

University of California, San Francisco School of Medicine and
University Of California School of Nursing
Presents

14th Annual Developmental Disabilities: An Update for Health Professionals

March 5-6, 2015
UCSF Laurel Heights Conference Center
San Francisco, CA

Course Co-Directors
Lucy S. Crain, MD, MPH, FAAP
Geraldine Collins-Bride, RN, MS, ANP, FAAN
University of California, San Francisco



University of California, San Francisco School of Medicine



University of California, San Francisco School of Medicine Presents

14th Annual Developmental Disabilities: An Update for Health Professionals

This annual interdisciplinary conference offers a unique, practical update for primary care and subspecialty health care professionals who care for children, youth, and adults with developmental disabilities and complex health care needs. This year's conference continues to cover topics across the lifespan on a broad range of developmental disabilities as well as focus on the self advocacy movement with presentations highlighting the 25th anniversary of the Americans with Disabilities Act. Included in that focus will be special presentations by leading experts in disability rights and autism policy development. Clinics specially designed to accommodate individuals with disabilities and mobility limitations, and current and future options for improved community living resources for individuals with disabilities, will be addressed by policy makers as well as clinic directors. Expert epidemiologic perspectives on the evolving demographics of Autism Disorders and Fetal Alcohol Disorders are among this year's topics. Exciting research on the importance of early screening and services, putting research into practice for children with autism disorders, will be addressed. Identification and diagnosis of Fetal Alcohol Disorders, children, youth and adults with multiple disabilities who are in foster or dependent care, and treatment of sleep disorders in individuals with developmental disabilities are among many of the 2015 topics.

Presentations should be of interest to pediatricians, family physicians, nurse clinicians, psychologists, and internists who are involved in health care of individuals with developmental disabilities, as well as to those in other health related disciplines including health policy, dentistry, epidemiology, psychiatry, school health, social work, occupational and speech therapy and case management services. While the conference is designed for health care professionals, we welcome families and individuals with developmental disabilities who wish to learn from various represented disciplines.

Non-profit conference exhibitors feature resources designed to help our audience better provide care for children, youth, and adults with developmental disabilities. We look forward to welcoming you to the 14th annual Developmental Disabilities Update Conference and hope that your patients and clients with special health care needs will benefit from your participation.

Lucy S. Crain, MD, MPH, FAAP
Course Co-Chair

Geraldine Collins-Bride, RN, MS, ANP, FAAN
Course Co-Chair

EDUCATIONAL OBJECTIVES

An attendee completing this course should be able to

1. Describe legislative advocacy and policy issues addressing the equal rights legislated by the Americans with Disabilities Act;
2. Implement solutions to adaptive clinical practice settings and care with relevance to developmental disabilities;
3. Consult with caregivers and parents on the importance of early screening and referral for autism spectrum disorders;
4. Review etiology/causes and epidemiology of fetal alcohol effects;
5. Consult with caregivers and parents regarding lifespan expectations and prognoses of autism spectrum disorders and other developmental disabilities;
6. Have patient education materials readily available during office visits, in multiple media formats, to patients to support the utilization of resources and health care services by children, youth, and adults with chronic developmental disabilities;
7. Facilitate access to information about community living options resources for children, youth, and adults with developmental disabilities;
8. Understand the history of the Americans with Disabilities Act and importance of the self advocacy movement for individuals with developmental disabilities and implications for health care;
9. Recognize signs of possible sleep disorders, know when to refer for specialized diagnostic studies and recommend treatment;
10. Screen for behavioral/mental health disorders in children and adults with developmental disabilities in foster/dependent care and know when and where to refer for diagnosis and treatment.

ACKNOWLEDGEMENT

This educational activity has been supported in part by a charitable contribution from The Special Hope Foundation, a non profit 501 C 3 organization.

Special Hope Mission Statement

The mission of the Special Hope Foundation is to promote the establishment of comprehensive health care for developmentally disabled adults designed to address their unique and fundamental needs.

Principal Program Exhibitors/Resource Center

Alameda County Developmental Disabilities Planning Advisory Council

The Arc San Francisco

Autism Society-San Francisco Bay Area

California Children's Services

Captain's Project

CBEM

Disability Rights California

East Bay Regional Center

Golden Gate Regional Center

North Bay Regional Center

Support for Families

TACT/Redwood Coast Regional Center

Toolworks

UCSF Office of Developmental Primary Care

Healthy People 2020: Disability and Health

Objective #1: Include in the core of Healthy People 2020 population data systems a standardized set of questions that identify “people with disabilities.”

Objective #2: Increase the number of Tribes, States, and the District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers.

Objective #3: Increase the proportion of U.S. master of public health (M.P.H.) programs that offer graduate-level courses in disability and health.

Objective #4: Reduce the proportion of people with disabilities who report delays in receiving primary and periodic preventive care due to specific barriers.

Objective #5: Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care.

Objective #6: Increase the proportion of people with epilepsy and uncontrolled seizures who receive appropriate medical care.

Objective #7: Reduce the proportion of older adults with disabilities who use inappropriate medications.

Objective #8: Reduce the proportion of people with disabilities who report physical or program barriers to local health and wellness programs.

Objective #9: Reduce the proportion of people with disabilities who encounter barriers to participating in home, school, work, or community activities.

Objective #10: Reduce the proportion of people with disabilities who report barriers to obtaining the assistive devices, service animals, technology services, and accessible technologies that they need.

Objective #11: Increase the proportion of newly constructed and retrofitted U.S. homes and residential buildings that have visitable features.

Objective #12: Reduce the number of people with disabilities living in congregate care residences.

Objective #13: Increase the proportion of people with disabilities who participate in social, spiritual, recreational, community, and civic activities to the degree that they wish.

Objective #14: Increase the proportion of children and youth with disabilities who spend at least 80 percent of their time in regular education programs.

Objective #15: Reduce unemployment among people with disabilities.

Objective #16: Increase employment among people with disabilities.

Objective #17: Increase the proportion of adults with disabilities who report sufficient social and emotional support.

Objective #18: Reduce the proportion of people with disabilities who report serious psychological distress.

Objective #19: Reduce the proportion of people with disabilities who experience nonfatal unintentional injuries that require medical care.

Objective #20: Increase the proportion of children with disabilities, birth through age 2 years, who receive early intervention services in home or community-based settings.

For more information, please visit:

<http://www.healthypeople.gov/2020/implement/plan.aspx>

DDS Early Start

<http://www.dds.ca.gov/EarlyStart/Home.cfm>

“Families whose infants or toddlers have developmental delay or disability can receive an "Early Start" in the State of California. Teams of service coordinators, healthcare providers, early intervention specialists, therapists, and parent resource specialists can evaluate and assess an infant or toddler and provide appropriate early intervention services to children eligible for California's Early Intervention system of services

Accreditation

The University of California, San Francisco School of Medicine (UCSF) is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

UCSF designates this live activity for a maximum of **14.50 AMA PRA Category 1 CreditsTM**. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

This CME activity meets the requirements under California Assembly Bill 1195, continuing education and cultural and linguistic competency.

Family Physicians This Live activity, Developmental Disabilities: An Update for Health Professionals, with a beginning date of 03/5/15, has been reviewed and is acceptable for up to 13.50 Prescribed credit(s) by the American Academy of Family Physicians. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Licensed Clinical Social Workers This course meets the qualifications on an hour-for-hour basis of continuing education credit for MFTs and/or LCSWs as required by the California Board of Behavioral Sciences. Approval No.PCE 1272.

Nursing For the purpose of recertification, the American Nurses Credentialing Center accepts *AMA PRA Category 1 CreditsTM* issued by organizations accredited by the ACCME.

Physician Assistants AAPA accepts category 1 credit from AOACCME, Prescribed credit from AAFP, and *AMA PRA Category 1 CreditsTM* from organizations accredited by the ACCME.

Psychologists This educational activity is recognized by the California Board of Psychology as meeting the continuing education requirements toward license renewal for California psychologists. The California Board of Psychology accepts *AMA PRA Category 1 CreditsTM* from organizations accredited by the ACCME. Psychologists are responsible for reporting their own attendance to the California Board of Psychology. Psychologists from other states should check with their respective licensing boards.

General Information

Attendance Verification/ Sign-In Sheet/ Electronic CME Certificate Claiming

Please remember to sign-in on the sign-in sheet when you check in at the UCSF Registration Desk on your first day. You only need to sign-in once for the course, when you first check in.

After the meeting, please visit this website <http://www.ucsfcmec.com/evaluation> to complete the online **Course Evaluation Part 2/ Electronic CME Certificate Claiming**

Upon completing the Electronic CME Certificate Claiming, your CME certificate will be automatically generated to print and/or email yourself a copy.

Evaluation

Your opinion is important to us – we do listen! We have a two part evaluation for this course.

The **Course Evaluation Part 1/Speaker Evaluation** is the bright yellow hand-out you received when you checked in. Please complete this during the meeting and turn it in to the registration staff at the end of the conference.

After the meeting, please visit this website <http://www.ucsfcmec.com/evaluation> to complete the online **Course Evaluation Part 2/ Electronic CME Certificate Claiming**

We request you complete this evaluation within 30 days of the conference in order to receive your CME certificate through this format.

Otherwise you will need to certify your hours with the registration office at registration@ocme.ucsf.edu

Wine and Cheese Reception

A networking wine and cheese reception will be held in the lobby area immediately outside the auditorium from 5:00-6:30pm on Thursday March 5th.

Lunch

A box lunch is provided to conference attendees on Thursday March 5th. Lunch is on your own on Friday March 6th. A list of nearby restaurants is included at the end of the syllabus.

Security

We urge caution with regard to your personal belongings and syllabus books. We are unable to replace these in the event of loss. Please do not leave any personal belongings unattended in the meeting room during lunch or breaks.

Exhibits

Exhibits will be available in the Chancellor's Room during breaks, the wine and cheese reception on Thursday March 5th and at lunchtime on both days.

Presentations

Final presentations will be available on our website approximately 2-4 weeks post event. We will only post presentations for those authorized by the presenters.

<http://www.ucsfcmec.com/2015/MOC15001/slides.html>

Federal and State Law Regarding Linguistic Access and Services for Limited English Proficient Persons

I. Purpose.

This document is intended to satisfy the requirements set forth in California Business and Professions code 2190.1. California law requires physicians to obtain training in cultural and linguistic competency as part of their continuing medical education programs. This document and the attachments are intended to provide physicians with an overview of federal and state laws regarding linguistic access and services for limited English proficient (“LEP”) persons. Other federal and state laws not reviewed below also may govern the manner in which physicians and healthcare providers render services for disabled, hearing impaired or other protected categories

II. Federal Law – Federal Civil Rights Act of 1964, Executive Order 13166, August 11, 2000, and Department of Health and Human Services (“HHS”) Regulations and LEP Guidance.

The Federal Civil Rights Act of 1964, as amended, and HHS regulations require recipients of federal financial assistance (“Recipients”) to take reasonable steps to ensure that LEP persons have meaningful access to federally funded programs and services. Failure to provide LEP individuals with access to federally funded programs and services may constitute national origin discrimination, which may be remedied by federal agency enforcement action. Recipients may include physicians, hospitals, universities and academic medical centers who receive grants, training, equipment, surplus property and other assistance from the federal government.

HHS recently issued revised guidance documents for Recipients to ensure that they understand their obligations to provide language assistance services to LEP persons. A copy of HHS’s summary document entitled “Guidance for Federal Financial Assistance Recipients Regarding Title VI and the Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons – Summary” is available at HHS’s website at: <http://www.hhs.gov/ocr/lep/> .

As noted above, Recipients generally must provide meaningful access to their programs and services for LEP persons. The rule, however, is a flexible one and HHS recognizes that “reasonable steps” may differ depending on the Recipient’s size and scope of services. HHS advised that Recipients, in designing an LEP program, should conduct an individualized assessment balancing four factors, including: (i) the number or proportion of LEP persons eligible to be served or likely to be encountered by the Recipient; (ii) the frequency with which LEP individuals come into contact with the Recipient’s program; (iii) the nature and importance of the program, activity or service provided by the Recipient to its beneficiaries; and (iv) the resources available to the Recipient and the costs of interpreting and translation services.

Based on the Recipient’s analysis, the Recipient should then design an LEP plan based on five recommended steps, including: (i) identifying LEP individuals who may need assistance; (ii) identifying language assistance measures; (iii) training staff; (iv) providing notice to LEP persons; and (v) monitoring and updating the LEP plan.

A Recipient’s LEP plan likely will include translating vital documents and providing either on-site interpreters or telephone interpreter services, or using shared interpreting services with other Recipients. Recipients may take other reasonable steps depending on the emergent or non-emergent needs of the LEP individual, such as hiring bilingual staff who are competent in the skills required for medical translation, hiring staff interpreters, or contracting with outside public or private agencies that provide interpreter services. HHS’s guidance provides detailed examples of the mix of services that a Recipient should consider and implement. HHS’s guidance also establishes a “safe harbor” that Recipients may elect to follow when determining whether vital documents must be translated into other languages. Compliance with the safe harbor will be strong evidence that the Recipient has satisfied its written translation obligations.

In addition to reviewing HHS guidance documents, Recipients may contact HHS's Office for Civil Rights for technical assistance in establishing a reasonable LEP plan.

III. California Law – Dymally-Alatorre Bilingual Services Act.

The California legislature enacted the California's Dymally-Alatorre Bilingual Services Act (Govt. Code 7290 *et seq.*) in order to ensure that California residents would appropriately receive services from public agencies regardless of the person's English language skills. California Government Code section 7291 recites this legislative intent as follows:

"The Legislature hereby finds and declares that the effective maintenance and development of a free and democratic society depends on the right and ability of its citizens and residents to communicate with their government and the right and ability of the government to communicate with them.

The Legislature further finds and declares that substantial numbers of persons who live, work and pay taxes in this state are unable, either because they do not speak or write English at all, or because their primary language is other than English, effectively to communicate with their government. The Legislature further finds and declares that state and local agency employees frequently are unable to communicate with persons requiring their services because of this language barrier. As a consequence, substantial numbers of persons presently are being denied rights and benefits to which they would otherwise be entitled.

It is the intention of the Legislature in enacting this chapter to provide for effective communication between all levels of government in this state and the people of this state who are precluded from utilizing public services because of language barriers."

The Act generally requires state and local public agencies to provide interpreter and written document translation services in a manner that will ensure that LEP individuals have access to important government services. Agencies may employ bilingual staff, and translate documents into additional languages representing the clientele served by the agency. Public agencies also must conduct a needs assessment survey every two years documenting the items listed in Government Code section 7299.4, and develop an implementation plan every year that documents compliance with the Act. You may access a copy of this law at the following url: <http://www.spb.ca.gov/bilingual/dymallyact.htm>

COURSE CO-CHAIRS

Lucy S. Crain, MD, MPH, FAAP

Clinical Professor Emeritus, Department of Pediatrics, UCSF School of Medicine
Clinical Professor of Pediatrics, LPCH at Stanford University School of Medicine

Geraldine Collins Bride, RN, MS, ANP, FAAN

Clinical Professor and Vice Chair, Department of Community Health Systems
UCSF School of Nursing

GUEST FACULTY

Tony Anderson

Executive Director, The Arc California;
Director of the Collaboration for The Arc UCP in California

Paniz Bagheri

CSEC Specialist and Consultant

Alicia Bazzano, PhD, MD, MPH

Pediatrician, The Achievable Health Center;
Chief Physician Consultant, Westside Regional Center;
Clinical Faculty, Pediatric Emergency Medicine,
University of California, Los Angeles

Barbara A. Bennett, MD

Child Development Center, Pediatric Specialty Clinics,
Department of Pediatrics, California Pacific Medical Center

Barbara L. Bentley, PsyD, MS Ed

Pediatric Psychologist,
Lucile Packard Children's Hospital,
Stanford University, Stanford, CA

Mary Lou Breslin, MA

Senior Policy Advisor,
Disability Rights Education and Defense Fund, Berkeley, California

Jennifer A. Dresen, MSW, MPH

Director, Center for Health & Wellness
The Arc San Francisco

Ann England, MA, CCC-SLP-L

Assistant Director, Diagnostic Center, Northern CA, CDE;
CAPTAIN Leader
(California Autism Professional Training and Information Network)

George A. Fouras, MD

Staff Psychiatrist, Foster Care
Mental Health Program & Juvenile
Hall (Special Programs for Youth),
Department of Public Health, San Francisco, CA;
Consultant, Human Services Agency

GUEST FACULTY, CONT.

Matt G. Holder, MD, MBA

President, American Academy of Developmental Medicine and Dentistry;
Global Medical Advisor, Special Olympics, Inc.;
Vice-President, Council on Developmental Disabilities;
CEO, Lee Specialty Clinic, Louisville, KY

Kenneth Lyons Jones, MD

Distinguished Professor of Pediatrics;
Medical Director, California
Teratogen Information Service and Clinical Research Program,
University of California, San Diego, School of Medicine

Robin May, LCSW, EdM

Alta California Regional Center, ASD Clinical Specialist

Glenn Motola, PsyD

Chief Executive Officer, The Arc San Francisco

Ari Ne'eman

Public Policy Team Co-Lead, LEAD Center
President and Co-Founder, Autistic
Self Advocacy Network (ASAN)

Bruce Oka

Commissioner (retired), San Francisco Transportation
Authority, Disability Rights Advocate

Rafael Pelayo, MD

Professor, Psychiatry & Behavioral Science,
Stanford Center for Sleep
Sciences and Medicine,
Stanford University School of Medicine

Santi J. Rogers

Director, California Department of Developmental Services,
Sacramento, CA

Patty Schetter, MA, BCBA

Project Coordinator, Center for Excellence in Developmental
Disabilities, UC Davis MIND Institute

Allen Wong, DDS, EdD

Professor and Director AEGD Program
Director, Hospital Dentistry Program
Pacific Dugoni School of Dentistry, San Francisco, CA

Marshalyn Yeargin-Allsop, MD

Medical Epidemiologist & Chief, Developmental Disabilities Branch,
Centers for Disease Control and Prevention, Atlanta, GA

UCSF FACULTY

Clarissa C. Kripke, MD, FAAFP

Clinical Professor and Director,
Developmental Primary Care,
Department of Family and Community Medicine

Elysa Marco, MD

Associate Professor of Neurology, Pediatrics, and Psychiatry;
Director of Research, Autism and Neurodevelopment Program

Pratik Mukherjee, MD, PhD

Professor of Radiology and Biomedical Imaging

Alice Wong, MS

Staff Research Associate, Community Living Policy Center, UCSF;
Project Coordinator, Disability Visibility Project

Disclosures

The following faculty speakers, moderators, and planning committee members have disclosed no financial interest/arrangement or affiliation with any commercial companies who have provided products or services relating to their presentation(s) or commercial support for this continuing medical education activity:

Lucy S. Crain, MD, MPH, FAAP
Geraldine Collins-Bride, RN, MS, ANP, FAAN
Tony Anderson
Paniz Bagheri
Alicia Bazzano, PhD, MD, MPH
Barbara A. Bennett, MD
Barbara L. Bentley, PsyD, MS Ed
Mary Lou Breslin, MA
Jennifer Dresen, MSW, MPH
Ann England, MA, CCC-SLP-L
George A. Fouras, MD
Matt Holder, MD, MBA
Clarissa Kripke, MD, FAAFP

Kenneth Lyons Jones, MD
Elysa Marco, MD
Robin May, LCSW, EdM
Glenn Motola, PsyD
Ari Ne'eman
Bruce Oka
Rafael Pelayo, MD
Santi J. Rogers
Patty Schetter, MA, BCBA
Alice Wong, MS
Allen Wong, DDS, EdD
Marshalyn Yeargin-Allsopp, MD

The following faculty speakers have disclosed a financial interest/arrangement or affiliation with a commercial company who has provided products or services relating to their presentation(s) or commercial support for this continuing medical education activity. All conflicts of interest have been resolved in accordance with the ACCME Standards for Commercial Support:

Pratik Mukherjee, MD, PhD

Grant/Research Support,
Board Member

GE Healthcare

This UCSF CME educational activity was planned and developed to: uphold academic standards to ensure balance, independence, objectivity, and scientific rigor; adhere to requirements to protect health information under the Health Insurance Portability and Accountability Act of 1996 (HIPAA); and, include a mechanism to inform learners when unapproved or unlabeled uses of therapeutic products or agents are discussed or referenced.

This activity has been reviewed and approved by members of the UCSF CME Governing Board in accordance with UCSF CME accreditation policies. Office of CME staff, planners, reviewers, and all others in control of content have disclosed no relevant financial relationships.