deficiencies exist and improvements are needed. Workgroup #4 was led by Dr. Sergio Aguilar-Gaxiola (UCD Center for Reducing Health Disparities) and Dr. Jan Blacher (SEARCH Family Autism Research Center, UC Riverside) and included representatives of consumers, providers, academia, advocacy, and healthcare. A complete list of Workgroup #4 members and their affiliations is provided in Appendix I.

As noted previously, performance measures and accountability factors related to equity and diversity have become an accepted standard of care among healthcare

organizations and other systems of care. For example, The National Quality Forum (NQF), an organization dedicated to improving healthcare quality, has endorsed 45 practices to guide healthcare systems in providing care that is culturally appropriate and patient centered (15). In the NQF 2009 report, "A Comprehensive Framework and Preferred Practices for Measuring and Reporting Cultural Competency" there is incontrovertible evidence that healthcare cannot be of high quality without being delivered in a culturally and linguistically competent manner. Furthermore, the NQF has identified the seven key domains for measuring and reporting cultural and linguistic competency that include: 1) leadership; 2) the integration of cultural competency into management systems and operations; 3) patient-provider communications; 4) care delivery and supporting mechanisms; 5) workforce diversity and training; 6) community engagement; and, 7) data collection and public accountability.

The importance of a culturally and linguistically competent healthcare is further underscored by the activities of the United States Office of Minority Health (OMH), which was created in 1986 and reauthorized by the Patient Protection and Affordable Care Act of 2010, to improve the health of racial and ethnic minority populations. The OMH not only funds numerous state and regional organizations, but also serves as an invaluable resource for research, best practices, and technical assistance to eliminate health disparities and achieve health equity. Based on an analytical review of key laws, regulations, contracts, and standards currently in use by federal and state agencies and other national organizations, OMH has issued a set of national standards for culturally and linguistically appropriate services (CLAS) in health care. These guidelines, similar to the work of Workgroup # 2 (see Chapter Three), who evaluated the methods by which the regional centers are providing information in a culturally and linguistically appropriate manner, are intended to ensure that factors of cultural and linguistic competency are fully integrated in all aspects of: 1) direct services; 2) linguistic services and communications; and 3) organizational resources and supports. A list and description of the CLAS standards are provided in Appendix D.

Commitment to Accountability by the Legislature

The Legislature has already established the importance of outcome indicators and performance measures for the regional center system. In 2009 trailer bill ABX4-9 was

signed into law on July 28, 2009 which added Section 4571 to the Welfare and Institutions Code (WIC) and directed the Department of Development Services (DDS) to "implement an improved, unified, quality assessment system" and also codified the following:

> *"(b) The department, in consultation with stakeholders, shall identify a valid and reliable quality assurance instrument that includes assessments of consumer and family satisfaction, provision of services, and personal outcomes. The instrument shall do all of the following:*
>
> *(1) Provide nationally validated, benchmarked, consistent, reliable, and measurable data for the department's Quality Management System.*
>
> *(2) Enable the department and regional centers to compare the performance of California's developmental services system against other states' developmental services systems and to assess quality and performance among all of the regional centers.*
>
> *(3) Include outcome-based measures such as health, safety, well-being, relationships, and interactions with people who do not have a disability, employment, quality of life, integration, choice, service, and consumer satisfaction."*

Although there are no provisions in this code section that limit its application to a specific subset of regional center consumers, DDS has indicated that WIC Section 4571 was implemented in order to consolidate two data collection efforts: 1) The Evaluation of People with Developmental Disabilities Moving from Developmental Centers into the Community, and 2) the Life Quality Assessments (LQA). Thereupon, DDS created the Quality Assessment Project, which established a contractual relationship with the National Core Indicators (NCI) program to perform the required assessments and to meet the statutory requirements.

The NCI is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The purpose of the program, which began in 1997, is to support NASDDDS member agencies to gather a standard set of performance and outcome measures that can be used to track their own performance over time, to compare

results across states, and to establish national benchmarks. Currently there are 28 other states which belong to the NCI. The NCI and HSRI websites are: http://nationalcoreindicators.org/ and http://www.hsri.org/

Currently, California is conducting two surveys that alternate each year. One survey is of adult regional center clients. The second survey is of families and guardians of adult regional center clients. The first survey of adult regional center clients was conducted between May 2010 and January 2011. During that time, the State Council on Disabilities (SCDD) interviewed 8,724 adults (age 18 and older) with a developmental disability. A total of 400 adult clients from each of the 21 regional centers were interviewed either face-to-face or by proxy. This report is a compilation of those interview results. In 2011, the first round of interviews of client families and guardians was conducted. The second round of interviews of adult clients was recently completed in June 2012.

Although there have been apparent discussions on developing a survey for the families of regional center clients under age 18, additional information about this process, such as when these data will be collected and analyzed are currently not available from DDS. Data and information related to services for children and youths are of vital importance for the following:

- Early intervention services for ASD are a major and rapidly increasing expense for regional centers.
- Early intervention services for ASD have been identified as a major inequity in programs that are being provided to underserved consumers, their families and communities.
- Early intervention services for ASD have been identified as an important effective intervention that can improve outcomes across the lifespan for consumers with ASD.
- Including these data are vital to establishing an efficient and effective regional center work plan.

The NCI report (882 pages) is available at http://www.dds.ca.gov/QA/index.cfm . This survey shows the results for the statewide average as well as for each of the 21 regional centers (16). According to DDS, this first survey is considered the baseline to which

future surveys may be compared against. Regional centers may use this information to establish quality improvement initiatives. The NCI publication which discusses how to use the NCI data for quality improvement initiatives is available at: http://nationalcoreindicators.org/resources/guides. At the present time, regional centers are not expected to prepare any reports to DDS, hold public meetings, or incorporate this information into their performance contract goals and objectives. The annual expenditure (fiscal year 20012-2013) by DDS for the NCI contract is currently $3,235,000.

A meeting of the Taskforce staff with DDS representatives did not identify any plans or strategies by the DDS or possible next steps by which the NCI data and reports will be evaluated and analyzed. Furthermore, there do not appear to be any indicators, benchmarks, or performance measures that will enable the DDS and regional centers to compare the performance of California's developmental services system against other states' developmental services systems or to assess quality and performance among all of the regional centers.

I. *Recommendations By Taskforce Staff:*

A. Amend Section 4571 of the Welfare and Institutions Code (WIC) shall be amended to include issues of equity and diversity. Specific goals, outcomes, and results related to issues of equity and diversity shall be identified and included in future legislation within Section 4571 of the WIC.

B. DDS should consider using existing resources to collect and use the data and information noted in (A) above. These specific parameters (i.e. goals, outcomes, and results related to issues of equity and diversity) should be used as measures for the regional centers to self-assess the implementation of their work-plans and their ability to provide timely and equitable services to underserved consumers, their families and communities.

C. DDS should establish a quality assurance instrument as mandated in WIC Section 4571 that includes consumers across the lifespan and not just limited to adults.

Leadership by the Department of Developmental Services (DDS) to Establish a Culture that Promotes Equity, Fairness, and Diversity within the Regional Center System of Care

The Taskforce and Workgroup #4 emphasized that a strong commitment and ongoing leadership by DDS to create a culture, among regional center staff and providers, that promotes equity, fairness, and diversity is crucial to providing culturally and linguistically appropriate programs and interventions to underserved families and communities. Although the implementation of specific programmatic changes on equity and diversity, both within DDS and the regional center system, will undoubtedly require further strategic planning and additional resources, there is a compelling and immediate need for a "call to action" by DDS on these issues.

The DDS must provide a proactive and dynamic leadership role in fully integrating issues of equity, diversity and cultural and linguistic competency within the regional center system. Therefore, DDS must actively seek to partner and to obtain funding and resources from federal, state, and local entities, in order to establish a robust section within the department that can assist regional centers in implementing appropriate measures and best practices to ensure that consumers have access to services in a manner that is timely, effective and culturally and linguistically competent.

As additional funding and resources become available, DDS should provide an ongoing assessment of these new interventions related to equity and diversity. These evaluations will not only determine the efficacy and effectiveness of these measures and interventions, but will also establish whether these actions would also be beneficial to individuals with a wide array of developmental disabilities. Furthermore, such actions would also provide regional centers with the appropriate and necessary tools for an ongoing self-evaluation process; thereby empowering the regional centers to provide more consistent and effective programs to diverse communities throughout California.

II. ***Recommendations By Taskforce Staff:***

A. DDS must recognize the importance of equity, fairness and diversity and establish a culture that promotes the appropriate access to and implementation of regional center autism programs and services to all Californians regardless of race, ethnicity, culture, language, geographic location, socio-economic background and other demographic factors.

B. DDS must establish a focus on accountability issues related to equity and diversity.

C. As the state's autism and related developmental disabilities leader, DDS must continuously inform consumers and their families, the public, program administrators, policymakers and other stakeholders on the performance of the regional centers on issues related to equity and diversity; whether access to appropriate and quality services are being provided in a timely manner; and recommendations as to how these services could be improved and/or enhanced.

D. DDS must ensure that protective structures and measures are in place to encourage reporting of disparities and other issues that are related to, equity, fairness and diversity for autism and related disabilities services from regional centers and their providers. DDS, in conjunction with consumers, families, regional centers, advocates, and other stakeholders should establish explicit policies that support reporting and recommendations with regards to ensuring that these services are provide to consumers, and their families, in an equitable and fair manner. Furthermore, any process, policy, or procedure, whether intentional or unintentional, that deviates from these goals and objectives be immediately reported to the appropriate persons at the involved regional center and at DDS.

The Department of Developmental Services (DDS) Must Provide Standards, Guidelines, and Outcome Measures that Regional Centers Can Utilize as Self-Assessment Tools in Promoting Equity and Diversity for Autism Services

The importance of establishing standardized outcome measures related to equity and issues are a crucially important issue as California becomes increasingly diverse. Census 2000 data revealed that non-Caucasian racial and ethnic groups have become the majority population of California. According to 2011 US Census Bureau estimates, California's population was 38.1 % Latino/Hispanic; 13.6 % Asian; 6.6 % Black or African American; and 1.7 % American Indian (http://quickfacts.census.gov/qfd/states/06000.html). Furthermore, this census noted that 43 % of Californians speak a language other than English in their homes.

The increasing diversity of our state provides a compelling host of opportunities and challenges that cannot be overlooked. Regional centers, and their providers, are struggling to address this increasing diversity and to meet their needs. Although sensitivity, good intentions, and empathic listening are important factors in promoting equity and diversity, these personal efforts are usually not enough to overcome the organizational barriers and challenges that may be presented to consumers from underserved families and communities.

Therefore, as resources and supports become available, DDS should undertake a statewide program to provide standards, guidelines and outcome measures related to equity and diversity. This information will not only assist the regional centers in implementing these programs, but will also provide regional centers with specific parameters by which regional centers can evaluate their efficacy and results.

III. Recommendations By Taskforce Staff

A. As additional funding and resources are available, the DDS Section on Quality Management System shall establish and adopt specific benchmarks, standards, and outcomes on issues related to equity, diversity and cultural and linguistic competency.

B. As additional funding and resources are available, DDS shall establish a methodology and process (including appropriate timelines) by which these specific benchmarks, standards, and outcomes on issues related to equity and diversity are established. This process should be fully transparent and

should include input from consumers and their families, providers, regional center representatives, academics and other experts, advocates, and other appropriate stakeholders and representatives.

C. As additional funding and resources are available, the DDS Section on Quality Management Systems should establish and adopt specific definitions, classifications, designations, terms, and other descriptors that are related to issues of equity and diversity. These designations will enhance self-assessment by the regional centers and will also promote statewide uniformity among regional centers on issues of equity and diversity. Examples of such terms and definitions are provided in Appendix M.

D. DDS shall work with regional centers to identify barriers to program improvements related to equity and diversity and alert policy-makers when and where policy changes are necessary, as well as identifying additional funding and resources that may be required, in order to mitigate these problems.

The Department of Developmental Services (DDS) Should Collaborate with Existing Resources to Provide Guidance and Oversight on Issues of Equity and Diversity

The notion of cultural and linguistic competence has been promoted for many years and throughout numerous venues and organizations at the national state, and local levels. These have included non-profit and other non-government organizations, academic institutions, as well as a wide array of health care organizations.

As previously noted, the United States Office of Minority Health (OMH), which was created in 1986, is one of the most significant organizations that is dedicated to providing resources toward improving the health of minority populations through the development of health policies and programs that will help eliminate health disparities. It is also important to note that the Patient Protection and Affordable Care Act of 2010 reauthorized OMH.

Since 1976, the Center for Multicultural Health (UC Berkeley School of Public Health) has worked in partnership with individuals, groups and organizations in the community to promote health and well-being in diverse communities. As its core mission is to promote the health and wellness of diverse communities--including

individuals from unserved and underserved, individuals with limited English proficiency, immigrants and refugees—the center thrives because of its innovative health advocacy, health promotion, disease prevention, and immigrant and refugee service programs.

DDS should also collaborate with the California Department of Public Health's Office of Health Equity (OHE), which was recently established by Assembly Bill 1467 to provide a key leadership role to reduce health and mental health disparities in vulnerable communities. The goals and objectives of the OHE, which is comprised of three sections (Community Development and Engagement Unit, Policy Unit, and Health Research and Statistics Unit), also includes the following:

- ***Ensure Health and Mental Health for All***: Achieve the highest level of health and mental health for all people, with special attention focused on those who have experienced socioeconomic disadvantage and historical injustice, including, but not limited to, vulnerable communities and culturally, linguistically, and geographically isolated communities.
- ***Collaborate to Increase Access to Quality Care***: Advise and assist other state departments in their mission to increase access to, and the quality of, culturally and linguistically competent health and mental health care and services.
- ***Eliminate Disparities and Inequalities***: Improve the health status of all populations and places, with a priority on eliminating health and mental health disparities and inequities.
- ***Engage Communities and Establish Partnerships***: Assist and consult with state and local governments, health and mental health providers, community-based organizations and advocates, and various stakeholder communities.

Significant resources and expertise exist within the Taskforce and Workgroups. For example, Dr. Sergio Aguilar-Gaxiola, Co-Chair of the Equity and Diversity Taskforce, heads the UC Davis Center for Reducing Health Disparities, which provides a multidisciplinary, collaborative approach to achieving health equity in access to and quality of care. The center focuses on raising awareness of the unique cultural and linguistic attributes of diverse populations, developing culturally and linguistically

sensitive communications for health-care professionals, and working with policymakers, administrators, practitioners, consumers and families to reduce health-care disparities in access and improve quality of care. The center's ultimate goal is to improve health outcomes for all through a comprehensive program for research, education and teaching, and community outreach and engagement and dissemination of best practices. Another important resource is the Special Needs Network (SNN), which was co-founded by Ms. Areva Martin, also a Taskforce Co-Chair. The SNN is a non-profit, community-based organization that offers extensive expertise in providing resources and supports to underserved families who are struggling to overcome the challenges of raising a child with autism and other developmental disabilities.

Support and funding may also be available to DDS from federal resources, foundations, and other non-government agencies. For example, the California Endowment is investing the majority of its resources into the 10-year, $1 billion "Building Healthy Communities Plan" which seeks to improve the health in 14 California communities where the need is great, but the potential for transformation is even greater with a major emphasis on preventive interventions, environmental and socioeconomic factors that address the root causes of adverse health consequences in these communities. Thus, the Endowment could potentially provide not only resources, but also guidelines, outcome measures, and other technical assistance that would assist DDS in establishing benchmarks, indicators, and outcome measures related to issues of equity and diversity.

IV. Recommendations By Taskforce Staff:

A. DDS, as additional resources and funding are available, should establish the DDS Equity and Advisory Council within its Section on Quality Management Systems that consists of appropriate representatives of consumers, their families, regional centers, providers, academics, and other stakeholders.

B. The DDS Equity and Advisory Council, as additional resources and funding are available, should provide a biennial report to the governor and to the legislature as to the status and progress of the regional centers in providing equitable and appropriate services to diverse and underserved consumers.

C. The DDS Equity and Advisory Council, as additional resources and funding are available, should work with DDS to provide information, guidelines, best practices and other assistance with regards to issues of cultural and linguistic competency to regional centers and to the public. DDS should serve as a clearinghouse for this information. (see Workgroup #2 , Chapter 3)

The Department of Developmental Services (DDS) Should Establish Performance Measures and Indicators That Are Consistent with Current Healthcare Standards

Healthcare systems of care have recently recognized that consideration and attentiveness to cultural competency will result in significant organizational and consumer benefits. Therefore, numerous healthcare providers and organizations have undertaken an intensive and systematic assessment approach to ensure that appropriate cultural and linguistic competence procedures are embedded as an integral component of their healthcare delivery systems. For example, the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program is a multi-year initiative of the Agency for Healthcare Research and Quality (AHRQ) to support and promote the assessment of consumers' experiences with health care. First launched in October 1995, the program has developed a wide array of surveys, and other assessment tools that are intended to gather relevant data and information to: 1) meet the needs of health care consumers; 2) improve health plans (e.g., IPPs and IFSPs); 3) train and retrain providers; and 4) encourage support from policymakers. These resources, which are all in the public domain, cover a wide array of topics that could be applied to equity and diversity issues related to regional center services. This information is available at the following website: https://www.cahps.ahrq.gov/ .

The National Quality Forum, another organization dedicated to improving cultural competence and healthcare quality, has also provided a report that endorses 45 practices that promotes equitable and patient-centered care for diverse and underserved populations. As discussed in the beginning of this chapter, the 2009 NQF report examined seven primary domains (i.e., leadership; integration within management systems and operations; patient-provider communications; care delivery

and supporting mechanisms; workforce diversity and training; community engagement; data collection, public accountability, and quality improvements). These seven factors should be considered as integral components of all future endeavors by DDS and the regional centers to address issues related to cultural competency, equity, and diversity.

The Office of Minority Health within the U.S. Department of Health and Human Services also offers a unique set of standards that center on equitable and effective treatment in a culturally and linguistically appropriate manner. These standards, referred as culturally and linguistically appropriate services (CLAS Standards), are intended to eliminate ethnic and racial disparities and are organized by the following themes: Culturally Competent Care; Language Access Services; Organizations Supports for Cultural Competence. The CLAS Standards are mandated Federal requirements for all recipients of Federal funds; are recommended for adoption by all national accrediting agencies; and are recommended by OMH for voluntary adoption by healthcare organizations. Appendix D lists the core CLAS Standards.

V. Recommendations By Taskforce Staff

A. As additional funding and resources are identified and allocated, DDS and regional centers shall develop benchmarks of equity and diversity based on performance indicators using the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Cultural Competence program.

B. DDS and regional centers should explore potential resources (i.e. federal funds; non-profit foundations; community/faith-based organizations; and other non-government entities) to establish these standards and benchmarks.

C. As additional funding and resources are identified and allocated, DDS and regional centers should develop benchmarks of equity and diversity based on the CLAS Standards.

D. DDS and regional centers shall develop, as additional resources and funding are identified and allocated, benchmarks of equity and diversity performance indicators that include:

a. The provision of understandable and respectful care that is provided in a manner compatible with consumers' cultural health beliefs and practices and in their preferred language.

b. The development and implementation of strategies to recruit, retain, and promote at all levels of the organization a diverse staff and leadership representative of the demographic characteristics of the service area.

c. The provision of ongoing education and training for staff at all levels in culturally and linguistically appropriate service delivery.

The Department of Developmental Services (DDS) Should Establish Performance Contract Outcome Measures to Provide Oversight on Issues of Equity and Diversity

In 1985, the California Supreme Court ruled that the Lanterman Act was an entitlement, meaning individuals must receive the services and supports that allow them to lead more independent and productive lives, as outlined in their Individual Program Plans (IPPs.) The Court also ruled that the DDS was responsible for providing services as outlined in the IPPs. Subsequently, in order to comply with these statutory mandates, while also conforming to meeting the State's budgetary requirements, the DDS contracts with regional centers in California to serve clients and families.

The current budget methodology employed by DDS requires that all regional centers establish detailed expenditure plans that are based on their annual allocations, while still meeting all of the mandates of the Lanterman Act. Furthermore, DDS has developed a series of regional center performance measures to assess how well the regional centers are fulfilling their mission and purpose. Thus, DDS measures performance in the form of performance contracts, which have been statutorily established in order to better measure the outcomes of service delivery, which have been established with each of the regional centers.

Pursuant to Welfare and Institutions Code (WIC) Section 4629, these performance contracts, which are established by the state and regional centers every five years, include annual performance objectives that are specific and measurable and are intended to assist consumers in achieving life quality outcomes, achieve meaningful

progress above the current baselines, and develop services and supports identified as necessary to meet identified needs. Additionally, the regional centers must develop the performance objectives through a public process, providing information, in an

understandable form, to the community about regional center services and supports, including budget information and baseline data on services and supports and regional center operations. The performance contracts also include public policy compliance measures, such as community living options, employment access, medical and dental service access, and audit accountability.

In addition to the requirements noted above, DDS is empowered by WIC Section 4629 to *"specify in the performance contract additional areas of service and support that require development or enhancement by the regional center."* To date there are do not appear to be any performance or outcome measures that related to issues of cultural competency, equity, or diversity. Current guidelines (August 8, 2011) on performance contracts provided by DDS to regional centers (Appendix) included only the following outcome measures:

- Regional center consumers residing in developmental centers;
- Location and type of residential placement;
- Consumer information with regards to employment and wages;
- Consumer access to medical and dental services;
- Consumers who were victims of abuse;
- Measures related to regional center, audits, budget and fiscal issues; and
- Measures related to intake process, Individual Program Plan (IPP), and Individual Family Support Plan (IFSP)

VI. Recommendations By Diversity Taskforce Staff

A. DDS should establish performance contract guidelines, which include outcome measures and measurement methodology, that will enable the regional centers to appropriately address issues of equity and diversity and

provide fair and equitable services that are consistent with the mandates of the Lanterman Act and consistent with the annual budget allocations that are provided to the regional centers by DDS.

B. DDS should establish that performance contract requirements related to equity and diversity, as stipulated noted above by section (A), must be commensurate with the appropriate resources that may be required by the regional center to achieve these performance contract requirements.

C. Regional centers should include within their annual performance report a "Cultural and Linguistic Competence Plan" that, as resources, technical assistance and supports become available, should include the following:

   a. Objectives and strategies for improving the regional center's cultural and linguistic competence.

   b. A population assessment and an organizational and services provider assessment focusing on issues of cultural competence and linguistic capability.

   c. A plan for the cultural and linguistic competence training of the regional center staff.

   d. A plan to evaluate and provide a network of culturally and linguistically competent providers.

   e. A listing of community-based organizations and resources that are engaged with and supporting the cultural and linguistic competency efforts of the regional center.

   f. The process by which the "Cultural and Linguistic Competency Plan" was developed.

CHAPTER SIX:
Guidelines and Best Practices on Issues of Equity, Diversity and Cultural Competency

A common theme through Chapters One to Five was that equity, diversity and cultural competency in services delivered by regional centers can be achieved and this achievement is largely based on having consistent service delivery mechanisms that account for performance measures and the identification and implementation of evidence-based practices that guide systemic changes. This chapter provides an overview of essential cultural and linguistic competency guidelines often found in regional centers deemed as best practices. This chapter also presents examples of successful regional center programs.

Cultural Competency and the Lanterman Act

To better help coordinate the 21 regional center efforts addressing the needs of the autism community, the Taskforce unequivocally endorsed the belief that issues of equity and diversity must serve as a fundamental basis for the services and responsibilities that are mandated by the Lanterman Act. These issues of cultural and linguistic competency are not only crucial to establishing a regional center system where all consumers are provided services in a timely, fair, appropriate, efficient and effective manner regardless of their cultural, linguistic, racial, ethnic, and other socio-economic factors, but will also improve outcomes for all regional center consumers.

Therefore, Workgroup #5 was established to identify the best practices on promoting equity and diversity for underserved consumers living with autism spectrum disorders (ASD) and who are receiving services from the regional centers. Another objective for this workgroup was to establish guidelines for successful implementation of strategies and solutions to these disparity and diversity issues. Workgroup #5 was led by Dr. Patrick Maher (North Bay Regional Center) and Mr. Jim Burton (Regional Center of the East Bay) and included representatives of consumers, providers, academia, advocacy, and healthcare. A complete list of Workgroup #5 members and their affiliations is provided in Appendix J.

However, implementing regional center strategies that achieve effective cultural and linguistic competency and overcome barriers related to equity and diversity may be a daunting undertaking. First of all, the issues of equity and cultural and linguistic competency were rarely, if ever considered, during the era (more than 40 years ago) when the Lanterman Act was first enacted. Subsequent amendments to this act have also excluded specific mandates or requirements related to these issues. The absence of equity and diversity factors within the Lanterman Act may be related to a variety of factors that include: precipitous changes in California's diversity; recent advances in our understanding of cultural and linguistic competency; lack of indicators, benchmarks and outcome measures related to cultural and linguistic competency; diminishing resources and funding for regional center programs; challenges in identifying and disseminating best practices related to equity and cultural and linguistic competency.

Cultural and Linguistic Competency – Essential Concepts and Fundamental Approaches

The Taskforce and Workgroups identified a number of services, programs and strategies at some of the regional centers that appeared to be highly effective in promoting effective cultural and linguistic competency. Many of these successful models often shared common and overarching characteristics that included the following:

- ***Committed Leadership***: Strong commitment and support by the regional center's executive director and leadership team.
- ***Community Partnerships***: Collaborative and supportive relationship between the regional center and multiple grass-roots organizations. Effective programs and services were frequently implemented in partnership with community and faith-based organizations that were able to provide supports to regional center consumers who are from diverse and potentially underserved communities.
- ***Ongoing Funding***: Specific allocation of funding and resources in order to achieve equity and diversity.

- *Responsive Process*: Dynamic and interactive process that is responsive to the changing needs and demographics of the community.

- *Diverse and Culturally Competent Regional Center Staff*: Effective programs were frequently spearheaded by a dedicated and committed regional center leadership team, and supported by a regional center staff that was reflective and consistent with the demographics of the regional center's catchment area. Furthermore, the regional centers who have implemented these successful programs demonstrated a commitment to provide effective, dynamic, and ongoing staff training on issues of equity and diversity.

- *Innovation*: Innovative approaches that advances the involvement and support of the regional center by leaders and advocates in the community who have strong relationships and ties with specific cultural, linguistic and ethnic groups.

- *Effective Outcome Measures*: Regional centers that have implemented effective cultural and linguistic competency outreach programs have established policies and procedures that not only promote greater transparency and collaboration with their community partners, but also attempt to collect outcome measures that provide information as to their efficacy as well as to insights on future improvements.

I. ***Recommendations By Taskforce Staff***

A. The Department of Developmental Services (DDS) in partnership with the regional centers should seek technical assistance and information from other state agencies and other appropriate entities with regards to best practice guidelines related to equity, diversity and cultural competency.

Cultural Competency Best Practices — Specific Examples of Effective Regional Center Programs

The Taskforce and Workgroups identified existing models and activities that are currently being implemented by some regional centers that appear to be highly effective and seem to hold great promise in providing appropriate services and supports for their consumers and families. Specific examples of programs and services

that were considered to be highly effective in promoting equity, diversity and cultural and linguistic competency included the following examples:

- The Regional Center of the East Bay.
- San Gabriel/Pomona Regional – Model for Autism Parent Education Program-Practices/Services.
- Monthly Orientation Sessions in Spanish.
- *Promotora* Model for Parent Autism Education.
- Pre-Established Health Fairs (*Congreso Familiar*) Model.
- Community-Based Screenings.
- Language Interpretation Services.

Equity and Diversity in all Requests for Proposals (RFPs): RFPs must seek information about practices related to addressing the needs of diverse underserved populations, such as hiring bilingual staff, outreach strategies to underserved communities, training and materials in various languages, and other suitable information related to issues of equity, diversity, and cultural competence. For example:

- The Regional Center of the East Bay (RCEB) requires that all new RFPs must include a section that addresses the issues of providing equity/diversity to consumers who are from potentially underserved communities. In this section of the RFP, information is requested regarding the agency's (or other contracting entities) plans and abilities to serve diverse populations, including disabilities, ethnicity and socio-economic status.

Effective Parent Education, Training, and Supports: Parent training must be ongoing, individualized, and responsive to the cultural needs of diverse communities. Therefore, these strategies and implementation policies are of crucial importance to achieving successful outcomes from the IPP process. Established successful best practices include the following:

- San Gabriel Pomona Regional Center (SGPRC) Model for Autism Parent Education Program (APEP): As soon as a child is accepted as a consumer, the parents are enrolled in a 16 hour training program (4-hour sessions given over 4 weeks). For instance, What is Autism? Socialization, Communication and Behavior," a topic and instruction designed to help parents develop a solid foundation of knowledge to work with a regional center to maximize the benefit of services. Additionally, SGPRC contracts with a local non-profit agency, *Fiesta Educativa* (a vendor) to create and implement the Autism Parent Education Program (APEP). The APEP is offered in both Spanish and English. Moreover, the benefits of APEP is described to the family of every consumer diagnosed with autism, followed by a referral to *Fiesta Educativa* to participate in the APEP course in their preferred language. A referral is made, unless the family declines. The key features of the Autism Parent Education Program (APEP) include:

    - 16 hours of instruction with master's level instructors (4 hours on 4 Saturdays)

    - Training in small groups (8 – 12 parents) as needed, based on enrollment

    - Topics: introduction to autism, socialization, communication and behavior.

  Fiesta Educativa's APEP coordinator serves as a liaison between the regional center and Spanish-speaking families. This liaison coordinates the training schedule and follows up on parent attendance. Communication continues between the Regional Center Service Coordinator and the APEP Coordinator to follow-up with the family after completing the course.

- Bilingual Monthly Orientation Sessions: Presently, the SGPRC implements a pilot, two-hour monthly orientations coordinated by the vendor (*Fiesta Educativa*) that is intended to meet specific language needs of many Spanish-speaking families. These Spanish sessions are conducted at community locations (i.e. at a school site while the child is attending preschool). This increases parent

access to information by delivering the training where the families are at and aligned with a time of day and location that works for families, and providing them with transportation and child care services. The key features of these monthly sessions include:

- Two trainers, one of whom is a parent.
- Introduction to autism and information about treatment options.
- Garner interest and enrollment for a full 16-hour training program; Vendor and the Service Coordinator to synchronize/provide follow-up with interested families.
- Additional sessions may be offered in English (or another language) such as Korean and Chinese.

Best Practices for Community Outreach by Regional Centers:

- *Promotora* Model for Parent Autism Education: This is a model and curriculum that has been established by Dr. Sandy Magana in Wisconsin (Appendix K). The initial evaluations of this program are extremely promising and indicate that parent education is provided in a culturally and linguistic competent manner that meets the unique needs of Latino parents. Parent education curriculum is delivered in Spanish by community health educators, or *promotores de salud*, who are themselves family members of children with autism (parents, grandparents, siblings, aunts/uncles) Participating parents receive two modules of intervention at their own home. Additional criteria of this program include:

  - The first module includes eight weeks of instruction about child development, autism diagnoses, understanding their child's behaviors, and explaining their child's behaviors to others.

  - The second eight-week module teaches parents how to reduce problem behaviors and improve their child's social and communication skills.

Consumers and their families are also provided information on the measures of family empowerment, caregiver burden, satisfaction and efficacy, symptoms of depression, knowledge about autism, use and social validity of targeted intervention strategies are collected pre- and post-intervention. Regional centers may work with private or public sources to fund and create a pilot program using this model. Data and information that is collected includes:

- The severity of autism symptoms, problem behavior, and parent knowledge about interventions are also collected pre- and post-intervention.
- Post intervention interviews provide information about a family's relationship with the *promotora,* how the relationship may have contributed to learning, and about the usefulness of information from each session.

- A draft proposal that was submitted by Ms. Emily Iland (Workgroup #5 Member and Adjunct Professor at California State University, Northridge) to implement a demonstration project is noted in Appendix L.

- Pre-Established Health Fairs (*Congreso Familiar*) Model: This *Congreso Familiar* model establishes a process by which regional centers are able to create access to information and services in the community in a culturally and linguistically competent manner. It is possible that many people are not accessing services they are eligible for because they do not understand what the regional center is or how it works. It is also possible that many people cannot attend programs offered by regional centers because of lack of transportation and child care services. Also, for some communities, the social stigma attached to disability and the lack of a cultural liaison to connect them to the may agency play a role.

  Regional Center of the East Bay (RCEB) partners with *Congreso Familiar*, a non-profit parent led organization with extensive contacts with many Latino families and Latino community-based organizations (CBO's) to provide informational/outreach events. The events are organized and run by *Congreso*

Familiar with CBO's and RCEB providing appropriate information, training and support. A similar model is also provided in the Asian/Pacific Islander community and in the African American community.

Activities and services that regional centers provide to underserved communities at these pre-established health fairs include the following:

- Set up a booth at an established local health fairs with a regional center with staff and/or community volunteers to provide general information about the regional center.

- Train *promotoras* (Latino community health workers who are parents of children with autism), other parent mentors who are part of the local culture, or regional center case managers to do outreach to passers-by in their own language.

- Encourage screening of at-risk children.

- Where indicated, refer for a regional center intake appointment.

- Assign a *promotora* or mentor to follow up on the regional center referral and help the mother get to the appointment.

- Take data on how many were screened, how many were referred for an intake appointment, how many came for the appointment, and of those, how many were found eligible for regional center services.

- Community-Based Screenings: This best practice establishes a partnership between a regional center and one or more community-based organizations to promote and implement early screening, diagnosis and assessment for ASD using a multidisciplinary approach that provides these services at "one-stop" center. Specific examples of these models include:

  - Autism Tree Project Foundation (ATPF) has screened over 4,000 preschoolers at numerous preschools throughout the San Diego County

and Bay Area communities. Children who show warning signs of language delay are referred to a regional center for further evaluation and possible treatment at an early age. It is important to mention that it costs ATPF $31 per child per screening.

- www.Happytalkers.org Screening and Referral: According to this organization, *"This outreach, now in its seventh year, selflessly brings physicians from different medical groups and practices together, along with the vital regional service agencies, as well as experts in insurance and other resources."* Each party graciously volunteers its time and expertise for the common good of the children. With all the critical agencies and professionals together in one place without the concerns of insurance or red-tape, the frustration and delays families commonly experience disappear. All the while, children are having a wonderful experience in a fun atmosphere with free food and activities.

Best Practices by Regional Centers for Language Interpretation Services: Current models and best practices on "Language Interpretation Services" that have been identified include the following:

- Health Care Interpretation Network (HCIN): Sally McFalone from Contra Costa County Health System reported the following: *"We belong to the Health Care Interpretation Network, which is a co-op of interpreters shared among HCIN members. All members must be safety net health care organizations and there are 19 members throughout California. We also contract with Language Line Services for our roll-over needs. There are 179 languages available and the cost varies between free, when using our own interpreters on the system to $.95/minute for Language Line (telephone only, no video). Cost of ASL (telephone and video) over HCIN is more expensive - up to $3.35/minute for the most expensive option."* Thus, the Department of Developmental Services (DDS)/Association of Regional Center Agencies ARCA/Regional Centers could look at the HCIN system and see if they could join it or explore other systems to see if it would be cost effective to join one of them. For this one to be cost effective it would probably require joining an existing system like HCIN or all the regional centers creating a co-op as the health care organizations have.

- Adobe Language Connect Model: Steve Lohrer, Ph.D., from Project Connect NBRC/Napa County Office of Education and ASD Best Practice Guidelines for Effective Intervention/DDS/NCOE reports that Project Connect NBRC/Napa County Office of Education just acquired an Adobe app that gives them the capacity to connect 20 locations via internet using laptops/tablets. He indicated that they bought this system so they could use it for large conferences and have breakout sessions but that if it was just limited to three different locations for interpretations one could use free apps like "Google chat" which apparently works very well. He added that there are a number of apps now like "Google chat" so one has alternatives to choose from. Thus, DDS/ARCA/Regional Centers could explore the use of the internet via a program like the Adobe one or one like "Google chat" for interpretation services. This one would be less expensive but would require the individual regional centers to have their own interpreters which sometimes are either nonexistent or lack the fluency of professional interpreters. Another possibility would be for DDS/ARCA/Regional Centers to develop a pool of interpreters that would be available to individual regional centers as needed. This would require the regional center system to agree to using one app such as "Google chat".

II. *Recommendations By Taskforce Staff:*

A. All new RFPs that originate from the regional centers and/or DDS, unless otherwise stipulated by DDS, should include a section that relates to issues of equity, diversity and cultural and linguistic competency.

B. DDS, in collaboration with the regional centers should identify programs and services within the regional center system that are effective in promoting cultural and linguistic competency; DDS should serve as a clearinghouse for these best practices; and DDS should provide technical assistance for the implantation of these best practices by regional centers.

C. DDS, in collaboration with the regional centers should provide technical assistance, resources, and supports to enable regional centers to pilot innovative approaches that will promote cultural and linguistic competency.

Resources and Supports — Innovative Approaches to Public-Private Partnerships

The DDS and regional centers should be pro-active in seeking non-state sources of funding and supports. These additional resources should not only be limited to the "generic resources" that are mandated by the Lanterman Act, but also include federal agencies, non-profit organizations and other entities. Particular attention should be directed to those organizations that are focused on early childhood development. For example, the First 5 California Commission oversees Prop 10 funding that was enacted in 1998 and has distributed approximately $500 to $700 million dollars annually to California's 58 counties. Many of these dollars have been allocated to specific childhood development programs that promote equity and diversity and provide effective outreach to underserved communities.

Autism Speaks is another organization that may be able to provide funding and assistance through the development of their recently launched "Move the Needle Initiative." This program has been created by Autism Speaks in response to a need for coordinated, strategic effort focused on addressing key barriers to ASD diagnosis and treatment. The goals are to lower the average age at diagnosis and to increase access to early intervention services. Specific objectives include: promoting awareness, increasing universal screening for ASD, reducing time from first concern to diagnosis, and disseminating and adopting evidence-based practices to increasing access to early intervention services for all families. Autism Speaks aims to accomplish these goals and objectives via the adaptation of new and existing technologies, utilization of existing community resources, collaboration with local, state and federal partners, use of parents and professionals as dissemination channels and provider training. This initiative is particularly relevant to underserved communities, such as racial and ethnically diverse children who are often under-diagnosed or diagnosed later compared to their white counterparts. As such, "Move the Needle" will target a number of its activities to underserved groups. This Workgroup will explore the possibility of future partnerships between Autism Speaks and its "Move the Needle Initiative" to provide models and best practices to promote equity and diversity for autism services for regional center consumers. A list of potential collaborative activities may include the following:

- Provide regional centers with existing Autism Speaks resources, materials and supports to enhance "equity/diversity" such as:
    - Make Autism Speaks/Autism Treatment Network Toolkits, including those that have been translated into Spanish and other languages, available to the regional centers.
    - Link regional centers websites to Autism Speaks Family Services and Spanish pages.
    - Promote the use of the Autism Response Team help line in Spanish.
    - Provide Los Angeles area Autism Treatment Network Information to interested families.
    - Collaborate with regional centers to promote greater awareness among existing consumers (Ad Council is partnering with Autism Speaks to develop a new awareness campaign targeting underserved communities, with a particular focus on the Latino community).
- Autism Speaks, in partnership with DDS and regional centers, would promote greater equity, diversity, and cultural and linguistic competency for underserved communities by developing new resources that could include the following:
    - Promote and develop materials that take into consideration: Lower literacy levels; cultural norms; linguistic competency.
    - Develop a comprehensive Autism Speaks website in Spanish.
    - Work with the regional centers to ensure that Autism Speaks Family Services Resources Library maintains the most up to date information on autism services in the state of California.
    - Make available to the regional center leadership and staff curricula on the basics of autism screening, diagnosis, and treatment.
    - Facilitate and enhance effective partnerships between regional centers and Autism Speaks field staff/office in California. Consider providing

outreach to the community and local providers through the Community Ambassadors Program – an initiative that field staff from the Chicago Chapter of Autism Speaks has implemented in their community

- Link regional centers to existing programs and services in California that expressly target underserved populations affected by autism, such as Los Angeles 211, which provides information on developmental disorder and autism screening in the Los Angeles area through the States' 211 call center.

- Promote partnerships between regional centers and community-based organizations and academic institutions through Autism Speaks grant mechanisms.

- Testing innovative strategies for building community capacity to provide evidence-based care.

III. ***Recommendations By Taskforce Staff:***

A. DDS, in collaboration with the regional centers, should seek to partner with academic institutions, state entities such as the First 5 California Commission, advocacy groups such as Autism Speaks, community-based organizations, and other appropriate organizations to establish a sustainable grant-funding mechanism that will leverage existing regional center resources and/or promote the development and implementation of innovative demonstration programs.

Additional Strategies to Implement Best Practices on Cultural and Linguistic Competency

A strong commitment by the Regional Center Executive Director, leadership team, as well as the ongoing involvement of the Regional Center Board of Directors is an important best practice in achieving cultural and linguistic competency for all DDS consumers. Current bylaws for the Regional Center Board of Directors do not appear to include any references, guidelines, or other information related to issues of equity, diversity and cultural and linguistic competency.

Therefore, it is appropriate for DDS and all of the regional centers to examine the current policies and practices, standards, requirements, and training that pertain to the regional centers' board of directors. Particular emphasis should be placed on issues of equity, diversity, and cultural and linguistic competency to ensure that these issues are compliant with all existing laws, regulations, and best practices. Specific recommendations that were provided by the Taskforce and Workgroup members included the following:

- Bylaws for Regional Center Board of Directors: All boards, committees, and other advisory groups established by regional centers should contain a section that affirms the regional centers' commitment to principles of equity, diversity, and cultural and linguistic competence.
    - The composition and membership of all boards, committees, and other advisory groups established by regional centers should, to the greatest extent possible, reflect the demographics and diversity of the regional centers' catchment area and surrounding community.
    - The bylaws of all Regional Center Board of Directors should establish policies and procedures with regards to training on issues of cultural and linguistic competency, equity, and diversity and that this training shall be provided to all Board members on an ongoing basis.
- Regional Center Leadership: Regional centers explicitly take into consideration the cultural and linguistic competence of all persons vetted for positions of management and leadership and that, to the greatest extent possible, these leadership positions reflect the cultural makeup of the population served by that specific regional center.
- Regional Center Needs Assessment on Diversity and Cultural and Linguistic Competency: This evaluation should be conducted to ascertain the level of cultural and linguistic competence that currently exists within an organization and to determine what additional training or experience employees, vendors and collaborating agencies may require in order to best achieve and fulfill the needs of their stakeholders. Conducting a cultural and linguistic competency self-assessment may involve others in the community besides staff. This process

is not only valuable in forging important partnerships with community-based organizations but also indicates to the community that the regional centers value diversity and is committed to increasing cultural and linguistic competence. Thus, the use of a self-assessment tool is a way of moving toward best practice in achieving the goals of equity and recognition of the inequalities that different groups face in service access and utilization.

IV. *Recommendations By Taskforce Staff:*

A. DDS, in partnership with regional centers should examine the statutory requirements and regulations with regards to the regional centers board of directors to ensure that they are compliant with current best practices on issues of equity, diversity, and cultural and linguistic competency.

B. DDS, in partnership with the regional centers, and as existing resources and funding are available, implement appropriate and effective and ongoing training on issues of cultural and linguistic competency for the regional centers' board of directors and other leadership members.

C. DDS, in partnership with the regional centers, and as existing resources and funding are available, implement appropriate and effective, and ongoing training on issues of cultural and linguistic competency for all regional center staff.

Appendices:

A. Taskforce on Equity and Diversity for Regional Center Services

B. Workgroup #1 Members

C. Workgroup #2 Members

D. The CLAS Standards

E. Case Management

F. Regional Centers Cultural Competence Organizational Assessment 2012 (CCOA)

G. Regional Center Client Satisfaction Survey

H. Workgroup #3 Members

I. Workgroup #4 Members

J. Workgroup #5 Members

K. Research by Dr. Sandy Magaña

L. Promotora Effectiveness Research

M. Definitions of Terms

Appendix A: Taskforce on Equity and Diversity for Regional Center Autism Services

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Appendix D: The CLAS Standards

National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health Care

Culturally Competent Care:

1. *Health care organizations should ensure that patients/consumers receive from all staff members effective, understandable, and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and preferred language.*
2. *Health care organizations should implement strategies to recruit, retain, and promote at all levels of the organization a diverse staff and leadership that are representative of the demographic characteristics of the service area.*
3. *Health care organizations should ensure that staff at all levels and across all disciplines receive ongoing education and training in culturally and linguistically appropriate service delivery.*

Language Access Services:

4. *Health care organizations must offer and provide language assistance services, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner during all hours of operation.*
5. *Health care organizations must provide to patients/consumers in their preferred language both verbal offers and written notices informing them of their right to receive language assistance services.*
6. *Health care organizations must assure the competence of language assistance provided to limited English proficient patients/consumers by interpreters and bilingual staff. Family and friends should not be used to provide interpretation services (except on request by the patient/ consumer).*
7. *Health care organizations must make available easily understood patient-related materials and post signage in the languages of the commonly encountered groups and/or groups represented in the service area.*

Organizational Supports:

8. *Health care organizations should develop, implement, and promote a written strategic plan that outlines clear goals, policies, operational plans, and management accountability/oversight mechanisms to provide culturally and linguistically appropriate services.*
9. *Health care organizations should conduct initial and ongoing organizational self-assessments of CLAS-related activities and are encouraged to integrate cultural and linguistic competence-related measures into their internal audits, performance improvement programs, patient satisfaction Assessments, and Outcomes-Based Evaluations.*
10. *Health care organizations should ensure that data on the individual patient's/consumer's race, ethnicity, and spoken and written language are collected in health records, integrated into the organization's management information systems, and periodically updated.*
11. *Health care organizations should maintain a current demographic, cultural, and epidemiological profile of the community as well as a needs assessment to accurately plan for and implement services that respond to the cultural and linguistic characteristics of the service area.*
12. *Health care organizations should develop participatory, collaborative partnerships with communities and utilize a variety of formal and informal mechanisms to facilitate community and patient/ consumer involvement in designing and implementing CLAS-related activities.*
13. *Health care organizations should ensure that conflict and grievance resolution processes are culturally and linguistically sensitive and capable of identifying, preventing, and resolving cross-cultural conflicts or complaints by patients/consumers.*
14. *Health care organizations are encouraged to regularly make available to the public information about their progress and successful innovations in implementing the CLAS Standards and to provide public notice in their communities about the availability of this information.*

Office of Minority Health, U.S. Department of Health and Human Services. (2000).National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health Care. Federal Register, 65(247), 80865-80879. http://www.omhrc.gov/clas/finalcultural1a.htm

CULTURE & MEDICINE

Physician Office Assessment of Culturally and Linguistically Appropriate Services (CLAS)

CLAS standards are the collective set of 14 mandates, guidelines and recommendations developed in 2002 by the Department of Health and Human Services, Office of Minority Health. They are intended to inform, guide and facilitate required and recommended practices related to culturally and linguistically appropriate health services. Please check the appropriate box if the statement is true in your practice setting.

Standard 1

Health care organizations should ensure that patients/consumers receive from all staff members effective, understandable and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and preferred language.

- ❑ Our staff feels comfortable in discussing a treatment plan with our patients that takes into consideration the patient's cultural preferences and lifestyle.
- ❑ We make every effort to assure that our patients fully understand questions, instructions and explanations from clinical, administrative and other staff.
- ❑ We explain technical or specialized terminology and verify that the patient understands what is being said by asking questions or having the patient repeat the information in their own words.
- ❑ Our office staff shows respect at all times, such as addressing all patients the way they like to be addressed (e.g., Mr., Mrs., Rev.)
- ❑ Our staff understands cultural health and illness beliefs and practices of our patient population. This includes being aware of beliefs about alternative medicine and knowledge of medical procedures and approaches that may violate cultural and or religious traditions.
- ❑ We share ideas and tips with each other regarding how to take an accurate history and physical on individual patients based on their personal beliefs and traditions.
- ❑ We have easy access to information regarding cultural competency and diverse patient populations to help us understand the cultures of our diverse populations.

Standard 2

Health care organizations should implement strategies to recruit, retain and promote at all levels of the organization a diverse staff and leadership that are representative of the demographic characteristics of the service area.

- ❑ We have included diversity into our mission statement, goals and strategic plans.
- ❑ We have used activities such as mentoring programs, community-based internships and collaborations with universities to build a diverse workforce.
- ❑ We strive to recruit staff who represent the cultures we serve.

Standard 3

Health care organizations should ensure that staff at all levels and across all disciplines receive ongoing education and training in CLAS delivery.

- ❑ We have incentives for staff to complete cultural competency training.
- ❑ Cultural competency training and CLAS implementation are factors in staff evaluations.
- ❑ Cultural competency and CLAS education is included in the orientation for all new staff.
- ❑ We budget money to train staff in cultural competency or as medical interpreters.

Standard 4

Health care organizations must offer and provide language assistance services, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner and during all hours of operation.

- ❑ We provide interpreter services from established and credible persons/agencies to patients who need this assistance.

Standard 5

Health care organizations must provide to patients/consumers in their preferred language both verbal offers and written notices informing them of their right to receive language services.

- ❑ We post signs that show availability of interpreter services with instructions to encourage the patient to ask for this service.
- ❑ We have a chart flagging system to identify patients that need interpreter services.
- ❑ We have identified interpreter services and contract those services as needed.
- ❑ We train our staff in the use of interpreter services.
- ❑ Our appointment scheduler ensures that patients or their family members are aware of language services that are available to them.
- ❑ Our telephone messaging service offers information in the respective languages of our patients.

Standard 6

Health care organizations must assure the competence of language assistance provided to limited English proficient patients/consumers by interpreters and bilingual staff. Family and friends should not be used to provide interpretation services (except on request by the patient/consumer).

- ❑ We assess staff on their skills and comfort level when interpreting medical information.
- ❑ We use accredited interpreter services when needed.
- ❑ We use existing hospital services and other resources when necessary.

Standard 7

Health care organizations must make available easily understood patient-related materials and post signage in the languages of the commonly encountered groups and/or groups represented in the service area.

- ❑ We offer educational materials in the languages of our patients.
- ❑ We take into consideration the literacy levels of our patients in the written information we provide.

Standard 8

Health care organizations should develop, implement and promote a written strategic plan that outlines clear goals, policies, operational plans and management accountability/oversight mechanisms to provide culturally and linguistically appropriate services (CLAS).

- ❑ We have built accountability processes into staff evaluations to ensure the cultural competence of the individual members of our staff.
- ❑ We provide educational staff workshops and opportunities to identify CLAS goals, objectives and timelines.
- ❑ We have identified a CLAS/cultural competency champion from within our staff to monitor our activities and advancement in cultural competency.
- ❑ We have guidelines about working with patients from other religions, cultures or language backgrounds (e.g., chart flagging system for patients who need language assistance).
- ❑ We have a strategic plan in place that incorporates CLAS goals and activities.

Standard 9

Health care organizations should conduct initial and ongoing organizational self-assessments of CLAS-related activities and are encouraged to integrate cultural and linguistic competence-related measures into their internal audits, performance improvement programs, patient satisfaction assessments and outcomes-based valuations.

- ❑ We provide our patients with satisfaction surveys and encourage them to complete the forms.
- ❑ We use patient surveys and comments to make appropriate changes.
- ❑ We add CLAS questions to staff reviews and orientation activities for new staff.

Standard 10

Health care organizations should ensure that data on the individual patient's/consumer's race, ethnicity, spoken and written language are collected in health records, integrated into the organization's information systems and periodically updated.

- ☐ Staff receive information to prepare for the patient's visit, such as the need for language services and the patient's preferred way to be addressed.
- ☐ Patients are periodically asked to update information that will help keep staff knowledgeable about their current preferences and beliefs.
- ☐ We maintain information on the ethnicity of our patients in order to plan treatment that takes into consideration their individual needs and their culture and beliefs.

Standard 11

Health care organizations should maintain a current demographic cultural and epidemiological profile of the community as well as a needs assessment to accurately plan for and implement services that respond to the cultural and linguistic characteristics of the service area.

- ☐ Our staff have access to data and demographic and cultural profiles from various sources, including local stakeholders, national organizations and state/federal agencies.
- ☐ Our staff are familiar with community resources and leaders as well as activities and issues that may positively or detrimentally affect the patient's health care.

Standard 12

Health care organizations should develop participatory, collaborative partnerships with communities and utilize a variety of formal and informal mechanisms to facilitate community and patient/consumer involvement in designing and implementing CLAS-related activities.

- ☐ Our staff participate in community events such as health fairs.
- ☐ We are aware of the beliefs of key leaders of community and faith-based organizations and businesses regarding their perspectives about health care.

Standard 13

Health care organizations should ensure that conflict and grievance resolution processes are culturally and linguistically sensitive and capable of identifying, preventing and resolving cross-cultural conflicts or complaints by patient/consumers.

- ☐ We have a policy of conflict and grievance resolutions as part of the patient bill of rights.
- ☐ We have developed a process to address conflict and grievance incidents to include:
- ☐ Displaying signage notifying patients of the process.
- ☐ A short, simple form to report incidences.
- ☐ A clear process for follow-up within a limited time frame.
- ☐ Resources for resolution, such as mediation if necessary.

Standard 14

Health care organizations are encouraged to regularly make available to the public information about their progress and successful innovations in implementing the CLAS standards and to provide public notice in their communities about the availability of this information.

- ☐ We post information to let our patients know about our efforts to be culturally responsive.
- ☐ We submit articles in professional and community newsletters about our efforts.
- ☐ We educate other medical staff, such as hospital discharge planners, about our services that may be helpful to patients with needs associated to culture, health literacy and our ability to provide care following hospitalization.
- ☐ We inform community groups and legislative representatives about our efforts to provide culturally appropriate care.
- ☐ We provide information through formal and informal communication venues (such as in community meetings, via display ads, brochures, news articles, press interviews, public speaking engagements, etc) about our efforts to provide respectful care to all patients.

Appendix E: Case Management Training

CASE MANAGEMENT DEFINED

Case management includes principles and philosophical approaches from a variety of viewpoints including state legislation, agency regulations, and public and private organizations. At the center of any case management approach is the consumer and his/her unique developmental needs. It is a value based and relationship based case management approach. The case management process is directed toward meeting those individual needs and equipping the consumer to be as capable and self-sufficient as possible.
Case management entails:

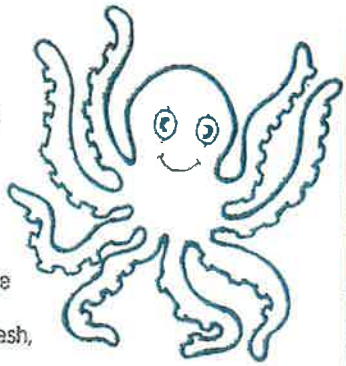
- assessment of client needs
- identification of resources to meet those needs
- coordination and monitoring of the services and supports that will enable the developmentally disabled individual to participate in the normal process of life in the least restrictive environment.

CASE MANAGEMENT VALUES

A set of basic values provides the foundation for case management decisions and services for individuals with developmentally disabilities. These values are:

- Empowerment and Choice: Supporting rather than controlling individuals and families by entering into partnerships that promote self-determination and interdependence.
    - Self-determination: Free choice of one's own acts or states without external compulsion. The ability to make choices without undue influence or pressure from others and the ability to control one's own behavior and emotions.
    - Interdependence: Relying on one another, mutually dependent. It is, 1 + 1 = 3. It is, the whole is greater than the sum of its parts.
- Respecting Diversity: Sensitivity to cultural preferences, values and lifestyles of consumers and families.
- Client & Family Support: Clients and families are respected and supported as primary decision makers. Services and supports build upon client/family strengths, natural supports and community resources.
- Community Integration & Inclusion: Supporting consumers to live, work and play in the mainstream of their
- community. Living in the neighborhood of their choice, and recreating with non-disabled peers in the activities of their choice.
- Teamwork: Working together with consumers, families, service providers, public agencies, community members and co-workers to achieve interdependent relationships and synergistic solutions to common goals.
- Integrity: Steadfast adherence to a strict ethical or moral code. It refers to what you do when nobody else is watching.
- Accountability: Accountability is the willingness to be responsible for one's own actions.

CASE MANAGEMENT ROLES AND FUNCTIONS



Counselor - The counselor provides support and consultation to assist clients and their families in making decisions and planning by providing them with the information necessary to assist in this process.
Evaluator/Assessor - The case manager assesses the client/family strength's, deficits and needs to help determine services and supports.
Consultant - Analyzes organizational or client problems and provides information, and helps to develop strategies to solve those problems.
Record Keeper - Documents all activities related to clients/families, case service coordination, agency interaction and interagency coordination efforts.
Service Coordinator - Sees that things work. Sees that needs and services mesh, and that monitoring, feedback and evaluation take place.
Collaborator & Community Liaison - Develops productive working relationships within the service agency and service network to help accomplish tasks.
Advocate - Represents clients and helps them speak for themselves.
Broker - Arranges for and sets conditions for service delivery.
Community/Service Organizer - Develops arrangements to facilitate interagency cooperation and coordination and/or plans for needed services with agencies and citizens.
Service Monitor - Keeps track of service delivery and its quality including arranging for and monitoring funding. Identifies and resolves service delivery problems when they are not meeting client needs.
Planner - Designs case plans, treatment, service integration and agency collaboration to meet the needs of clients.
Problem Solver - Acts with and on behalf of clients to assist them to find answers, resolve problems and to function as independently as possible.

CASE MANAGEMENTSKILLS & ABILITIES

- Active Listening: The act of acknowledging our receipt of a message, and paraphrasing our interpretation or understanding of that message.
- Clear Communicator: The ability to have others understand the information you are imparting.
- Empathetic: The capacity to view, value and appreciate the perspectives and emotions of another.
- Relationship Builder: It begins by: looking at the person in their environment with an emphasis on getting to know them, their strengths and weakness and the things that give them hope. It encompasses mutual respect and the ability to work together towards a common goal.
- Synthesize Information: The ability to compose, combine information to form a complete picture of a situation or problem.
- Good Observation Skills: The ability to scrutinize and examine people and situations to understand more than the obvious.
- Negotiation: A back and forth communication used to reach an agreement when you and the other side have some interests that are shared and some interests that are opposite.
- Self-awareness: An understanding of one's own biases, strengths and weaknesses.
- Self-control: The ability to act outside of one's own needs and self-interests.
- Facilitation: Enhancing a process for accomplishing a group's objectives.
- Good Planning Skills: The ability to anticipate and develop a detailed formulation of a program of action to achieve and end or objective.
- Creativity & Resourcefulness: The ability to create and develop unconventional, non-traditional solutions to create win-win situations.
- Ability to Prioritize: To determine and organize by order of importance.

MUTUAL INTERDEPENDENT SKILLS & ABILITIES

Adapted from: "Preparation for the Empowerment Process: Identifying Competencies and Developing Skills," Barr & Cochran, 1991

- Ability and commitment to identifying strengths in people and in groups.
- Genuine respect for diverse perspectives and lifestyles
- Ability to promote inclusion of a wide variety of stakeholders.
- A capacity to listen and reflect
- The capability of considering a range of issues which become more complex due to the addition of multiple viewpoints and opinions.
- Empathy, the capacity to view, value and appreciate the perspective of another.
- Intuition and ability to synthesize.
- An ability to subordinate one's own ego (to put oneself aside in the interest of the group)
- Skill and creativity in helping people become more aware and confident of their abilities.
- Appreciation of when to step back and the ability to help the individual or group assume decision-making and take action.
- Ability to analyze power relations and help others to do so.
  Ability to reflect and criticize ongoing processes, including one's own role in those processes.
- The flexibility to work with a broad array of service options and possibilities.

CULTURAL DO'S & DON'TS

	Do		Don't
1	Accept cultural values associated with religion and medical care.	1	Have preconceived ideas or stereotypes
2	Ask another person or agency for information regarding cultural characteristics.	2	Place your values on the client or family.
3.	Demonstrate a sincere interest in learning about the culture.	3	Assume that the client/family is incapable due to language barriers.
4.	Respect the client's/families choice about your level of involvement.	4.	Use non-verbal communication techniques which may by considered offensive.
5.	Identify similarities between your cultures.		
6.	Explain differences between your cultures to increase understanding.		
7	Learn basics words, phrases, and gestures.		
8	Realize your ideas of importance and common sense may not be the same.		
9.	Familiarize yourself with culture-specific acceptable and unacceptable non-verbal communication.		
10	Learn and follow culture-specific form and status distinctions.		
	List others you may know or learn:		List others you may know or learn:

A written statement from Maria Hernandez – CVRC Visalia Consumer Advocacy Specialist

I want to thank Diana for inviting me to speak to you today. My job as Consumer Advocacy Specialist means that I represent the consumers and act as an advocate for them. So today I'm here to tell you what I believe from my own experiences as a consumer.

I would like to speak to you about the Qualities of a Good Counselor. My counselor in Visalia is Sandy Mulligan. I am using her as a role model and you can too.

The first quality that I think is most important is to be a GOOD LISTENER. I want someone who hears me and understands what I am saying and WHAT I AM NOT SAYING. In other words you have to be a mind reader. By listening, we show respect.

TRUST is another important quality. I want someone I can trust to help me through anything. That means I can count on you to be my advocate, to stand by me, to be honest with me, and to keep confidential any information I may tell you that I don't want to share with others. I want someone who is available and will return my phone calls.

I want a counselor who has good problem solving skills. Someone who will help me to see all of my options and lead me to a good decision. My counselor also helps me plan for my IPP and set goals I can meet.

A good counselor will know about all kinds of resources that can help me - like where to live - work - go to school - and entertainment or how to develop a whole life style that works for me. I also need a lot of help and information about my medical problems. I count on my counselor for this important information.

I want a counselor who knows client's rights and respects them. Someone who encourages me to practice self advocacy and to stand up for myself and also to know my responsibilities. Most of your clients will not speak up. This is very difficult for us to do. All of our lives people have made choices for us and most of us are afraid that if we say what we want, someone will be mad at us.

Responsible choices are most important. I want good guidance. I want someone who will tell me the truth, even if it hurts my feelings and set me straight when I am not doing something I should be. This is being a true friend.

Please treat all consumers with respect and give us the benefit of the doubt. People who are mentally retarded, can't speak, hear or see still have the right to make choices as we all have strong feelings about what we think we want. I want to be included in the planning and decisions for my life. I don't want to be told what to do by a counselor who thinks they know what is best for me.

Consumers are REAL PEOPLE with REAL NEEDS. I want to close today with a verse that was written by students at the Creative Center:

We are PEOPLE first! We want others to know that we are people too. We love, we cry, we grow. We have problems, just like you. Don't put us down - give us a chance to laugh, to sing, to dance. We can make a difference is our world just open your eyes and you will see the beauty that lies within us!

I hope that you will all enjoy your new jobs. Remember that you can make a big difference in the lives of your clients and I know you will. Thank you.

Appendix F: Regional Centers Cultural Competence Organizational Assessment 2012 (CCOA)

Thank you for participating in this agency-wide assessment of cultural and linguistic competence (CLC). Conducting a self-assessment is considered a first step in an agency's goal towards a system wide implementation of CLC's. Your input will provide the Regional Centers with an opportunity to learn about its own strengths and challenges, as well as to ensure a systematic approach toward achieving competency goals.

Cultural and linguistic competence for an organization is the coming together of attitudes, behaviors, and polices that enables an organization and its staffs to work effectively in cross-cultural situations. It requires a new level of knowledge and accountability about individuals and communities, which is in turn, integrated into specific practices and policies. The achievement of organizational cultural and linguistic competence and the elimination of disparities require changes at every systems level including organizational values, policy making, governance, human resource development and retention, service delivery, research and evaluation, allocation of resources, and communications strategies. This assessment tool is designed to highlight these key areas of interest to the Regional Centers. Thank you in advance for your participation!

SECTION 1: PARTICIPANT INFORMATION

Staff members ☐ **Executive Office**

☐ **Administration** ☐ ****Include other categories***

2. Please indicate which applies to you. Check all that apply:

Category of Representation	
Sex:	
• **Male**	
• **Female**	
Persons who self-identify as LGBTQ -- Lesbian/Gay/Bisexual/Transgender/Questioning	
Persons who self-identify with a *MH/SU condition	

Family members of persons with *MH/SU conditions	
Persons who self-identify as having a disability other than MH/SU.	
Race and/or ethnicity:	
• American Indian/Alaska Native	
• Asian origin	
• Black, not of Hispanic origin	
• Hispanic/Latino origin	
• Middle Eastern origin	
• Native Hawaiian	
• Pacific Islander	
• White, not of Hispanic origin	
• Multi-racial	
• Other _____	

*Mental Health and/or Substance Use Condition

3. Do you provide services to persons who speak a language other than English?

____ Yes ___ No

4. In addition to English, what language proficiencies do you provide? Choose all that apply.

_____Arabic **_____Russian**

_____Braille **_____Sign Language**

_____Cantonese **____ Spanish**

____ French or Haitian Creole **____Tagalog**

_____Korean **____ Vietnamese**

_____Mandarin **_____Other (tell us)_____**

Source: Office of Management and Budget (OMB) and the U.S. Census Bureau, 2007

5. How long have you worked or been associated with a Regional Center?

- ☐ Less than 1 year
- ☐ 1 to 3 years
- ☐ 4-8 years
- 9-15 years
- 16-25 years
- More than 25 years

6. What is the highest degree that you have earned?

- ☐ High school Diploma
- ☐ Associate's degree
- ☐ Bachelor's degree
- ☐ Master's degree
- ☐ Doctoral Degree
- ☐ Other? (Please specify)

SECTION 2: VALUING CULTURE AND DIVERSITY

Instructions: Please read each statement and question carefully and check *the one best response* that describes the Regional Center's current status to which you are affiliated. Feel free to add additional comments below, or after any single answer.

1. **The Regional Center has a policy in place that addresses the value of cultural and linguistic competencies (CLC) that all staff and board members are expected to understand.**
   - ☐ Yes
   - ☐ Maybe
   - ☐ No
   - ☐ I don't know

2. **Does the Regional Center consider factors such as the role of culture, race, ethnicity, sexual orientation and language when planning and designing studies, programs, services and policies?**
   - Yes
   - No
   - Maybe
   - I don't know

3. **Is the Regional Center able to identify the culturally diverse communities represented amongst the population it serves?**
   - ☐ Yes
   - ☐ Maybe
   - ☐ No
   - ☐ I don't know

4. **Does the Regional Center and the its Board advocate for culturally and linguistically diverse consumers?**

☐ Yes ☐ Maybe

☐ No ☐ I don't know

5. The Regional Center is working towards developing cultural and linguistically diverse services?

☐ Yes ☐ Maybe

☐ No ☐ I don't know

6. When the Regional Center develops targeted projects, reaching out to culturally and linguistically diverse populations is essential.

☐ Yes ☐ Maybe

☐ No ☐ I don't know

7. Is the Regional Center familiar with current and projected demographics for the California catchment area where it operates?

☐ Yes ☐ Maybe

☐ No ☐ I don't know

8. The Regional Center considers factors such as the role of culture, race, ethnicity, sexual orientation, gender identity, level of disability, and language when working with state and community partners and other stakeholders.

☐ Yes ☐ Maybe

☐ No ☐ I don't know

9. Employees at the Regional Center understand the impacts of health disparities among the culturally and linguistically diverse and underserved populations?

☐Not at all ☐Sometimes ☐Fairly Often ☐Very Often

10. The Regional Center describes and includes the social determinants of health (e.g., poverty, unsafe housing, dispersed families, etc.) when examining and reporting the mental health of diverse cultural groups represented across the country?

☐Not at all ☐Sometimes ☐Fairly Often ☐Very Often

11. At the Regional Center, programs, services and practices reflect and show respect for diversity, such as culture, race, ethnicity, sexual orientation, gender identity and age.

☐Not at all ☐Sometimes ☐Fairly Often ☐Very Often

12. Does the Regional Center consider culture, race, ethnicity, sexual orientation, gender identity, and language when crafting and directing communication documents (i.e. pamphlets, web info, fact sheets, etc.)? Describe Not at all ☐Sometimes ☐Fairly Often ☐Very Often

13. Does the physical work environment contain décor that is inclusive of culturally diverse populations?

☐ Yes ☐ Maybe

☐ No I don't know

14. Does the Regional Center identify and participate in culturally diverse events or functions (African American History Week, etc)

☐Not at all ☐Sometimes ☐Fairly Often ☐Very Often

15. Does the Regional Center identify opportunities for you to share with colleagues your experiences and knowledge about diverse communities?

☐Not at all ☐Sometimes ☐Fairly Often ☐Very Often

16. The Regional Center leadership encourages staff to subcontract from a variety of vendors.

☐Not at all ☐Sometimes ☐Fairly Often ☐Very Often

SECTION 3: HUMAN RESOURCES

COMMENTS:

Instructions: Please read each statement and question carefully and check *the one best response* that describes your experience at the Regional Center. Feel free to add additional comments below or after any single answer.

1. The Regional Center makes every effort to hire employees that are representative of different cultural, racial, ethnic, sexual orientation, consumer, and age, etc. diversity.

☐ Yes ☐ Maybe

☐ No ☐ I don't know

2. Are the staff and leadership at the Regional Center reflective (comprised) of individuals who are culturally and linguistically (CLC) diverse?

☐ Yes ☐ Maybe

☐ No ☐ I don't know

3. The Regional Center Board composition is reflective of the diversity across the state, such as culture, race, ethnicity, sexual orientation, gender identity and language.

Yes Maybe No I don't know

4. The Regional Center has cultural and linguistic competence standards that everyone is expected to understand.

Yes Maybe

No I don't know

5. The Regional Center encourages and provides adequate training opportunities for staff to become more proficient about cultural and linguistic competencies and health equity and disparities?

Not at all Sometimes Fairly Often Very Often

6. The Regional Center includes targets related to cultural competence standards in the annual performance plan and evaluation.

Yes Maybe

No I don't know

7. The Regional Center provides in-service training activities on cultural and linguistic competence in mental health, for staff at all levels of the agency.

Not at all Sometimes Fairly Often Very Often

8. Does the Regional Center provide incentives for the improvement of cultural and linguistic competence throughout the organization?

Yes Maybe

No I don't know

9. The Regional Center treats everyone equally, regardless of culture, race, ethnicity, gender, age, sexual orientation or gender identity.

Not at all Sometimes Fairly Often Very Often

10. At the Regional Center, staff work together and appreciate their similarities and differences.

Not at all Sometimes Fairly Often Very Often

11. Does the Regional Center have procedures in place to achieve the goal of a culturally and linguistically competent workforce that includes:

Staff recruitment? ☐Yes ☐No ☐Maybe ☐I don't know

Hiring? ☐Yes ☐No ☐Maybe ☐I don't know

Retention? ☐Yes ☐No ☐Maybe ☐I don't know

Promotion? ☐Yes ☐No ☐Maybe ☐I don't know

12. The Regional Center has integrated standards of cultural and linguistic competence to organizational results and appropriately rewards staff when results are achieved.

☐ Yes ☐ Maybe ☐ No I don't know

13. Does the Regional Center Board and leadership officially recognize and value cultural and linguistic competencies?

☐Not at all ☐Sometimes ☐Fairly Often ☐Very Often

14. The Regional Center work environment allows you to bring your concerns discrimination, diversity, cultural competence, etc. to the attention of your immediate supervisor, without fear of reprisal.

☐Not at all ☐Sometimes ☐Fairly Often ☐Very Often

15. The Regional Center staff are open to including concepts of cultural and linguistic competency, health equity and disparities and diversity to any conversation.

☐Not at all ☐Sometimes ☐Fairly Often ☐Very Often

16.The Regional Center leadership and board are open to and encourage including concepts of cultural and linguistic competency, health equity and disparities and diversity to any conversation.
☐Not at all ☐Sometimes ☐Fairly Often ☐Very Often Comments:

SECTION 4: RESOURCES AND LINKAGES

1. Does the Regional Center collaborate with other state and national mental health groups to address the health and mental health needs of culturally and linguistically (CLC) diverse populations? ☐Not at all ☐Sometimes ☐Fairly Often ☐Very Often

2. Does the Regional Center work with social, professional contacts, and/or organizations (e.g. experts in cultural and linguistic competence, diversity and health equity and disparities, etc.) to help you understand the base of health and mental health beliefs of culturally diverse populations?

Not at all **Sometimes** **Fairly Often** **Very**

3. Has the Regional Center established formal relationships with these individuals, groups, or agencies to assist in building CLC capacity? **Yes** **Maybe** **I don't know**

4. The Regional Center uses resource materials that are culturally and linguistically appropriate to inform diverse groups about health and mental health issues.

Not at all **Sometimes** **Fairly Often** **Very Often**

5. The Regional Center uses state of the art communications (Podcasts, the internet, social media, etc.) to raise awareness about mental health for diverse and underserved populations.

Not at all **Sometimes** **Fairly Often** **Very Often**

COMMENTS:

Sources: Child Welfare League of America, Cultural Competence Agency Assessment Self -Assessment Instrument. (2002); National Center for Cultural Competence, Georgetown University, Cultural and Linguistic Competence Policy Assessment (2006); Department of Health and Human Services, CLAS Standards (2001); Mental Health America, Cultural and Linguistic Competence Committee, 2007.

Appendix G: Regional Center Client Satisfaction Survey

Family's primary language: _____ **Client's Age** _____ *By answering this survey you are assisting us to improve and maintain a high quality of services. Based on your most recent meeting with your regional center service coordinator, please rate your level of agreement with the following statements.*

1. **I understand the services that my regional center offers.**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

2. **I am encouraged to ask questions, and my SC gives me complete and easy to understand answers.**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

3. **My opinion and preferences are incorporated into the IPP.**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

4. **My service coordinator (SC) understands my child's needs, & implements the IPP goals promptly.**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

5. **I understand the goals and objectives in the IPP.**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

6. **I understand my rights and responsibilities under the Lanterman Act.**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

7. **I am informed about due process if I disagree with my IPP.**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

8. **I feel understood, supported and respected by my regional center service coordinator (SC)?.**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

9. **If I need more information about my child's disability, my SC helps me to the appropriate resources.**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

10. **My regional center SC advocates for my child with other agencies whenever necessary.**

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

11. **Written communication with the regional center is translated into my primary language.**

1	2	3	4	5
Never	Sometimes	Usually	Frequently	Always

12. **I have access to a translator when needed.**

1	2	3	4	5
Never	Sometimes	Usually	Frequently	Always

13. **Is this survey written in your primary language?** Yes / No. **Does your SC speak your primary language?** Yes / No
Frequency of contact with your regional center: ___yearly___6 months __quarterly ___other

Appendix H: Workgroup #3 Members

Areva Martin, Esq.*
Special Needs Network; Martin & Martin

Rick Rollens*
The MIND Institute; Rick Rollens Consulting

Barbara Firestone, Ph.D.*
The Help Group

Martha Matthews, Esq.*
Public Counsel Law Center

Lori Banales
Alta California Regional Center

Charlene Harrington
Institute for Health and Aging

John Papadak
Association of Regional Center Agencies

Eva Casas-Sarmiento
Client Rights Advocate

Ricki G. Robinson, M.D.
Descanso Medical Center for Development and Learning

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(* indicates a Taskforce member)

Appendix I: Workgroup #4 Members

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Dennis Dixon, Ph.D.
Center for Autism and Related Disorders

Vicki Smith
Alta California Regional Center

Len Abedutto, Ph.D.
The MIND Institute

Monisha Coelho, J.D.
Disability Rights California

Sherisse Cherin, M.A.
Verdugo Hills Autism Project

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Appendix J: Workgroup #5 Members

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North Bay Regional Center (Workgroup Leader)

Jim Burton*
Regional Center of the East Bay (Workgroup Leader)

Emily Iland*
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Jim Lantry*
Creative Legislative Solutions

Gwendolyn Hamilton, M.D.
Contra Costa Health Services

Kristin Jacobson
Alliance of California Autism Organizations

Monte Perez
Los Angeles Mission College

Drew Ngyuen
Behavior Functions, Inc.

Amy Daniels
Autism Speaks

Soryl Markowitz
Westside Regional Center

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Appendix K: Research by Dr. Sandy Magaña

Health Education for Latina mothers of children with developmental disabilities: My research shows that Latina mothers caring for children with disabilities are in poor health and have high rates of depression; yet services are typically focused on the needs of the child and not on the needs of parental caregivers. We developed a health education intervention that is focused on Latina mothers of children with disabilities and is based on a promotora de salud (lay health educators) model. A unique aspect of our project is that Latina mothers of children with disabilities serve as promotoras and are trained to provide health education to other similar mothers. We will be adapting this program for African American mothers of children with IDD as well.

Caring for myself: African American caregivers and health: Similar to the findings for Latino mothers, African American mothers caring for children with developmental disabilities are also in poor health African American mothers who do not care for a child with a disability; yet services are typically focused on the needs of the child and not on the needs of parental caregivers. Building on the promotora de salud (community health advisor) model we developed for Latina mothers, we are working with Catholic Charities on adapting this model to support African American caregivers of children with developmental disabilities. We hope to establish the program at Catholic Charities, which has extensive experience in providing services to families of children with disabilities. The project takes a community based research approach and encourages students to engage in public service that contributes to a just society. This project is funded by United Way and the Morgridge Center Matching Fund.

Addressing the informational needs of Latino immigrant parents of children on the autism spectrum: One in 150 children is diagnosed with autism. With intensive, early intervention, many children escape the most serious outcomes associated with the diagnosis such as segregated educational settings, serious problem behavior such as aggression towards self or others, and lack of a means to communicate verbally with family and friends. Without intervention, these symptoms persist over time and lead to worsened child and family outcomes. For Latinos, the largest minority group in the United States and one of the fastest growing groups in Wisconsin, there are significant challenges to obtaining timely diagnosis, and service systems are not prepared to help families navigate them. Once diagnosis is received, Latino families continue to face difficulty obtaining detailed information about the disorder, and in obtaining early intervention services. There is a wealth of information about autism and some research on successful intervention strategies; however, this information and these interventions have not been available to Spanish-speaking immigrant families. Latino parents of children with autism desperately need information and education on these issues. We are developing a parent education program that takes existing knowledge about autism, treatments, and services and makes it accessible to the Spanish speaking Latino community in a culturally competent and economical way. Our intervention differs from any other parent education study, because education will be provided in culturally competent ways that meet the unique needs of Latino parents. For instance, our parent education curriculum will be delivered in Spanish by community health educators, or promotoras de salud, who are themselves mothers of children with autism. Participating parents will receive two modules of intervention in their own home. The first module will provide 20 parents with eight weeks of instruction about child development, autism diagnoses, understanding their child's behaviors, and explaining their child's behaviors to others. The second eight week module will teach 20 parents how to reduce problem behaviors and improve their child's social and communication skills. Our community based-collaborator, the

Wisconsin Family Assistance Center for Education Training and Support (WI FACETS), is a non-profit organization serving Wisconsin children and adults with disabilities, their families and those who support them. WI FACETS have made an effort to include the Spanish speaking community in their programs, have key staff members that work with this community, and are very interested in programs that serve this population in a culturally sensitive way.

Cultural Equivalence of Autism Assessment for Latino Children: This study to be funded by NICHD will examine the cultural equivalence of the Autism Diagnostic Interview Revised (ADI-R) for a US Latino population. We propose 3 aims: (1) to assess the reliability of the ADI-R Spanish version among Spanish speaking parents of children with autism and intellectual disabilities; (2) To investigate the validity of the ADI-R in a sample of Latino parents of children with autism and intellectual disabilities; and (3) To investigate the meaning and perceived severity of symptoms in relation to the norms of the participant's family and culture. The proposed study builds on an existing study of Latino children on the autism spectrum and their families and will recruit 25 additional children who have intellectual disabilities. The study will utilize the expertise of bicultural and bilingual researchers that have extensive training experience with the ADI-R and cross cultural research. This study will establish a body of knowledge about the reliability and validity of a commonly utilized diagnostic measure with Latino populations which will reduce barriers for Latino children with ASD to receive important intervention services.

Latino families of children on the autism spectrum: The focus of this study is on understanding the experiences of Latino family members who have a child with an autism spectrum disorder (ASD). Autism is being diagnosed at increasing rates and services for children with autism are expanding. However, there is some evidence of disparities in rates of diagnosis and service utilization for Latino children as compared to non-Latino white children. In-home interviews with families were utilized to investigate barriers to service use for Latino children and their families, cultural interpretations of autism for these families, and maternal vulnerability and resiliency factors.

Below are Research reports and presentations of the project:
Instituto Filius article: English version; Instituto Filius article: Spanish version Power Point English: University of Puerto Rico Presentation Power Point Español: Presentación a la Universidad de Puerto Rico

Appendix L: "Promotora" Effectiveness Research

Project Description

Definition of the issue: It is well documented that Latino children with Autism Spectrum Disorders (ASD) are under-represented in the health, education and service systems in California and across the country, disadvantaging the child and family. Latino children with ASD are often diagnosed later than other children with autism, after more doctor visits. Latino families may encounter social, cultural, economic, political, and healthcare obstacles in their efforts to recognize their child's exceptional needs, secure a diagnosis, and access needed services. Culturally competent parent education in Spanish is essential to help parents understand autism, help their children, and learn to navigate the service systems.

The promotora pilot program: The promotora model may be ideal way of meeting the unique educational needs of Latino parents of children with autism in California. A *promotora de salud* or lay health educator is a member of a local community who promotes health and wellness within the community. Promotoras are typically women who are trained to provide education, guidance, and referral services around a particular health issue. (Men may also be promotores, but because so many women serve in this role, the term promotora is more commonly used). Dr. Sandy Magaña developed and led a pilot program using the promotora model for parent autism education in Wisconsin, starting in 2010 and continuing to the present. This model may be an excellent framework for a collaborative partnership involving regional centers, local organizations, and community members. In the pilot program, the parent education curriculum was delivered in Spanish by promotoras de salud who are themselves mothers of children with autism. This is one of the most unique features of this model. Participating parents received the educational program in their own home. The in-home delivery of the education creates access to information for the entire family and overcomes multiple practical obstacles including transportation, child care and work schedules. The program curriculum was developed by Latino and non-Latino parents and autism experts.

Two intervention modules, each made up of eight lessons, address the parents' most pressing needs for information, skill building, and advocacy.

- The first module includes instruction about child development, the autism diagnosis, understanding their child's behaviors, and explaining their child's needs to others.
- The second module teaches parents how to reduce problem behaviors and improve their child's social, play and communication skills.
- Each module is presented over an eight-week period, in education sessions lasting about two hours.

The model includes measures of effectiveness, as follows:

- Consumers and their families were provided with measures of family empowerment, caregiver burden, satisfaction and efficacy, depressive symptoms, knowledge about autism, use and social validity of targeted intervention strategies are collected pre- and post-intervention.
- The severity of autism symptoms, problem behavior, and parent knowledge about interventions were collected pre- and post-intervention.
- Post intervention interviews provided information about a family's relationship with the *promotora,* how the relationship may have contributed to learning, and about the usefulness of information from each session.

Project Proposal

It is proposed that the **Promotora Pilot Program for Parent Autism Education (PPP PAE)** be replicated by three Regional Centers in California. The pilot program will provide 30 families with 16 weeks of in-home parent education. Each Regional Center site will train three promotoras. Each promotora will provide ten families with educational services. All families will receive the first module of eight lessons, and it is expected that almost all families will continue with the second module of eight lessons. The participating Regional Centers will be free to use the project materials and expand the program as needed once the pilot program is completed. Dr. Sandy Magaña will oversee the project with the assistance of a principal investigator, Emily Iland, M.A. Ms. Iland, a resident of north Los Angeles county, was a primary author and leader in the pilot program. Under their expert leadership, the pilot program can be implemented with fidelity. Measures of program outcomes can be used to document the effectiveness of the model for Latino families in California. Due to logistical issues, it is recommended that the PPP PAE be piloted with three volunteer Regional Centers in the geographical area from Los Angeles to Bakersfield. This will result in economies of scale for training and consultation services from the project coordinator and principal investigator.

Once effectiveness is documented, the model can be replicated by Regional Centers throughout California as a culturally-competent way that meets the unique needs of Latino parents. The project materials are also available in English, and the model may be expanded for use with other populations, such as residents of rural areas and other underserved communities.

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Appendix M: Definitions of Terms

Diversity refers to the variety of personal experiences, values, and worldviews that arise from differences of culture and circumstance. Such differences include race, ethnicity, gender, age, religion, language, abilities/disabilities, sexual orientation, gender identity, socioeconomic status, and geographic region, and more. Diversity as a core value embodies inclusiveness, mutual respect, and multiple perspectives and serves as a catalyst for change resulting in health equity." https://www.aamc.org/members/gdi/

Health equity is when everyone has the opportunity to attain their full health potential and no one is disadvantaged from achieving this potential because of their social position or other socially determined circumstance." Extracted from: https://www.aamc.org/members/gdi/ . **Health equity** is achieving the highest level of health for all people. Health equity entails focused societal efforts to address avoidable inequalities by equalizing the conditions for health for all groups, especially for those who have experienced socioeconomic disadvantage or historical injustices." Source: Healthy People 2020.

Culture refers to integrated patterns of human behavior and cognition that include the language, thoughts, communications, actions, customs, beliefs, values and institutions of a particular social group (e.g., ethnic or racial group, faith community, language group).
Source: http://minorityhealth.hhs.gov/assets/pdf/checked/finalreport.pdf

Cultural Competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations." Source: Cross, T. L., Bazron, B. J., Dennis, K. W., & Issacs, M. R. (1989). *Toward a culturally competent system of care.* Washington, D. C.: Georgetown University Child Development Center.

Cultural Competence in an individual or organization implies having the capacity to function effectively within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities. **Source**: adapted from the Task Force on Community Preventive Services. *American Journal of Preventive Medicine*, 24(3S), 2003: 68-79.
A **Culturally Competent Approach** to care would result in:

- Reducing barrier to access by improving coordination across sectors of care in ways that are consonant with consumer' expectations
- More accurate diagnosis and treatment planning that reaches across cultural boundaries and is acceptable to consumers and their families
- Better consumer and family engagement with the treatment process leading to improved retention and adherence (http://nyspi.org/culturalcompetence)

Compiled by Sergio Aguilar-Gaxiola, M.D., Ph.D.

Appendix N: DDS Performance Contract Guidelines

STATE OF CALIFORNIA–HEALTH AND HUMAN SERVICES AGENCY EDMUND G. BROWN JR., Governor

DEPARTMENT OF DEVELOPMENTAL SERVICES
1600 NINTH STREET, Room 320, MS 3-9
SACRAMENTO, CA 95814
TDD 654-2054 (For the Hearing Impaired)
(916) 654-1958

August 8, 2011

TO: REGIONAL CENTER EXECUTIVE DIRECTORS AND BOARD PRESIDENTS

SUBJECT: CALENDAR YEAR 2012 PERFORMANCE CONTRACT GUIDELINES

INTRODUCTION

This document contains the guidelines and specific time lines for submitting calendar year 2012 outcome-based performance plans. Enclosure A is a chart that describes the overall structure and components for performance contracting. These guidelines are consistent with the legal requirements for developing and implementing performance contracts, as specified in Welfare and Institutions Code (Welf. & Inst. Code) section 4629, and support the quality management system framework.

GUIDELINES

The following are instructions and specific requirements to which regional centers must adhere for development of the performance contract.

Community Involvement: Outcome-based performance plans must be developed through meaningful participation with each regional center's local community. The regional center shall conduct at least one public meeting, with 10 calendar days advance notice, where participants can provide input on the performance plan, and shall use focus groups or surveys to collect information from the community. See Enclosure B, Statement of Assurances form, for additional required components of the public process. Centers must provide the signed Statement of Assurances form to confirm their adherence to the public process requirements, when submitting their year 2012 outcome-based performance plan to the Department for review and approval.

Minimum Information Required: The following information must be submitted for review before the Department's approval of the center's performance plan:

- Activities, developed with input from the local community, for addressing each of the public policy measures identified in Enclosure A. Statewide averages and baseline measures for some of these measures are under development (UD).
- Signed Statement of Assurances, Enclosure B (includes required components of the public process, and confirms the Board of Directors' adoption of the year 2012 outcome-based performance plan).

"Building Partnerships, Supporting Choices"

- Any locally developed public policy outcomes (optional), accompanying baselines or description of how baseline information will be obtained, and plan for measuring progress in achieving outcomes.

Time lines: The time lines for submitting the outcome-based performance plan and the year-end reports are as follows:

November 1, 2011:	Submit the performance contract plan to the Department for calendar year 2012.
January 31, 2012:	Submit the calendar year 2011 Performance Contract Year-End Report to the Department (locally developed public policy outcomes only, if applicable).

Year-End Reports: Regional centers are responsible for providing any locally developed public policy outcomes and associated performance data by which progress can be assessed. Please specify the source of the performance data.

The Department will provide performance contract year-end reports to each regional center, displaying baseline and year-end data for public policy measures and the regional center's status on compliance measures not currently under development (Enclosure A). Draft performance contract year-end reports will be provided to regional centers to facilitate input, prior to finalizing. For calendar year 2011, draft year-end reports will be transmitted by February 29, 2012. For calendar year 2012, draft year-end reports will be transmitted by February 28, 2013.

Regional centers need to review draft data and insert applicable regional center information on the draft performance contract year-end reports; then return the reports to the Department for final review and approval. Regional centers should not alter the Department issued year-end reports beyond inserting information where indicated.

Please mail all performance contract correspondence to:

Brian Winfield, Manager
Regional Center Operations Section
Department of Developmental Services
P.O. Box 944202 MS 3-9
Sacramento, CA 94244-2020
brian.winfield@dds.ca.gov

Revisions: Revisions to an approved performance plan must be submitted to the Department in writing.

Data Generation: Semi-annually, the Department provides Client Master File and Client Development Evaluation Report data for relevant public policy and compliance measures. Mid-year (June) data will be provided by July 15th and year-end (December) data will be provided by January 15th. Draft data will be provided one month prior to the dates above, to facilitate regional center input, prior to finalizing. All other data is provided annually with the issuance of the draft year-end report by the end of February.

Individualized Family Service Plan (IFSP) Development Data: As you are aware, the Department is transitioning to the new Early Start Report (ESR) in order to meet changing federal reporting requirements and to ensure an appropriate level of oversight. During the 2012 Performance Contract Year, the Department will use four data elements that are available on both the old ESR and the new ESR. These elements are:

1) IFSP meeting held within 45 days of receipt of referral;
2) Location of services identified;
3) Justification present for services not provided in natural environment; and,
4) Transition plans are present where applicable.

Based on ESR's completed by each regional center, beginning at the end of 2011 (baseline for 2012), Department staff will combine the four above elements to arrive at an IFSP Development composite for each regional center.

Dispute Resolution: Within 10 calendar days of receipt of the mid-year and/or year-end draft data, the regional center shall notify the Department of data issues or disagreements with the public policy or compliance measure data provided by the Department. The Department will review the information provided by the regional center, and within 30 days, inform the regional center of the outcome of its review. If the regional center disagrees with the Department's determination, the regional center may take action as referenced in Welf. & Inst. Code section 4632.

Evaluation criteria for regional center performance: The Department will review baseline and year-end performance data for the statewide public policy and compliance measures, by regional center. There are two categories of outcome measures that will be applicable to assessing performance: (1) statewide items applicable to all regional centers, and (2) local items developed by a specific regional center that is unique to that regional center. A regional center would be considered to have successfully achieved an item upon demonstrating the following:

- **Statewide indicator:** When any one of the following three criteria is met for the respective outcome:

  1. The outcome has improved over the prior year's baseline, or
  2. The performance exceeds the statewide average, or
  3. The performance equals a standard that has been defined by the Department

- **Local Indicator:** When the outcome reflects progress over the prior year's performance (baseline). The outcome must be related to a positive impact on consumers and/or families and not be included in the statewide measures above, e.g., increased presence of natural supports, persons with foster grandparents, etc.

If you have any questions regarding performance contracts and the performance contract process, please contact Brian Winfield, Manager, Regional Center Operations Section, at (916) 654-1569.

Sincerely,

Original Signed by Brian Winfield for

RITA WALKER
Deputy Director
Community Operations Division

Enclosures

cc: Area Board Executive Directors
Association of Regional Center Agencies

MEASUREMENT METHODOLOGY FOR PUBLIC POLICY AND COMPLIANCE MEASURES

Public Policy Performance Measures

Measure	Measurement Methodology
Number and percent of RC caseload in DC	CMF status code 8
Number and percent of minors residing with families	CMF residence code data for status 1 and 2 minors (< 18 y.o.) residing: • In own home • In foster home, or • With guardian
Number and percent of adults residing in independent living	CMF residence code data for status 2 adults (18 y.o. and above) residing in independent living
Number and percent of adults residing in supported living	CMF residence code data for status 2 adults (18 y.o. and above) residing in supported living
Number and percent of adults residing in Adult Family Home Agency homes	CMF residence code data for status 2 adults (18 y.o. and above) residing in Adult Family Home Agency homes
Number and percent of adults residing in family homes (home of parent or guardian)	CMF residence code data for status 2 adults (18 y.o. and above) residing in family homes (home of parent or guardian)
Number and percent of adults residing in home settings	CMF residence code data for status 2 adults (18 y.o. and above) residing in: • Independent living, • Supported living, • Adult Family Home Agency homes, and • Family homes
Number and percent of minors living in facilities serving > 6	CMF res. code data for status 1 & 2 minors residing in following facilities serving > 6: • ICF/DD's • ICF/DD-H's • ICF/DD-N's, • SNF's, and • CCF's
Number and percent of adults living in facilities serving > 6	CMF res. code data for status 2 adults residing in following facilities serving > 6: • ICF/DD's • ICF/DD-H's • ICF/DD-N's, • SNF's, and • CCF's (RCFE's not included)

Measure	Measurement Methodology
Number and percent of adults with earned income and average wage (aggregate)	UD—Anticipated implementation in conjunction with Revised CDER
Number and percent of adults in supported employment	UD—Department of Rehabilitation funded supported employment (group + individual) data currently unavailable. New code added to CMF to capture regional center funded supported employment, per Technical Bulletin, dated September 13, 2001 Revised CDER to capture wage information, hours of paid work, work environment (sheltered/community), and paid supports information to replace above data sources.
Number and percent of adults in competitive employment	UD—Anticipated implementation in conjunction with Revised CDER
Access to medical and dental services	UD—Anticipated implementation in conjunction with Revised CDER (Personal Outcomes Element, Section B, questions 13, 14 and 15)
Number of consumers per thousand who are victims of abuse	UD—Anticipated implementation in conjunction with Revised CDER (Personal Outcomes Element, Section B, question 16) and revisions to the Early Start Report

Compliance Measures

Measure	Measurement Methodology
Unqualified independent audit with no material finding(s)	Yes/No—based on regional center independent audit findings
Substantial compliance with DDS fiscal audit	Yes/No—based on DDS internal document criteria
Accuracy percent of POS fiscal projections (based on February SOAR)	Yes/No—Actual expenditures plus late bills as of 1/03 do not exceed ten percent of the high end of the range or fall below ten percent of the low end of the range reported in 2/02, with stipulations and exceptions noted in July 17, 2001, ARCA Administrators' memo. Year two recommendations contained in July 17, 2001, ACRA Administrators' memo, agreement Number 8.
Operates within OPS budget	Yes/No—actual expenditures plus late bills do not exceed OPS budget
Certified to participate in Waiver	Yes/No—based on most recent waiver monitoring report
Compliance with Vendor Audit Requirements per contract, Article III, Section 10	Yes/No—based on documentation regional center forwards to DDS

Measure	Measurement Methodology
CDER/ESR Currency	CMF status codes 1 and 2 with current CDER or ESR
Intake/assessment and IFSP time lines (0-3)	UD—Anticipated implementation with revisions to Early Start Report
Intake/assessment time lines for consumers ages 3 and above	CMF—calculated by subtracting the status date from the CMF date
IPP Development (W/C requirements)	Biennial DDS review per Welfare & Institutions Code section 4646.5 (c)(3)
IFSP Development (Title 17 requirements)	Early Start Report

Updated: 8/8/11

REFERENCES

1. Alegria M, Vallas M, Pumariega A. Racial and ethnic disparities in pediatric mental health. *Chil Adolesc Psychiatr Clin N Am*. 2010 Oct; 19(4): 759-774.

2. Finke HE, Drager DK, Ash S. Pediatricians' perspectives on identification and diagnosis of autism spectrum disorders. *J Earl Child Res*. 2010; 8(3): 254-268.

3. Rosenberg ER, Daniels MA, Law KJ, Law AP, Kaufmann EW. Trends in autism spectrum disorder diagnosis. *J of Autism and Dev Disorders*. 2007; 39(8), 1097-1111.

4. Balo J. Prevalence of autism spectrum disorders: Autism and developmental disabilities monitoring network, 14 sites, United States, 2008. *Surveillance Summaries*. 2012; 61 (5503), 1-19.

5. Parish LS, Magana S, Rose AR, Timberlake M, Swaine GJ. Health care of Latino children with autism and other developmental disabilities: Quality of provider interaction mediates utilization. *Am J Intel Dev Dis*. 2012; 117(4), 304-315.

6. Schnittker J, McLeod JD. The social psychology of health disparities. *Annual Rev of Soc*. 2005; 31:75-103.

7. Smedley B, Stith A, Nelson A. Unequal treatment: Confronting racial and ethnic disparities in health care. (Eds.). Washington, DC: The National Academies Press, 2003.

8. Magaña S, Parish LS, Rose AR, Timberlake M, Swaine GJ. Racial and ethnic disparities in quality of care among children with autism and other developmental disabilities. *Am J Intel Dev Dis*. 2012; 50(4), 287-299.

9. U.S. Census Bureau. (2011). Projections of the population by sex, race, and Hispanic origin for the United States: 2010 to 2050. Retrieved on October 15, 2012, from www.census.gov/population/www/projections/summarytables.html

10. Zarembro A. Discovering autism: A four part series. Los Angeles Times. http://www.latimes.com/news/local/autism/la-me-autism-day-one-html,0,1218038.htmlstory. Accessed on October 20, 2012.

11. U.S. Department of Health and Human Services. Healthy people 2010: Understanding and improving health (2nd ed.). Washington, DC: U.S. Government Printing Office, 2000).

12. Institute of Medicine. Health literacy: A prescription to end confusion. Washington, DC: National Academies Press, 2004.

13. Kutner M, Greenberg E, Jin Y, Paulsen C. The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy (NCES 2006–483). U.S. Department of Education. Washington, DC: National Center for Education Statistics, 2006.

14. Patton MQ. Qualitative evaluation and research methods (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc., 2002.

15. National Quality Forum (NQF). A Comprehensive Framework and Preferred Practices for Measuring and Reporting Cultural Competency: A Consensus Report. Washington, DC: NQF; 2009. www.qualityforum.org. Accessed on September 15, 2012.

16. National Core Indicators: California adult consumer survey report. Quality assessment project. California Department of Developmental Services, published in 2011. Available at http://www.dds.ca.gov/QA/index.cfm. Assessed in September 20, 2012.

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HealthData Management

CMS uses data to tackle disparities in care

By

- **Joseph Goedert**

Published

- **April 22 2016, 2:55pm EDT**

A data analytics project done at the Centers for Medicare and Medicaid Services has the agency acknowledging that the Medicare Advantage managed care program suffers from racial and ethnic disparities in care.

According to a report from CMS, African Americans and Hispanic beneficiaries had significantly more difficulty receiving needed care and making medical appointments than Whites, and African Americans had a tougher time getting prescriptions than Whites.

"While these data do not tell us why differences exist, they show where we have problems and can help spur efforts to understand what can be done to reduce or eliminate differences," Cara James, PhD, director of the CMS Office of Minority Health, said in a statement.

The data comes from the Healthcare Effectiveness Data and Information Set of medical and administrative data on how well the needs of Medicare beneficiaries are being met, as well as the Medicare Consumer Assessment of Healthcare Providers and Systems.

Measures reported include patient experiences of the ease of getting care and information about their drug coverage and costs, and clinical care measures such as

appropriate disease screenings and whether beneficiaries' medical conditions are being adequately controlled. In total, there are eight patient experience measures and 27 clinical care measures.

The report compares these measures for African American, American Indian/Alaska Native, Asian or Pacific Island, and Hispanic beneficiaries against measures for Whites. In measuring patient experience getting needed care, the data shows American Indian/Alaska Native only slightly had less difficulty than Whites, but other ethnicities had considerably more difficulty.

American Indian/Alaska Native beneficiaries also had easier experiences with getting appointments and care quickly—even outpacing Whites—as well as reporting easier access to health plan information.

Based on a scoring range of 0 to 100, all ethnicities except Asian/Pacific Island had better scores than Whites on how well doctors communicated with patients. Scores for how well care was coordinated ranged from 81.0 for Asian/Pacific Islander to 87.4 for American Indian/Alaska Native. Asian/Pacific Islander beneficiaries also lagged other groups in getting needed prescription drugs.