15th Annual
Developmental Disabilities: An Update for Health Professionals

March 3-4, 2016
UCSF Laurel Heights Conference Center
San Francisco, CA

Course Co-Directors
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The 15th annual interdisciplinary conference celebrates MAXIMIZING POTENTIAL FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES, offering a unique update for primary care and subspecialty health care professionals and others who care for children, youth, and adults with developmental disabilities and complex health care needs. The 2016 conference continues to cover topics across the lifespan on a broad range of developmental disabilities including autism spectrum disorders, Down syndrome, and co-morbidities of dementia and aging with developmental disabilities. Experts will discuss how systems of care will be transformed for the 21st century for children and adults with developmental disabilities. Perspectives of various California departmental spokespersons will provide insight on planning for improved services to help maximize the potential of people with disabilities. Of special interest will be discussions of developmental disabilities plus deafness, resources and treatment modalities, and the development of communication with its implications for autism spectrum disorders and other disabilities.

Cultural diversity will be highlighted with presentations on mental health disparities and DD. Policy updates on supportive decision making and self determination will be defined and discussed. Examples of transition to supported and independent employment in different communities for youth and adults with DD will be presented. We are excited to present cutting edge talks on “The New Dentistry” and Psychopharmacology, intriguing research on Autism Spectrum Disorders, Genetic breakthroughs in a variety of disorders associated with DD, the role of neuropeptides in social cognition, and the impact of maternal depression and mental health on child development.

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 15th 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  Geraldine Collins-Bride, RN, MS, ANP, FAAN  
Course Co-Chair  Course Co-Chair
EDUCATIONAL OBJECTIVES

An attendee completing this course should be able to

1. Become knowledgeable about state and national plans, advocacy, and policy issues addressing special needs and interventions for children and adults with developmental disabilities in the 21st century;

2. Understand expanded concepts and impact of diversity in the DD population with particular focus on those with hearing impairment or deafness;

3. Define the development of communication and how it pertains to autism spectrum disorders, other developmental disabilities, and deafness;

4. Consult with caregivers and parents regarding lifespan expectations and prognosis of Down Syndrome and other developmental disabilities;

5. Increase awareness of mental health care disparities, and implications for health, in Latino families caring for an individual with developmental disabilities;

6. Describe supportive decision making and self-determination;

7. Understand the importance of long term follow up to anticipate co-morbidities of Autism Spectrum Disorder;

8. Appropriately identify differences between Early Dementia and Alzheimer’s in individuals with Down Syndrome and those in the geriatric population with DD;

9. Address higher education options and career opportunities for youth and adults with DD;

10. Refer patients or caregivers to programs that assist transition, support employment choices, and maximize potential for individuals with DD;

11. Define new innovations in dental practice for individuals with DD;

12. Describe social cognition in people with autism and the role of neuropeptides;

13. Better understand how continuing neuro-genetic research holds promise for putting research into practice;

14. Define the potential impact of maternal depression and mental health issues on child development;

15. Improve identification of at risk infants and young children and appropriately access resources;

16. Gain new knowledge about psychotropic medications and develop a strategy for when to prescribe or not, and when to refer.
ACKNOWLEDGEMENT

This educational activity has been supported in part by charitable contributions from The Special Hope Foundation, a non profit 501 C 3 organization, and the American Academy of Developmental Medicine and Dentistry.

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

CBEM

Center for Early Intervention on Deafness

Disability Rights California

Down Syndrome Connection of the Bay Area

East Bay Regional Center

Golden Gate 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 15.00 AMA PRA Category 1 Credits™. 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, 15th Annual Developmental Disabilities: An Update for Health Professionals, with a beginning date of 03/03/2016, has been reviewed and is acceptable for up to 14.50 Prescribed credits 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 Credits™ 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 Credits™ from organizations accredited by the ACCME.

Psychology This educational activity is recognized by the California Board of Psychology as meeting the continuing education requirements toward license renewal for California psychologists. 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.ucsfcmecom/evaluation to complete the online Overall Course Evaluation / 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 Speaker Survey 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.ucsfcmecom/evaluation to complete the online Overall Course Evaluation / 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 3rd.

Lunch
Lunch is on your own. 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 during breakfasts, breaks, and the wine and cheese reception on Thursday March 3rd.

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.ucsfcmecom/2016/MOC16001/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.

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.

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
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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:

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Elliott H. Sherr, MD, PhD  Board Member  Invitae
Consultant  Personalis

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.
THURSDAY MARCH 3, 2016

7:15-7:50am Registration and Continental Breakfast

7:50-8:00 Welcome and Course Overview
Lucy S. Crain, MD, MPH, FAAP & Geraldine Collins-Bride, MS, ANP, FAAN

8:00-8:30 Transforming the System for Developmental Disabilities Services for the 21st Century & the Sonoma Developmental Center Closure
James L. Shorter, BA, MBA, JD

8:30-9:15 Transforming the System: Panel on Various Perspectives
Panelists: Shelton Dent, MA, Clarissa Kripke, MD, Laurie Weaver

9:15-9:30 Break, Exhibits

9:30-10:15 Cultural Diversity and Developmental Disabilities: Latino Families in Therapy
Celia Jaes Falicov, PhD

10:15-11:00 The Development of Communication: What's the Right Language to Teach Children with Deafness?
Heidi M. Feldman, MD, PhD

11:00-11:45 Communication and Program Opportunities for Children who are Deaf or Hard of Hearing
Panelists: Jill M. Ellis, BS, MEd, John Digges, MD, PhD, MPH, FAAP, Sean M. Virnig, PhD

11:45-11:55 Q & A

11:55-1:15 Lunch (On Your Own)

1:15-2:00 Policy Updates: Supported Decision Making & Self-Determination
Samantha Crane, JD

2:00-2:45 Health Issues of Adults with Autism (Including Q & A)
Lisa Croen, PhD & Maria Massolo, PhD

2:45-3:00 Break, Exhibits

3:00-3:45 Down Syndrome: Updates & Comorbidities
Nancy J. Roizen, MD

3:45-4:30 Aging, Dementia, and Disabilities
Seth M. Keller, MD

ANNUAL SHRIVER LECTURE & AWARD

4:30-5:00 Maximizing Potential for Individuals with DD: Toolworks and the Source Program
Kristy Feck

5:00-6:30 pm Networking Reception
FRIDAY MARCH 4, 2016

7:15-7:50am Registration and Continental Breakfast

7:50-8:00 Welcome and Daily Overview
Lucy S. Crain, MD, MPH, FAAP & Geraldine Collins-Bride, MS, ANP, FAAN

8:00-8:30 People with Disabilities & Developmental Disabilities: Opportunities in San Francisco
Carla Johnson, CBO, CASp

8:30-9:30 Promoting Transition & Maximizing Potential for Youth & Adults with DD in San Francisco
Panelists: Heidi Seretan, MEd, Sara Murphy, MEd, Kevin Hickey, MA

9:30-10:10 Jobs & People with Developmental Disabilities: The Seattle Story
Heather Weldon

10:10-10:30 Break, Exhibits

10:30-11:10 Transitions: Medical and Other Issues
Nancy J. Roizen, MD

11:10-11:40 The New Dentistry
Paul E. Subar DDS, EdD & Allen Wong, DDS, EdD

11:40-1:00pm Lunch (On Your Own)

THE CUTTING EDGE

1:00-1:30 Exploding Genetic Information, Neurology & DD...
Elliott H. Sherr, MD, PhD

1:30-2:00 Social Cognition in People with Autism: Role of Neuropeptides
Karen J. Parker, PhD

2:00-2:10 Q & A

2:10-2:30 Break, Exhibits

2:30-3:15 Maternal Depression & Mental Health: Impact on Child Development: Putting Research into Practice
Carol D. Berkowitz, MD, FAAP, FACEP

3:15-4:00 Enhancing Early Intervention: Putting Research Into Practice To Serve Infants, Toddlers and Families
Marie Kanne Poulsen, PhD

4:00-4:45 Dual Diagnosis: Assessment, Diagnosis and Psychopharmacology Update
Michael S. Marcin, MD, MSCR

4:45-5:00 Q & A

5:00pm Course Adjourns
Transforming the System for Developmental Disabilities Services for the 21st Century & the Sonoma Developmental Center Closure

James L. Shorter, BA, MBA, JD

Disclosures:
None

Notes:
The level of support an individual needs to be safe, healthy, and happy in their living situation is one of the most important issues Interdisciplinary Teams (IDT) must review and discuss at a person's annual Individual Program Plan (IPP) meeting. Listed below are the various options for community living arrangements that California regional centers are able to provide for consumers they serve and support.

**DEPARTMENT OF SOCIAL SERVICES/COMMUNITY CARE LICENSING - LICENSED RESIDENTIAL OPTIONS**

**Community Care Facilities (CCF):** CCFs are licensed by the Community Care Licensing Division of the State Department of Social Services to provide 24-hour non-medical residential care to children and adults with developmental disabilities who are in need of personal services, supervision, and/or assistance essential for self-protection or sustaining the activities of daily living.

There are expectations that all CCF providers:

- Provide a supportive program of supervision and training using a staff to client ratio that can vary from a minimum of 1:6 to 1:1 (depending on the facility's program design) when people are under supervision at the facility;
- Participate with the IDT to develop the IPP which establishes objectives and training methods that will be implemented by the staff;
- Maintain written ongoing progress notes for the individual; and
- Prepare reports (monthly, quarterly, etc.) as required regarding progress toward meeting IPP objectives.

Based upon the types of services to be provided and individual needs, a CCF may be vendored by a regional center at one of the following Alternative Residential Model (ARM) service levels or as a Specialized Residential Facility.

- **ARM Service Level 1:** Care and supervision for persons with self-care skills.
- **ARM Services Level 2:** Care, supervision and incidental training for persons with some self-care skills and no major behavior challenges.
- **ARM Service Level 3:** Care, supervision and ongoing training for persons with significant deficits in self-help skills, and/or some limitations in physical coordination and mobility, and/or disruptive or self-injurious behavior.
- **ARM Service Level 4 A-I:** Care, supervision and training for persons with deficits in self-help skills, and/or severe impairments in physical coordination and mobility, and/or severely disruptive or self-injurious behavior. Service Level 4 is subdivided into Levels 4A through 4I in which staffing levels are increased to correspond to the individual needs.

**Specialized Residential Facilities:** Provide care, supervision and training for persons with deficits in self-help skills and/or severe impairments in physical coordination and mobility, and/or severely disruptive or self-injurious behavior whose needs cannot be appropriately met within the array of...
other community living options available as determined by the planning team. Rates are negotiated between the regional center and vendor and cannot exceed the median rate for regional center or the state, whichever is lower.

**Adult Residential Facilities for Persons with Special Health Care Needs (ARFPSHN):** Adult residential facility that provides 24-hour health care and intensive support services in a homelike setting licensed by Community Care Licensing, certified by DDS, and vendoered by Regional Centers associated with the closure of any developmental center statewide. (Also known as 962/853 homes.)

**Delayed Egress/Secured Perimeter Homes:** Limited authority now exists for residential facilities to be equipped with both delayed egress devices and secured perimeter fences. These safety features are carefully designed for individuals who, due to difficult-to-manage behaviors or a lack of hazard awareness and impulse control, would pose a risk of harm to themselves or others. The addition of a secured perimeter ensures that individuals are supervised when they wish to go outside the property limits. The statutory authority and program standards identify a number of safeguards and protections for utilizing secured perimeters.

These homes have a delayed exit door, or doors, of the time delay type, which will automatically open after a programmed amount of time, not to exceed 30 seconds. Additionally, the facility has a perimeter fence (typically non-scalable) which is locked. There must be sufficient space within the fenced perimeter to provide for a safe gathering place at a minimum of 50 feet from the building in case of fire. The delayed egress is automatically disabled in the case of fire. The house must have a fire sprinkler system. The secured perimeter program for the home must be certified by DDS before it can be licensed by DSS, and is limited to a combined total of 150 beds. A minimum of 50 beds shall be available for programs designed for individuals who are designated incompetent to stand trial pursuant to 1370.1 of the Penal Code. Homes with delayed egress devices need not have secured perimeters; however, secured perimeter homes must also utilize delayed egress devices.

**Enhanced Behavioral Supports Homes:** A pilot project certified by DDS and licensed by DSS. These homes provide non-medical care for individuals who require enhanced behavioral supports, staffing and supervision in a homelike setting. They also have enhanced monitoring by regional center case managers, regional center behavior professionals, and DDS. Additional enhancements include more staffing and staff training. Regulations for the Enhanced Behavioral Supports Homes were released for public comment in January 2016.

**Community Crisis Homes (CCH):** A facility certified by DDS and licensed by DSS as an adult residential facility, providing 24-hour non-medical care to individuals in need of crisis intervention services, who would otherwise be at risk of admission to the acute crisis center at Fairview or Sonoma Developmental Center, an out-of-state placement, a general acute hospital, an acute psychiatric hospital, or an institution for mental disease. A CCH shall have a maximum capacity of eight consumers; however, based on stakeholder input, regional centers are developing homes with a maximum capacity of four. Regulations are under development.
Health Facilities: These facilities are licensed by the Licensing and Certification Division of the California Department of Public Health to provide 24 hours per day services. These facilities are typically funded through Medi-Cal and serve consumers of varying ages.

Intermediate Care Facility – Developmentally Disabled (ICF-DD): An ICF-DD is a 24-hour health care facility that serves 15 or more people and provides personal care, habilitation, developmental and supportive health services to consumers whose primary need is for developmental services and who have a recurring, but intermittent, need for skilled nursing services. ICF-DD facilities are generally larger facilities staffed 24 hours a day by a registered nurse or licensed vocational nurse, who must be on residence eight hours a day with on-call nursing after the eight hour on-site requirement has been met. Living units at the state developmental centers are licensed as ICF-DD facilities or Nursing Facilities.

Intermediate Care Facility – Developmentally Disabled/Habilitative (ICF-DD/H): An ICF-DD/H provides 24-hour personal care, developmental services, and nursing supervision. They may serve up to 15 people but typically serve no more than 6 consumers with developmental disabilities. These homes may serve individuals who have intermittent, recurring needs for nursing services, but have been certified by a physician and surgeon as not requiring availability of continuous skilled nursing care.

Intermediate Care Facility – Developmentally Disabled/Nursing (ICF-DD/N): An ICF-DD/N provides 24-hour personal care, developmental services, and nursing supervision for consumers who have intermittent recurring needs for skilled nursing care but have been certified by a physician and surgeon as not requiring continuous skilled nursing care. These consumers may have chronic, non-acute medical conditions that require more regular nursing and monitoring (tube feedings, suctioning, etc.) than an ICF-DD/H. This type of facility may have 15 or fewer beds and must provide a minimum of 1.5 hours per day direct service (RN) nursing staff for each resident, in addition to the consultant hours which are defined by consumer need.

Intermediate Care Facility – Developmentally Disabled/Continuous Nursing (ICF-DD/CN): The ICF-DD/CN program provides continuous nursing care to medically fragile beneficiaries in a small community-based residential setting, avoiding more restrictive care in hospitals, sub-acute facilities and developmental centers. Currently about 44 consumers reside in 7 homes located in Santa Rosa, San Bruno, Fresno, Northridge, Gardena, Desert Hot Springs, and San Jose. This is a limited option with room for growth.

Nursing Facility (NF): An NF provides continuous skilled nursing and supportive care to consumers whose primary need is for skilled nursing care on an extended basis. It provides 24-hour in-patient care and minimally would include a physician; skilled nursing, dietary, and pharmaceutical services; and an activity program.
OTHER COMMUNITY LIVING OPTIONS

Parent/Family Member's Home: Some consumers may live with parents or relatives. Regional centers generally provide additional supports for the family which include, but are not limited to: Day Services; In-Home or Out-of-Home Respite Services; Consultant Services; Behavior Intervention; Transportation; and/or, Independent Living Training. Various generic services, such as In-Home Support Services may also be available to the consumer.

Independent Living Skills (ILS): Regional centers provide ILS services to an adult consumer, consistent with his or her IPP, that provide the consumer with functional skills training that enables him or her to acquire or maintain skills to live independently in his or her own home, or to achieve greater independence while living in the home of a parent, family member, or other person. ILS are provided in non-licensed living arrangements. Individuals most often live alone or with roommates in their own homes or apartments. Independent living programs, which are vendored and monitored by regional centers, provide or coordinate support services for individuals in independent living settings. They focus on functional skills training for adults who generally have acquired basic self-help skills or who, because of their physical disabilities, do not possess basic self-help skills, but who employ and supervise aides to assist them in meeting their personal needs. ILS training may include money management, shopping, meal preparation, health/medical, laundry, advocacy, psycho-social support, etc. Living expenses are paid from Supplemental Security Income or other benefits/income. Consumers may also receive rental assistance through HUD's Section 8 Housing Program.

Supported Living Services (SLS): SLS consist of a broad range of services to adults with developmental disabilities who, through the IPP process, choose to live in homes they themselves own, rent or lease in the community. SLS may include assistance with: selecting and moving into a home; choosing personal attendants and housemates; acquiring household furnishings; common daily living activities and emergencies; becoming a participating member in community life; and, managing personal financial affairs, as well as other supports. These services help individuals exercise meaningful choice and control in relationships, full membership in the community, and work toward their long-range personal goals. Because these may be life-long concerns, SLS are offered for as long and as often as needed, with the flexibility required to meet a person’s changing needs over time, and without regard solely to the level of disability. Typically, a SLS agency works with the individual to establish and maintain a safe, stable, and independent life in his or her own home, but it is also possible for some individuals to supervise their services themselves. Support services are funded by the regional center and/or In-Home Support Services. Living expenses are paid by the consumer through Supplemental Security Income or other benefits/income. Consumers utilizing SLS are also eligible for HUD's Section 8 Housing Program and must be 18 years or older to participate in this living arrangement.

Family Home Agency (FHA): An FHA is an agency that approves Adult Family Homes and Family Teaching Homes for individuals with developmental disabilities. An Adult Family Home may serve two individuals in the same home; a Family Teaching Home may serve up to three individuals. These individuals reside with a family and share in the interaction and responsibilities of being part of a family. The individual with developmental disabilities receives the necessary services and supports from the family, agencies, and the community to enable him/her to be a participating member of the family and the community where the family resides. The FHA arrangement allows the sharing of food, shelter, experience, and responsibilities. The FHA is a
private organization under contract to, and vendored by, a regional center. FHAs are responsible for recruiting, training, approving, and monitoring Adult Family Homes and Family Teaching Homes, as well as providing ongoing support to the homes. Social service staff employed by the FHA makes regular visits to the Adult Family Home and Family Teaching Home to ensure that necessary services and supports are in place and that the match between the family and the new family member is viable and continues to be viable. FHA and Adult Family Home/Family Teaching Home services and supports are among the newer options which enable adults with developmental disabilities to enter into partnerships with families that promote self-determination and interdependence. Along with the regional centers, the Department of Developmental Services (DDS) has monitoring responsibility for these homes.

**Self-Determination Program:** The Department of Developmental Services is developing a new program, called the Self-Determination Program, that will let participants have more control over selecting their services and supports. One of the ways this can be done is by giving participants (or their parents or legal representatives) a specific budget to purchase the services and supports that they need to make their person centered plan work better for them. Participants may choose their services and pick which providers deliver those services. Participants are responsible for staying within their annual budget.

The Self-Determination Program is based on beliefs that people --

- Plan their own lives and make their own decisions
- Determine how funding is spent for their services and supports
- Plan and choose their own formal and informal supports
- Take responsibility for the decisions made
- Validate those decisions through maintaining ongoing control
Transforming the System for Developmental Disabilities Services: Health Care

March 3, 2016
Clarissa Kripke, MD

Disclosure

I have no financial relationships with commercial interests.

Thanks to the Special Hope Foundation, Redwood Coast Regional Center, Golden Gate Regional Center, Far Northern Regional Center, North Bay Regional Center, Alta Regional Center

Building Capacity
Three Areas of Focus

- Communication
- Behavioral Support Systems
- Advanced Health Care Planning
Communication

- Foundation of patient care and self-direction
- Presume competence
- Everybody communicates
- Expand access to communication technology
- Train health care and service providers
- Plain language resources
- Monolingual resources and translation
- Access to broad band internet/mobile devices
- Communication rights – choice of method

Behavior Supports

- New service models will be needed
- Whole person approach (people are not a collection of behaviors)
- Range of positive behavior support methods
- Trauma informed thinking
- Community based (DC closure means that, the systems have to work!)

Problem: Dysfunctional Cycle

1. New Home
2. Behavioral Crisis
3. Crisis Home
4. 911/Crisis
5. Hospital
### Proposed solutions

- New Home
- Behavioral Crisis
- Enhance Homes
- Crisis Home
- More crisis homes; limit stay; fund empty
- Crisis Teams
- 911/Crisis
- Hospital

### Problem with Proposed Solutions

1. Traumatic
2. No continuity or stability
3. Doesn’t develop expertise
4. New homes and service plans take >90 days to develop backing up the system
5. Crisis homes are either full or empty wasting housing and staff resources
6. Backs up to hospital
7. Patient’s can’t stabilize—problems tend to escalate; expensive; misuse of resources

### Break the Cycle with Person Centered Planning in Forever Homes in the Community!

- Enhanced Home
- Behavioral Crisis
- Expert Team
- Enhanced Supported Living
- Hospital
- Forever Home
End of Life Option Act Implementation

- Physicians influence public perceptions
- Talking about losing function and needing support as undignified, suffering, burdensome, unfortunate, or tragic, reinforces the idea that people with disabilities lives are not meaningful or valuable.
- Unconscious bias about people with disabilities can impact the treatments they are offered and the prognosis they receive.

Advanced Planning

- Supported Health Care Decision Making
- Thinking Ahead (Advanced Directives)
- POLST
- Power of Attorney
- Plan if substituted decisions are needed

http://odpc.ucsf.edu/supported-health-care-decision-making;

Coming Soon!

CART Center in Developmental Primary Care

Office of Developmental Primary Care
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RECOMMENDATIONS FOR GGRC BOARD OF DIRECTORS
Submitted by GGRC Health Care Task Force on October 20, 2015

RECOMMENDATION:

The GGRC Health Care Task Force recommends that the GGRC Board of Directors adopt the following strategic goal for the Health Care Road Map 2020:

All individuals served by GGRC have access to the health care services they need to maximize their wellness and function.

Indicators:
1. Individuals have access to primary care clinicians, dental services providers, therapists, and behavioral health providers who have the resources and training to meet their needs.
   Metrics:
   a. By June 30, 2016, GGRC will establish a taskforce with individuals with developmental disabilities and representatives from the CART Center in Developmental Primary Care, local Medi-Cal health plans, local health systems, mental and behavioral health agencies, and regional center community services and clinical staff to ensure that individuals served by GGRC have access to appropriately-resourced and enhanced primary care.
   b. By June 30, 2016, GGRC will establish a taskforce with individuals with developmental disabilities and representatives from University of Pacific School of Dentistry and community partners to implement Virtual Dental Home in community agencies and residential facilities.
   c. By June 30, 2020, all individuals served by GGRC for whom enhanced primary care is appropriate will have access to enhanced primary care.

2. Individuals who require paramedical services such as medication administration or assistance with tube feeding receive these services safely.
   Metrics:
   a. By June 30, 2017, training protocols and materials for paramedical services will be selected or developed.
   b. By June 30, 2020, all individuals served by GGRC who self-direct their own paramedical services and supports will have access to trainings and support by nurse consultants.

3. Health and medication issues are identified and addressed.
   Metrics:
   a. By June 30, 2017, yearly nurse health assessments will be piloted.
   b. By June 30, 2020, all individuals served by GGRC over the age of 16 will be offered a standardized yearly nurse health assessment with recommendations tailored specifically to the needs of the individual.

4. Individuals are provided information on supported health decision making.
   Metrics:
   a. By June 30, 2017, all individuals served by GGRC over the age of 18 will be offered information on “Thinking Ahead: My Way, My Choice, My Life at the End” and Supported Health Decision Making Agreements and/or Power of Attorney for health care documents during interdisciplinary team meetings for their Individual Program Plan (IPP).
b. By June 30, 2020, individuals served by GGRC who do not have capacity to give their own consent for health care and who do not have guardian or conservator legally authorized to consent to such treatment, will have an ethics committee, limited conservator, or other mechanism for health advocacy and medical decision-making specified in the Individual Program Plan (IPP).

Respectfully Submitted,

Clarissa Kripke, M.D.
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BACKGROUND
In order to retain Federal waiver funding, by 2019, states are required to come into compliance with the new Home and Community Based Settings (HCBS) regulations. These regulations define community in terms of the ability of people with disabilities to choose where, how and with whom they live, and to choose their own supports. Furthermore, the State of California has announced the closure of its remaining developmental centers. This represents a significant shift in state and federal policy. It will require investment in health service infrastructure to support individuals served by regional centers to live successfully in the community. This poses a significant challenge for those with complex medical and behavioral needs. In January 2014, Secretary of the California Health and Human Services Agency, Diana Dooley, submitted a “Plan for the Future of Developmental Centers in California” to the State Legislature, and initiated a Developmental Services Task Force to recommend investments in community infrastructure.\(^1\) There is broad stakeholder consensus that investments will be needed in the areas of health professional workforce development; system monitoring and accountability; proactive outreach to individuals served by regional centers to monitor their health status; improved access to care; and specialized health care services and service delivery systems. Strategic planning and leadership will be required to ensure good outcomes and cost effective, quality health care for this high risk, high need population.

STRATEGY:
For the next five years, GGRC will actively build collaborations with Northern California regional center partners, representatives from the CART Center in Developmental Primary Care, local Medi-Cal health plans, local health systems, and mental and behavioral health agencies to implement strategies to achieve the proposed metrics. In addition, GGRC will engage in advocacy with the State Departments of Health Care Services, Managed Health Care, and Developmental Services, the Association of Regional Center Agencies, public universities, medical centers, and health plans to promote the adoption of the proposed metrics statewide for individuals with developmental disabilities.

GGRC strongly feels that the CART Model, which was developed by a coalition of stakeholders in the Bay Area, will be an essential framework and set of strategies to achieve the proposed metrics statewide. CART stands for:
- Clinical services
- Advocacy to support policy and patients
- Research programs in health services, health policy and education
- Training and technical assistance for medical professionals, people with developmental disabilities and their supporters.\(^2\)

The CART Model has four functional components that will ensure an infrastructure to support the health and safety of individuals with developmental disabilities as well as compliance with the new Home and Community Based Services regulations:
- CART Center in Developmental Primary Care
- Yearly nurse health assessments
- Enhanced primary care and multidisciplinary services
- Health advocacy services


CART Center in Developmental Primary Care
The CART Center in Developmental Primary Care is a hub of experts in developmental primary care that provide clinical service, policy advocacy, research, training and technical assistance. It will provide clinical consultation through phone, email, telemedicine and mobile clinical consultation team services. The CART Center will also provide primary care services for some of the most medically fragile and behaviorally complex individuals with developmental disabilities. It will disseminate best practices and assist the State with implementing recommendations from the Developmental Services Task Force.

Yearly Nurse Health Assessments
A yearly nurse health assessment of all seniors and persons with disabilities is currently a requirement for health plans. The CART Center will work with health plans to develop and implement coordinated, comprehensive, and standardized assessments for individuals with developmental disabilities. With the individual’s permission, the results will be relayed back to caregivers, doctors, and care coordinators to help improve health outcomes for individuals with developmental disabilities.3,4,5

Enhanced Primary Care and Multidisciplinary Services
Home care and clinic-based enhanced primary care services for individuals served by regional centers with complex needs will be coordinated with health plans. Ideally, these clinical services will integrate care coordination; dental services; mental and behavioral health; and specialty therapies such as speech therapy, occupational therapy, and physical therapy. Enhancements can include features such as home visits, longer appointment times, specially trained staff and clinicians, physical and programmatic accessibility, and enhanced care coordination.

Health Advocacy Services
Health advocacy services are the direct support to help people partner effectively with their health care providers—going to appointments, supporting communication, and following through on the health care plan. Several models of health advocacy services will be established including supported decision making models, training for supporters, professional health advocacy, and nurse case coordination.

CK-IL10142015
Enhanced Primary Care Services
Primary Care
Care Coordination
Dental Services
Therapies
Mental Health

CART Center
Clinical Services
(Consult/Assessment)
Advocacy (policy)
Research
Training/Technical Assistance

Patients and Caregivers

Health Advocacy Services
Patient and Caregiver Support
Medical Case Management
Wellness
Transition Support

Yearly Nurse Health Assessment
Health Surveillance Data Collection
Independent Comprehensive Assessments and Recommendations
Transforming the System: Panel on Various Perspectives

*Laurie Weaver*

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**Disclosures:**

None

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**Notes:**
Providing Culturally Responsive and Empowering Services for Latino Families with Developmental Disabilities

Celia Jaes Falicov, Ph.D.
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No conflict of interest
UCSF Developmental Disabilities Conference, March 2016

What we know about Latinos and DD
ADHD, Autism, Deafness, Intellectual Disabilities

a. Diagnosed at ½ the rate of African American and White Children
b. Diagnosed later (average 2.5 years)
c. Receive medication and educational interventions at a lower rate

Latinos and DD
- Less likely to get services and to seek psychological or neuropsychological testing
- 80% of physicians screened for autism but only 29% offered Spanish language screening for children and families
- Early intervention, home services and sign language occur much later than critical age or not at all for the hard of hearing
Understanding Challenges and Strengths of Immigrants

Barriers to Detection and Seeking Services:
1. Transportation, child care, limited time, lack of insurance and money to seek services, immigration status.
2. Low parent education: unfamiliarity with health care system, fear of stigma and discrimination
3. Lack of language and culturally related assessment and treatment

The Practice Encounter is not Culturally Neutral

MULTICULTURALISM

Encompasses two different but related aspects

CULTURAL DIVERSITY
Values, beliefs and meaning differences (ethnicity, religion, nationality)
RESPONSIVENESS

SOCIAL JUSTICE
Contextual Stressors tied to power differences (race, class, immigrant) EMPOWERMENT
**Culture-Specific Competence with Latinos**

Equated with ethnic values such as:

- *Familismo* (family-centered lives)
- *Machismo* (men’s predominance)
- *Personalismo* (social manners)
- *Respect* for parents and elders
- *Religiosity*

**The Problem with Ethnic Values only**

- They may *perpetuate stereotypes* because values:
  - Are not static, they evolve
  - Are Contextual (class, education, nationality, urban-rural)
  - Latinos come from many different cultures & generations
  - They may have bicultural or multicultural identities

**M E C A**

- **MULTIDIMENSIONAL**
- **ECOLOGICAL**
- **COMPARATIVE**
  
  Same 4 domains
- **APPROACH**
Cultural Competence or "Cultural Humility"?
Practitioner's self-reflection
about her or his own personal and professional culture (race, class, beliefs and values)
Clients as Experts
on their culture and context
Practitioners become aware of power dynamics and give more voice to clients
(Tervalon and Murray-Garcia, 1998)
Cultural Diversity

Meaning and Belief differences tied to

- Ethnicity
- Religion
- Nationality
- Profession

Clinical Approaches

- Curiosity & Respect
- Culture-Attuned Therapies (traditional healing)
- Transformations of Theory (attachment, individuation)

Social Justice

Contextual Stressors tied to

- Gender
- Race
- Social Class
- Minority Status

Clinical Approaches

- Empowerment
- Social Action
- Legitimize Local Knowledge

Migration (Impact on Families)
MIGRATION STRESSORS

• LANGUAGE BARRIERS

• UNDOCUMENTED OR TEMPORARY VISA STATUS

• LACK OF KNOWLEDGE OF INSTITUTIONS AND SERVICES

Deafness example:
Trilingual challenge

• Decisions about what type of communication (sign language, English, Spanish

• Sign language is based on English

• Very difficult for parents who do not speak English, most opt for what they are advised to do about English and ASL but hope for a trilingual future for their child

New forms of SEPARATIONS and REUNIFICATIONS

• Grandparents and Extended Family

• Father

• Father and Mother

• Mother (Feminization of Migration)
  Ratio of Latina women to men has increased considerably
A confusing picture

The interaction between migration family stress, trauma and ADHD

Diagnosis of Attention Deficit and Hyperactivity
Oscar (10) was diagnosed by the school counselor and the teacher as having ADHD and referred for medication, without consideration of the child as new immigrant, the tensions of family separation and reunification and cultural attitudes towards medication.

Attitudes towards medication
• Belief in risk of addiction
• Related to drug use in the neighborhood
• Preference for natural and home remedies—fear toxic and addictive effects of medication
A candid parent said:
  “It could be the beginning of a life in the streets”
Trauma
Pre-migration trauma may be involved as precipitating events for migration
Post-migration trauma, at reunification there may be increased risk of child maltreatment
Symptoms of trauma can look like ADHD

Recommendation
• Explore migration stresses, separations, trauma
• Avoid suggesting medication initially or explore parents’ attitude towards it
• Use translators and cultural consultants when needed, use “promotoras” with information about Family Resource Centers in Spanish

Ecological Context
(Isolation, low interaction with Institutions-schools, medical system)
Re-Building Community

Increases social capital:
• protects against depression in women,
• alcohol abuse in men
• gang involvement in youth


Doubly Challenged: Many Latinos with DD

• Poverty
• Unsafe neighborhood
• Lack of Transportation
• Lack of Child Care
• Overwork
Lack of entitlement to question types of services, timing of appointments, or voicing their opinions unless encouraged towards shared decision making

Community Empowerment Group:
UCSD Medical Student-Run Free Clinic

• Weekly Participants: underserved, uninsured, isolated patients and medical students, physicians, psychologists, social workers
• Facilitator or “promotora”: experienced community member/ STRENGTH BASED
• Discussion of current issues in ALL of our lives and communities.
• Patients are the experts. Topics for discussion: forgiveness, gratitude, self-care…
CULTURAL BELIEFS ABOUT HEALTH & CURE

<table>
<thead>
<tr>
<th>Problems</th>
<th>Medical</th>
<th>Religious</th>
<th>Witchcraft</th>
<th>Traditional Illnesses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Universal illnesses</td>
<td>Life tragedies</td>
<td>Illnesses</td>
<td>Sin &amp; Guilt</td>
<td>Bewitchment</td>
</tr>
</tbody>
</table>

| Helpers | Physicians | Priests | Pastors | White & Black witches | Espiritistas | Yerberos | Curanderos | Sobadores |

SPIRITUAL BELIEFS ABOUT CHILD WITH DD

- A gift or a blessing from God to be accepted with dignity and devotion. Parents report an increase in faith after diagnosis.
- A smaller number believe disability may be a punishment from God.
- Mothers viewed child as bringing positive transformations in their lives. (Skinner, Bailey, Correa and Rodriguez, 1999)

Ask families about beliefs

- 1. What thoughts do you have about may have caused the condition?
- 2. Who else have you consulted with? (relatives, priests)? What do they advise you to do?
- 3. What do you think will happen over time?
Recommendation: the power of networks

- Explore ecological context
  (social network, work, schools, church, traditional healing)
- Explore neighborhood health and education services

Recommendation: the power of the local

- Provide services in the school
  (Latino parents expect intervention and support from school)
- Primary health care clinic in the community is the second preferred place
- Provide parent support groups in Spanish "in the clinic, the church or the school"
- Be open minded about local healing

*Lynch and Stein (1987)*
Family Organization
(models of nuclear and extended family life)

The Family as the Unit of Treatment
Who is Family?
Grandparents, siblings, uncles, aunts, nephews, cousins, godfathers and godmothers (padrinos, madrinas—they have considerable authority and responsibility towards the child) compadres, comadres (close friends of father and mother—their help and opinion matters)
Highly interconnected network—functions long distance via Skype, WhatsApp, phone and text

Family Size & Practitioner’s Ideals

<table>
<thead>
<tr>
<th></th>
<th>SMALL FAMILIES</th>
<th>LARGE FAMILIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>PARENTHOOD</td>
<td>Intensive</td>
<td>Extensive</td>
</tr>
<tr>
<td>INDIVIDUAL ATTENTION</td>
<td>High</td>
<td>Limited</td>
</tr>
<tr>
<td>CONTROL</td>
<td>Democratic</td>
<td>Authoritarian</td>
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<tr>
<td>KIN NETWORK</td>
<td>Exclusion</td>
<td>Inclusion</td>
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<tr>
<td>SIBLINGS</td>
<td>Small</td>
<td>Large</td>
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<td></td>
<td>Independent</td>
<td>Involved</td>
</tr>
<tr>
<td>PROBLEMS</td>
<td>Magnified</td>
<td>Minimized</td>
</tr>
</tbody>
</table>
Grandmothers

◆ They are often “Other-Mothers”

◆ Are integral to the lives of minority youth

◆ Inquire and include Latino extended family relationships in our inquiries

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Extended Family “Wait and See”

◆ Noisier, higher levels of activity, closer physical and emotional space.

◆ Larger number of caretakers may accept wider range of behaviors than small nuclear families, make less use of medical labels and have a broader definition of normal.

◆ Relying on family interventions to make a difference with ADHD and Autism.

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RECOMMENDATION:
Family Centered interviewing

◆ Regard family members as the experts on the child’s care, strengths and viable treatments

◆ Inquire about how each parent is doing in general and with the child

◆ Inquire about the opinion of other family members about the child and treatment

◆ Invite significant extended family members: grandparents, siblings, friends or neighbors to meetings even if it means repeating information
Latino siblings of DD child
A population at risk

Compared to Whites they have more emotional difficulties (anxiety, lower school performance, poorer relationships with parents and with peers)

Why? Cultural Differences in communication, information and emotional expression

(Kao et al, 2013; Lobato et al; 2005)

Latino SIBLINGS of DD child, cont.

• More involved in daily care of child with mental retardation or deafness than fathers.
• They see mother as worried, frustrated and sad.
• They feel overburdened with caretaking but reluctant to express feelings to parents out of respect and sense of family loyalty.

(Magaña, 1999; Canary, 2008)

Siblings (continued)

• Parents protect siblings by not talking to them about the child’s disability, normalizing the situation and minimizing its impact on the family, therefore Latino siblings have less accurate information in spite of their desire to know and talk more.

Refer to SIBLINK---a support group for siblings of child with DD or other chronic illness.
Family Life Cycle
(timing and meanings of normative stages and transitions)

Life Cycle: Childhood and Adolescence

CHILD REARING GOALS

• Good Manners and Consideration of Others (Relational focus, aggression control and shaming);
  “bien educado” (well educated, obedient)
  vs. Autonomy and Self-Maximization
  (Individual focus, assertiveness)
  (Harwood et al., 1995; Domenech-Rodriguez, 2006, 2009)

When do parents seek or respond to treatment for DD?

• When they see the problem as bothering others outside family (misbehavior, peer aggression, academic complaint by authority) OR
• When behavior is disruptive within the family: disrespectful of adults, isolated, very reclusive rather than polite and interactive, but quiet is fine
• Recommendation: Important to ask what is a problem for parents rather than focus on a list of specific symptoms
Strengths: Cultural and Personal

- Resilience in coping with loss, trauma, poverty and discrimination
- Deeply caring for the next generation
- A spirit of acceptance of disability yet struggle to adapt to it
- Endurance and hard work
- Valuing family bonds
- Pride in cultural traditions

Summary of MECA topics to explore for assessment and treatment planning for special needs Latinos

- Migration Stressors
  - Language and lack of knowledge, separations, trauma

- Ecological context
  - Community supports, work, transportation, use of traditional healing and spiritual acceptance

- Family Organization
  - Single parent, extended, grandparents, siblings, values of large families

- Family Life Cycle
  - Child rearing goals, protective, relational focus, obedience, aggression control, manners

Providing family/community centered services for Latinos and DD using MECA

- Migration
  - Use translators and cultural consultants. Explore separations, trauma for complex treatment

- Ecological context
  - Encourage community life. Provide local services-school and primary care clinic. Collaborate with cultural local healing

- Family Organization
  - Provide family culturally oriented services by including siblings, grandparents

- Family Life Cycle
  - Acknowledge different parenting styles and child rearing goals
REFERENCES FOR LATINOS FAMILIES AND DEVELOPMENTAL DISABILITIES

Presenter: Celia J. Falicov


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The Development of Communication: What’s the Right Language to Teach Children with Deafness?

Heidi M Feldman MD PhD
UCSF 15th Annual Developmental Disabilities Update
March 9, 2016
San Francisco

Financial Disclosures

• None

Itinerary

• Background definitions
• Language development
  • Typical verbal language development
  • Bilingual language development
• Non-verbal communication for individuals with intact hearing
  • Gesture
  • Baby sign
• Nonverbal communication for children with delays in development of verbal language
  • Bimodal bilingual language development
• Communication in children with deafness
Conclusion and Recommendation

• For children who are deaf, the benefits of learning sign language clearly outweigh the risks
• For parents and families who are willing and able, exposing the deaf child to sign language is clearly preferable to an approach that focuses solely on oral communication.

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Definitions

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>Act of conveying, transmitting, exchanging information</td>
</tr>
<tr>
<td>Language</td>
<td>A form of communication that • is distinctly human • uses symbols to represent meaning • is governed by rules • allows expression and understanding of an infinite number of messages</td>
</tr>
<tr>
<td>Speech</td>
<td>Output of the language system that • uses the respiratory and oral motor system</td>
</tr>
</tbody>
</table>
### Types of language

- **Typical**—Aural-Oral
- **Sign language**—Visual-Manual

### Sign language is a language

- Complete, complex system
- Uses symbols made by moving the hands combined with facial expressions and postures of the body
- Follows grammatical rules
- Allows the transmission of an infinite number of messages
- Equal linguistic complexity and expressiveness than that of spoken language

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Typical language development

- Learned rapidly at young ages; learned more slowly at older ages
- Learned through observational and social participation
- Learned even among children with severe intellectual disability
- Requires biological factors
  - Infants able to pick up statistical properties in speech
  - Infants able to link speech perception to motor output
- Dependent on environmental factors
  - Children learn language of their environment
  - Amount and type of input affect rate of learning

Early Communication Milestones

<table>
<thead>
<tr>
<th>Age</th>
<th>Receptive Skills</th>
<th>Expressive Skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newborn</td>
<td>Attends to voice, regards face</td>
<td>cries</td>
</tr>
<tr>
<td>6 months</td>
<td>Recognizes name, begins to babble</td>
<td></td>
</tr>
<tr>
<td>9 months</td>
<td>Learns non-verbal routines, such as &quot;Wave-bye-bye&quot;</td>
<td>Points speech by saying &quot;ma-ma&quot; or &quot;da-da&quot; nonspecifically</td>
</tr>
<tr>
<td>12 months</td>
<td>Follows simple commands with gestures</td>
<td>Says &quot;ma-ma&quot; or &quot;da-da&quot; specifically, says first words</td>
</tr>
</tbody>
</table>

Language Development

<table>
<thead>
<tr>
<th>Age</th>
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<th>Expressive Skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>12-18 months</td>
<td>Follows single command without gesture</td>
<td>Acquires words slowly, uses simple and idiosyncratic forms</td>
</tr>
<tr>
<td>18-24 months</td>
<td>Understands sentences</td>
<td>Vocabulary reaches 50 words, vocabulary explosion, two-word phrases</td>
</tr>
<tr>
<td>24-36 months</td>
<td>Follows 2 and 3-step commands</td>
<td>Short sentences, uses increasing complex grammar</td>
</tr>
<tr>
<td>36-48 months</td>
<td>Understands concepts, such as same/different</td>
<td>Grammar matures, constructs scripts and narratives</td>
</tr>
<tr>
<td>48-60 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-72 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>72 months</td>
<td></td>
<td>Mature speech sounds, applies language skills to reading</td>
</tr>
</tbody>
</table>
Bilingual language development

- About half of the world is bilingual
  - In US, 20.8% of families reported speaking another language besides English at home
  - In California, 43% of families speak another language at home
- Children all over the world learn more than one language
  - Bilingual children meet language milestones at same ages as monolingual children
  - Code-mixing or code-switching are early issues
- Bilingualism characterized as simultaneous or sequential
  - Simultaneous: both languages learned concurrently, as when one parent speaks L1 and the other L2
  - Sequential: L1 is learned in the home and later L2 is learned at school
  - When L2 is introduced, some children reduce output transiently for a period that might last weeks to months
  - Differential skills and use of L1 and L2 common; depend on history, environment, and communication needs of the child

Bilingual Advantage

- Individuals who know two languages are able to converse with a wider range of people than individuals that know one language
- Bilingualism has a profound positive effect on the brain
  - Improves executive function — a command system that directs attention, remembers and manipulates memories, organizes and plans for solving problems, and performs cognitively demanding tasks
  - Shields against dementia in old age
- No evidence bilingualism is a hindrance or detriment

Bilingualism and developmental disorders

- Most children who can learn one language can learn two languages
- Children with Down syndrome and autism can learn two languages; no reduction in rate
- Unpublished results
  - Compared children with autism exposed to one or two languages
  - No differences in rate of vocabulary growth
  - Half of the children with autism had vocabulary only in one language, English
  - Child determines if she learns one or two languages
- Many parents cannot be able to provide majority language to children because of weak skills; warm parent-child interactions are more important for development than English language
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Gesture common accompaniment to speech

• Gestures that hearing speakers produce with speech contribute to communication
• Gestures robust; they appear in congenitally blind individuals who have never seen gesture
• Different gesture types
  • Some gestures provide emphasis
  • Other gestures provide information
• Children produce gestures before they produce words
  • Pointing as the first gesture

Gesture in Development

• Gestures often reflect thoughts that don’t appear in the speaker’s language or speech
  • Emergence from single words to phrases
  • Emergence from pre-operational to logical thinking
• Use of gestures for teaching
  • Children learned more math problems quickly when teachers used gestures in addition to verbal explanation
Baby Sign

- Use of manual signing to communicate with infants and toddlers
- Based on finding that manual skills acquired before verbal skills
- Infants taught simple signs for common words such as "eat", "sleep", "more", "hug", "play", "cookie"
- Research suggests that any advantages of baby sign are transient
- Consensus: Baby sign not harmful to children, enjoyable for parents, parental choice about whether to use

Sign language for children with delays

- Speech-language pathologists (SLP) use sign language in selective children with language or speech delays; doesn't further delay
- Recommendations for baby sign for children with Down syndrome
  - Children with DS generally have better language understanding than ability to speak
  - Fine motor skills are adequate
  - Parents encouraged to Total communication (TC), combined use of signs and gestures with speech to teach language
  - Sign language conceptualized as a transitional system
- No concerns that children with DS will become dependent on signs; they typically drop signs from communication when they learn to speak because spoken language used consistently by greater community

Bimodal-bilingual language development

- Hearing children of deaf parents faced with learning two language in different modalities
- These children are capable of learning both languages
- Like other bilinguals show code-mixing and code-switching
- They may also do code-blending—expressions in both speech and sign simultaneously—a unique option for bimodal bilingual
- Skills in both languages depend on experience
  - Deaf parents vary in frequency and quality of verbal language
  - Spoken language development in these children may resemble sequential rather than simultaneous bilingual language development
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Deafness

- Every year, 10,000 infants are born in the United States with sensorineural deafness; 95% of deaf children are born to hearing parents
- Additional infants become deaf before 2 years
- What is the best language education for these children?
- Based on the research available in the 1960-1990s, answer was relatively clear: total communication with sign and speech simultaneously

Limitations of aural-oral language

- Reliance of oral mode results in linguistic deprivation for many children who are deaf
- Resulted in slow development and limited communication
- Teenager may only know 100 words
- Speech reading (lip-reading plus facial expression) can be useful but only achieves 60% accuracy
Sign language development

- Sign language provides the earliest possible mode through which children can learn expressive language skills
- Early acquisition of sign language by deaf children of deaf parents is as quick and effortless as hearing children acquire spoken language
- Skills in sign language development correlate positively with skills in spoken and written language
- Deaf children of deaf parents surpass those born to hearing parents in regards to academic performance
- Deaf children typically need to interact with hearing world
- Can expose children to sign and speech simultaneously = total communication
- Total communication blended advantages of sign language with dense exposure to verbal language
- Equivalent to bimodal-bilingual development

Home Sign

- Children who deaf and not exposed to sign language create a visual-manual communication, called home sign
- Home sign shares properties of conventional sign languages
  - Vocabulary
  - Grammar
- Parents picked up home sign from the children, used it inadvertently
- Home sign is limited in various ways
  - Differentiation of past and present
  - Discussion of future, hypothetical and abstract
- So, even if child is not taught sign language, she develops sign language

New Issue: Cochlear Implants (CI)

- Small, complex electronic device that can help to provide a sense of sound to a person who is profoundly deaf or severely hard-of-hearing
- Unlike hearing aid, CIs bypass damaged portions of the ear and stimulate auditory nerve
- CI does not restore normal hearing; can give a deaf person a useful representation of sounds in the environment to understand speech
- When child who is deaf unable to gain meaningful speech recognition from hearing aids, candidate for CI; decision follows a period of waiting
- Dilemma for parents
  - Should my child receive a cochlear implant (CI)?
  - How shall we proceed to educate the child for communication?
More on CI

- About ½ US children with early-onset deafness have received CI
- Children with CIs require intensive rehabilitation throughout childhood to learn to communicate orally
- Even with training, oral communication skills vary in children with CI
  - No guarantee that the implant will work
  - No assurance that CI will result in clear, intelligible speech
- Professional concerns
  - Sign language may interfere with extensive and intensive rehabilitation necessary to reap the most benefit from CI
  - Parents may have difficulty learning a new language to communicate with their child

Issues to consider

- Even under best scenario, children often cannot hear
  - CI may malfunction
  - CI is off during sleep or swimming or bath
  - Like hearing aids, CI works best in quiet environments without competing background noise
  - Children with deafness may choose to associate with Deaf children or adults who communicate in sign language

Recommendation: Pre-CI Era

- Early sign language may be a bridge to spoken language, cannot hurt, and may be beneficial
  - Sign language may support a child’s participation in bidirectional parent–child interactions
  - Enable communication skills, such as joint attention
- At the same time, use of any residual hearing should be maximized
  - Prospective, national trial indicate that verbal language learned before CI implantation associated with accelerated rates of spoken language learning after implantation
- Total communication achieves both verbal and non-verbal exposure
- If child successful in both, s/he is bimodal bilingual
Recommendations: Post-CI

• After CI, device must be activated
• After activation begins a fuller experience with sound
• Auditory rehabilitation begins
• That is time to capitalize on new ability and offer verbal language
• Inadequate auditory input that fails to support spoken language learning may compromise speech and language development after CI
• However, exclusive focus on verbal language limits child's ability to communicate in specific circumstances
• **Total communication** achieves exposure to both verbal and non-verbal language

Conclusion and Recommendation

• For children who are deaf, the benefits of learning sign language clearly outweigh the risks
• For parents and families who are willing and able, exposing the deaf child to sign language is clearly preferable to an approach that focuses solely on oral communication

Thank you. Questions?
A Bay Area Model Program: Family Centered Early Intervention

Jill Ellis, M.Ed.
Founder
Center for Early Intervention on Deafness

Disclaimer

I have nothing to disclose.

What is CEID?
The Hearing Society & First Congregational Church

- Student photos

1980-1983
San Francisco
NHS in the 1970’s & 1980’s

Average age of ID: 2.5 years
No state NHS
50% unknown etiology
1/2000 babies
Body hearing aids
No Early Start

1035 Grayson Street
West Berkeley

Services available at CEID

- Home Visits
- Parent-Child Playgroups
  - Sign Language
  - Deaf-Blind
  - Listening & Spoken Language
- Down Syndrome
- Toddler & Preschool Classes
- Deaf Mentors
- Family Support Activities
- Speech Therapy
- Occupational Therapy
- First 5 - Home Visit (3-5)
- Comprehensive Audiology
  - Diagnostic and Dispensing
  - Community Hearing Screenings
- Pediatric Provider Training
- Other Consulting
  - Charter Schools
  - Medical Providers
  - Early Start Professionals
The CEID Team
Toddler & Preschool

Pediatric Residency Training
Sunshine Preschool & Childcare

First Step:
California NHS Program: Legislation

- **AB2780 (passed 1998 – December 2002 full implementation)**
- Required: Establishment of a comprehensive hearing screening program for the early detection of hearing loss in newborns and infants, with access to diagnostic evaluations and follow-up services, and provisions for data collection and reporting.
- Department of Health Care Services (DHCS), specifically the Children’s Medical Services (CMS), holds responsibility for the implementation and oversight of this program
- **1-3-6 Goals**
  - 70% of babies (400,000 of 520,000 births)

**1993: Early Start implemented in California**

California NHSP

Hearing Coordination Center Staff
- Director
- Registered Nurse
- Audiologist (Paneled)
- Administrative Support
- Parent Advocate
- IT Support

Screen all infants
- FDA approved to screen hearing
- Must be capable of detecting mild hearing loss (30-40 dB)
Hearing Coordination Centers (HCCs)
NHSP: 1-877-388-5301

- Bay Area/Northern Cal HCC (Region A & B yellow and white)
  800-645-3616 #3
- Southern California HCC (Region D - blue)
  866-609-5439
- South Eastern California HCC - Loma Linda Medical Center (pink)
  877-388-5301

Referral and Eligibility
- Ages 0-5 who are deaf or hard of hearing (DHH)
- Any type or degree (including unilateral, mild, moderate, severe, profound, auditory neuropathy, conductive, sensorineural, mixed, or fluctuating)
- A child who has a severe language delay and needs a visual language
- A child who qualifies for IDS with ASL as their home language
- A child who is High Risk

Faces at CEID
- 8 student faces
Family Support

- Home Visits
  - Hearing Support
  - Early Special Education

- Family Events
  - Swimming at Silliman; Day at Crab Cove; Camping; Deaf Plus Family Picnic; Kindergym; Habitot

- Parent Education
  - Sign Classes; Support Groups; Speech and Language Topics
  - Panels: High School Students, Parents, Deaf Adults
  - Parenting Strategies; Storytelling; Importance of Play!
  - Understanding IFSPs and IEPs

Parent-Identified Essentials of Appropriate Early Intervention

- Contact with other parents
- Unbiased information
- Time to process information
- Skillful and supportive professionals

Parents and Their Deaf Children: The Early Years

DHH Specialized Instruction Topics

- Understanding hearing loss: cause, prognosis, and impact on the child and family
- Reading an audiogram
- Decision making regarding communication options
- Language instruction services including: teaching American Sign Language (ASL), Signed Exact English (SEE), Cued Speech, and auditory/oral language (IDEA 303.13(b)(12)).
- Visual technologies, including alerting systems, safety systems, and communication technologies
- Adapting the home to make it a visual environment.
DHH Specialized Instruction Topics

- Hearing aid care, maintenance, tolerance, monitoring, and troubleshooting
- Cochlear implant decision making, candidacy process, preparation, use, care, maintenance, follow-up
- FM System use, care, decision making
- Cognitive development issues related to hearing loss
- Emergent literacy in deaf and hard of hearing children
- Social–emotional development and identity issues.

Deaf/Hard of Hearing Specialized Instruction Topics

- Deaf culture and communities
- Advocacy and empowerment issues related to hearing loss
- Current research in deaf education
- Special concerns related to mild, unilateral, and conductive hearing losses
- The synergistic effect of hearing loss and other disabilities, including visual, motor, social, or cognitive impairments

Communication Possibilities

- Listening and Spoken Language
- Cued Speech
- American Sign Language (ASL)
- Signing Exact English (SEE)
- Conceptually Accurate Signed English
- Sign Supported Speech
- Total Communication (TC)
- Bi-Lingual/Bi-Cultural
Toddler Class Music Time: Parents and Children in Action

- Video

Deaf Plus & SENSORY INTEGRATION

The ability to take in sensory information from one's body and the environment, to organize this information, and to use it to function in daily life

A Sensory Diet incorporates:
- Tactile
- Proprioceptive
- Vestibular

Tactile:

- Light Touch:
  - 2 students with different experiences

- Deep Touch:
  - Bear hugs;
  - Bouncing a big ball on a child

Student/class photo
Accommodations in Classroom and Therapy Sessions

Salient Considerations for a child who is Deaf Plus:

* Positioning/Motor Control

Processing Time

Attention

Eye Contact

Peer Lead Speech Therapy - Preschool

* Video with Ron and Izzy

Audiology Services

* Hearing Screenings
  - For infants under 3 months old who have been referred from an initial screening or who have never received a screening
  - Preschool students (HeadStart, Private Preschools)
* Diagnostic Hearing Evaluations
  - For children and adults
* Hearing Aid Dispensing
  - Hearing aids and devices, ear molds, hearing aid accessories
CEID & Rising Harte Wellness Center
A Collaborative Model for Alameda County

- School-linked health center and collaboration serving students at Bret Harte Middle School and Transition Age Youth (young adults, ages 16-25)
- Almost 90% of BHS students and 87% of transition age youth report experiencing barriers to accessing affordable, competent health care.

- Screening for key risk factors
- Provision of treatment and services
- Preventative services and dental examinations
- Health education, recreation and social programs
- Case management and linkage

CEID Fundraising Activities

Annual Walk-A-Thon
- Add photo

Benefit Golf Tournament
- Add photo
Ron’s Message on Behalf of CEID

- Ron’s personal Bio and video clip

CEID Publications

- Pediatric Resource Guide to Infant and Childhood Hearing Loss
  - Photo of GUIDE cover

- CI Prep
  - DVD
  - Book
  - Home Visit Kit

Thank You!

- Photo of 3


Joint Committee on Infant Hearing: [www.jcih.org](http://www.jcih.org)


California Newborn Hearing Screening (NHSP)
Toll Free: 1-877-388-5301

Regions A & B
- Bay Area/Northern California Hearing Coordination Center (BA/NCHCC)
  1501 Industrial Road San Carlos, CA 94070
  Phone: 800-645-3616, Press #3       Fax Number: 800-866-1074
  E-mail: hccnorthern@natus.com

Region C
- South Eastern California Hearing Coordination Center (SECHCC)
  1200 California St. Suite 108  Redlands, CA 92374
  Phone: 909-793-1291       Fax: (909) 498-7982
  Toll Free: 1-877-388-5301       Email: HCCRegionC@natus.com

Region D
- Southern California Hearing Coordination Center (SCHCC)
  1 Centerpointe Drive, Suite 410  La Palma, CA 90623
  Phone: (661) 591-4300       Fax: (661) 244-2865
  Toll Free: (866) 609-5439       Email: HCCRegionD@natus.com
OVERVIEW

• DEAF CHILDREN BY THE NUMBERS
• UNIQUE CHALLENGES FOR DEAF CHILDREN
• AGE OF ENTRY
• REASONS AND FORECAST
• ACADEMIC ACHIEVEMENT AND TRANSITION
• LEGAL LANDSCAPE
• QUESTIONS
DEAF CHILDREN BY THE NUMBERS

- 350,000 Deaf and hard of hearing children in the USA
- 17,000 Deaf and hard of hearing children in California
- 14,000 on IEPs
- 3,000 on 504 plans
- Around 850 attend California Schools for the Deaf = 5%
- National average of attendance at school for the deaf = 8% to 50%*
- Majority of students transfer to CSD in Middle School/High School = 67%


UNIQUE CHALLENGES FOR DEAF CHILDREN

- 90%+ of Deaf children are born to hearing families
- Early intervention services
  - Audiologist
  - Speech therapy
  - ASL classes if available
- Language and communication issues along with deprivation
- Deaf children vary in hearing levels—many use technology to varying levels of success
- 10% of students with cochlear implants do not need any type of accommodations, 30-40% fare well with accommodations, the rest do not benefit/discontinue*


OVERVIEW OF CALIFORNIA SCHOOLS FOR THE DEAF

- Academic environment in both languages (ASL and English)
- High expectations for all students by teachers who are role models
- Early Childhood Education program, K-12, and Career Technical Education
- Special education and speech therapy services available
- Strong athletics and extracurricular with full communication access
- Provides workshops and classes to parents free of charge
- Provides both day schooling and residential program for students who live too far to commute (85% of students)
- All teachers and staff have the appropriate credentials
- Adheres to all CDE/Federal requirements (assessments, reporting and IEPs, etc.)
- Provides free information and resources state-wide
- Annual Open House - November 12, 2015

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REASONS AND FORECAST

- Some counties have a small population of Deaf students. They send what they have.
- Parents or counties not familiar with what CSD offers or are not interested due to distance or other reasons

  - Some counties have set up their own programs serving Deaf students.
  - Misconception on the real costs of CSD. The cost for a county to send a student to CSD to provide educational services (including room and board) is $6,530.40 per year. Some thought they were paying over $40,000 per year. Compare this to costs per student.
  - Forecast: Increased collaboration with school districts, cross-training, increase of regional programs, provision of assessments and resources

Information gathered from Pupil and Personnel Services, CSD Fremont, 2014 and California Department of Education

ACADEMIC ACHIEVEMENT

MAP© is Measures of Academic Progress, a computer-based adaptive assessment that precisely measures student progress and growth for each individual.
TRANSITION

- In addition to academics, CSD offers Career Technical Education with 10 programs of study (Auto Body technology, biotechnology, computer service technology, food education and service, digital media, engineering and more)
- All students are provided career awareness training starting in middle school along with featured Deaf adult speakers in various occupations
- Upon graduation, students attend a variety of colleges/universities and training programs
- Examples of successful alumni

QUESTIONS

- WHAT PATTERNS DO YOU SEE?
- HOW CAN WE WORK TOGETHER TO INCREASE ACADEMIC SUCCESS ACROSS THE BOARD?
- ANY IDEAS FOR CREATIVE COLLABORATION?
- ANY OTHER QUESTIONS?
Supported Decision-Making for People with Developmental Disabilities

Samantha Crane, J.D., Policy Director
The Autistic Self Advocacy Network
2013 H St. 7th Floor • Washington, DC 20035
Voice: (202) 596-1056
www.autisticadvocacy.org

What is Supported Decision Making?

- System of supporting an individual with a disability to make his or her own choices
- May include assistance with gathering information, understanding options, and communicating with third parties
- Level of support may vary with level of need or importance of decision

We All Need Support!

- Nobody can make all their own decisions without "support" and advice
- People may get decision-making support from:
  - Doctors
  - Financial advisors, agents
  - Lawyers
  - Counselors
  - Informational materials (online or elsewhere)
  - Family and friends
  - Clergy
  - Support groups
People with ID/DD Can Face Additional Challenges

- Difficulty understanding and remembering advice and information, or need for cognitive supports (e.g., visual explanations, simplified materials)
- Difficulty communicating information or decisions, or need for communication supports (e.g., AAC, written communication)
- Need for support to learn and carry out decision-related tasks (e.g., following health care regimen, balancing checkbook, navigating neighborhood)
- Lack of accessible information

How it Works

- Person with a disability chooses supporter
- Supporter helps to:
  - Gather, organize, translate information
  - Communicate with doctors, bankers, etc.
  - Explain and explore options and consequences
- Person with disability makes final decision

Supported vs. Substituted Decisionmaking

**Supported Decisionmaking**
- Individual makes own decisions (with support)
- Individual decides who will provide support
- Level of support may vary according to situational factors

**Substituted Decisionmaking**
- Another person makes decisions for the individual
- Individual may not have opportunity to decide who will provide support
- Individual loses legal capacity to act independently across entire domain
Isolating Effects of Guardianship

In guardianship:

• Person with disability cannot make decisions without approval of guardian

• People with disabilities become “disconnected” from decision process and fail to gain – or may even lose – decision-making skills

• People with disabilities may be “constructively isolated” from community due to inability to enter into contracts, find housing, see doctor, or go shopping without guardian. - Leslie Salzman

More Isolating Effects of Guardianship

In guardianship:

• Challenges to guardian’s decision and/or resolution of conflicts among family members require lengthy court process
  – If person with disability lacks assistance with this process, a challenge may not be possible at all

• Crowded dockets -> Limited court oversight

• Courts often avoid “limited” guardianships – even though they’re supposed to favor them – because they want guardians to have as much authority as possible
  – Will assume that limited guardians will eventually come back to court seeking additional authority, adding burden to court docket
Public Guardianships: Special Problems

- Guardians with multiple wards may opt for "one size fits all" approach to decisionmaking
- Guardians do not have personal relationship with ward, may face communication barriers, may lack background information about ward's preferences and personality

Example: Washington State

- Professional guardians tried to "bill" wards for the time they spent advocating against Olmstead enforcement
- Court denied payment because there had been no individualized determination that this advocacy was in the "individualized best interest" of each ward.
- Guardians represented dozens of individuals at a time.
  - In re Guardianship of Lamb, 265 P.3d 876, 877 (Wash. 2011)(en banc).

Long-Term Consequences of Presumed Incompetence

- Inadequate focus on building skills that the person doesn’t already have – especially in preparation for transition to adulthood
- Third parties may speak directly to support persons instead of including people with ID/DD in conversations about their own lives
- Doctors may refuse treatment to people with ID/DD who don’t have a guardian, out of fear that people with ID/DD can’t provide "informed consent" to own care
- Landlords, banks, car dealers, etc. may not recognize person’s ability to sign contract without help from guardian, fearing it will be voided
How SDM helps

- Centers person with a disability in decision-making process
- Tailors support to amount needed
- Helps build decision-making experience and skills
- Requires supporters to commit to interactive process
- Holds supporters accountable to person with disability

Beyond “Guardianship Reform”: Combining Autonomy with Support

- Under guardianship model, autonomy of a person with cognitive or intellectual disability must be limited to protect the person from exploitation, manipulation, or “bad choices”
- Early civil libertarian critiques focused on imposing guardianship only when a person is “truly unable” to make decisions independently
- Supported decision making acknowledges need for support while preserving autonomy

How to Make SDM Work for Everyone?

Reforms across multiple systems:
- **Courts**: change laws to favor supported decisionmaking over guardianship
- **Support Professionals**: stop “guardianship pipeline”
- **Service Systems**: ensure that people have actual access to decision-making supports
- **Third Parties**: make sure doctors, landlords, etc. understand SDM; provide certainty that acting consistently with SDM will result in enforceable contracts/health care decisions.
**Implications for Health Professionals**

- Look “beyond guardianship”:
  - Can person give informed consent with support?
  - Can you combine health care proxy or state surrogate decision-making laws with SDM principles?
  - Existence of a guardian does not mean that a person cannot use supported decision-making as well

**Challenges**

- Many professionals unfamiliar with supported decision-making
- Professionals may be concerned about liability
- Individuals may lack access to documents clearly outlining support relationship

**Supported Decision-Making Legislation**

- ASAN developed model legislation recognizing Supported Health Care Decision-Making Agreements, a new type of agreement designed to meet the needs of people with significant support needs
- Developed in collaboration with Quality Trust for Individuals with Disabilities – a D.C.-based non-profit focusing on self-determination for people with significant disabilities
- In process of creating broader legislation for financial, other decision-making
MODEL LEGISLATION

AN ACT RELATING TO THE RECOGNITION OF A SUPPORTED HEALTH CARE DECISION-MAKING AGREEMENT FOR ADULTS WITH DISABILITIES

Benefits of Supported Decision-Making Legislation

- Gives individuals clear option to create recognized support relationship
- Avoids costly, traumatic, and/or lengthy court proceedings
- Individuals are protected from many forms of abuse or exploitation because they retain capacity to go against wishes of support person

ASAN’s Model Legislation

- Allows supported decision-making arrangements in health care contexts
- Supporters can access health information, communicate with health providers under exception to HIPAA
- Includes standard form in simple language
- Provides protection to doctors who follow, in good faith, directions made through supported decision-making
How We Designed the Model Legislation

• Reviewed published guardianship decisions in past decade to identify why courts awarded guardianship in contested cases
  – Major factors were perceived lack of acceptable alternatives, desire to make sure person is “taken care of”
• Analyzed supported decision-making legislation in other countries, including Canada, Sweden, U.K.

Major Goals

• Accessibility to people with limited financial, educational resources
  – Litigating a guardianship case can cost thousands of dollars
  – Most Americans lack ready access to legal representation
  – Court proceedings may take a long time
• Availability to people with significant cognitive impairments
  – Process must be understandable
  – Agreement must be valid even if person has support needs
• Preservation of decision-making rights
  – Goal is self-determination
  – “Private” agreements that involve potential relinquishment of rights give rise to potential for abuse

Other Considerations

• Alleviating liability concerns that may contribute to discriminatory denial of care for people with ID/DD who don’t have guardian
• Respecting diversity in choice of supporter
• Avoiding conflict of interest
• Preventing abuse / providing clear process for reporting abuse
• Preventing fraud
Overview of Legislation

- Allows person with ID/DD to execute Supported Health Care Decision-Making Agreement, naming a supporter
- Supporter is authorized to assist in decision-making, including communicating with doctors, obtaining records, making appointments, accompanying person to appointments, assisting in daily health routines
- Person with disability makes all final decisions
- Decision made with support can count as "informed consent"

Preventing Fraud

- "Private" agreement eliminates need for court involvement (in most cases) – this is necessary to ensure access
- Agreement must be witnessed and notarized, reducing potential for fraud
  - Many similarly high-stakes agreements, like powers of attorney, often have similar protections (depending on state)
- Person with disability must actively participate in decision-making; supporter cannot fulfill most support functions without person's knowledge

Minimizing Conflicts of Interest

- Conflict of interest provisions restrict who may serve as supporter
  - Treating physicians, people with major financial conflicts of interest, and staff in institutional settings cannot serve as supporters
- Conflict of interest provisions designed to ensure that spouses, parents, friends, and home support workers are not automatically excluded from serving as supporters
Ensuring Availability to People with Significant Disabilities

- Agreement is valid even if person with ID/DD is considered unable to execute a valid power of attorney or provide “informed consent” without support
- This is necessary because otherwise people would be forced into unnecessary guardianship or would risk denial of care
- Agreement preserves individual’s right to make final decisions and to terminate agreement – unlike powers of attorney which can allow agents to make “unilateral” decisions for the individual. This ensures that people are protected in the case of an unforeseen problem with the supporter.

Preserving Doctors’ Role

- Health providers retain ability to exercise professional judgment regarding treatment
- Do not have to provide care that they feel is harmful or not medically beneficial
- Do not have to provide care if they believe that the supporter hasn’t conveyed important information to the individual, or suspect consent was obtained through abuse or coercion

Solving Disputes and Preventing Abuse

- Doctors or others may report suspected abuse to adult protective services agency
  - These agencies often investigate complaints faster than guardianship courts can hold hearings on challenges of guardians’ conduct
  - Substantiated complaints will result in removal of supporter
  - In states with mandatory reporting laws, reports are mandatory
State Implementation

• In 2015, Texas passed supported decision-making legislation
  – ASAN model legislation incorporates key elements, but differs in some ways
  – Texas will pilot SDM agreements
• Other target states: DE, MD, NY, CA
• Some courts, including ones in New York and Virginia, recognize that people with ID/DD can make decisions with support – but these relationships are often informal and lack clear definitions

Next Steps

• The form in ASAN’s model legislation can be used to help people express their intention to form a supported decision-making relationship – but may not be legally recognized or binding
• Advocates can ask their state legislators to pass legislation recognizing supported decision-making agreements
  – The model legislation may serve as a “starting point”

In the Meantime…

• The supported decision-making agreement in the model legislation can still be created using special powers of attorney
• There still may be challenges to capacity if families are in conflict, and third parties may need to be educated about this type of agreement.
• National Resource Center for Supported Decisionmaking is developing a supported decision-making “forms bank”
Children with ASD have increased rates of medical and psychiatric conditions
Rate of Autism in Children is Increasing

1 in 68

Children with ASD become adults with ASD

Overview of Presentation

- Health status of adults with ASD
- Health care utilization among adults with ASD
- Healthcare provider knowledge and experience
- Next research steps
- Questions
Kaiser Permanente Northern California

- Group practice prepaid integrated health program
- 3.6 million patients
- 8,000 physicians
- 21 hospitals
- Fully electronic health record
- Serves ~30% of population in geographic region

Health Status and Healthcare Utilization Study Population

- Adults 18+ years of age
- Kaiser Permanente Northern California (KPNC) member for 9+ months per year
- 2008-2012
- Autism Spectrum Disorder CASES (N = 1,507)
  - 2+ ASD diagnoses recorded in KPNC medical record
  - Anytime through Dec 31, 2012
- CONTROLS (N = 15,070)
  - No ASD diagnoses
  - Randomly sampled at 10:1 ratio
  - Matched to cases on total length of KPNC membership, sex, and age
- Health status - medical and psychiatric conditions recorded in the electronic medical record over 5-year study period
- Health care utilization – in 2012

Phenotypic Characteristics

<table>
<thead>
<tr>
<th>Adults with ASD (N=1,507)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Autistic Disorder</td>
<td>37.2%</td>
</tr>
<tr>
<td>Asperger Syndrome</td>
<td>29.7%</td>
</tr>
<tr>
<td>ASD</td>
<td>33.1%</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>19.2%</td>
</tr>
<tr>
<td>Mild</td>
<td>12.8%</td>
</tr>
<tr>
<td>Moderate</td>
<td>3.1%</td>
</tr>
<tr>
<td>Severe</td>
<td>6.2%</td>
</tr>
<tr>
<td>NOS</td>
<td>77.9%</td>
</tr>
<tr>
<td>No</td>
<td>80.8%</td>
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</table>
Demographic Characteristics

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<th>Adults with ASD (N=1,507)</th>
<th>Controls (N=15,070)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD)</td>
<td>29.0 (12.2)</td>
<td>29.4 (12.3)</td>
</tr>
<tr>
<td>&gt;35</td>
<td>26%</td>
<td>26%</td>
</tr>
<tr>
<td>Racial/ethnicity, %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>65.6%</td>
<td>44.0%</td>
</tr>
<tr>
<td>White, Hispanic</td>
<td>3.9%</td>
<td>4.2%</td>
</tr>
<tr>
<td>Black</td>
<td>7.6%</td>
<td>7.3%</td>
</tr>
<tr>
<td>Asian</td>
<td>13.1%</td>
<td>16.8%</td>
</tr>
<tr>
<td>Other</td>
<td>11.7%</td>
<td>27.7%</td>
</tr>
<tr>
<td>Sex, %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>73.5%</td>
<td>73.2%</td>
</tr>
<tr>
<td>Female</td>
<td>26.9%</td>
<td>26.9%</td>
</tr>
</tbody>
</table>

Psychiatric and Medical Conditions

Psychiatric Conditions
Neurologic Conditions

- Epilepsy: OR=32
- Other CNS disorders: OR=4.4
- Stroke: OR=16
- Parkinsons: OR=5.0
- Dementia: OR=2.1

Alcohol and Tobacco Use
Self-Reported

- Alcohol use: ASD vs Controls
- Smoking: ASD vs Controls

Healthcare Service Utilization
Outpatient Visits

- Psychiatric
- Mental Health
- Endocrine
- Gastro
- Respiratory
- Other

OR = 1.59
OR = 1.31
OR = 0.76
OR = 0.00
OR = 1.75

Inpatient Visits

- Emergency department visit
- Inpatient hospitalization
- Hospitalization for unattended care sensitive diagnosis

Annual average rate of healthcare service utilization

Prescription Medication

- Antidepressants
- Antipsychotics
- Acute Care Medications
- Diabetes
- Hypertension
- Other

OR = 6.13
OR = 32.70
OR = 7.38
OR = 4.40
OR = 1.21
OR = 1.68
OR = 2.00
OR = 1.42
Possible explanations for findings

- Communication and social impairments and deficits in sensory processing may be barriers to preventive health care, and lead to missed or delayed diagnosis.
- Social isolation and communication difficulties may lead to depression and anxiety.
- Core impairments may lead to limited diets with poor nutritional value, lack of participation in organized sports and physical activity, in turn leading to obesity and other chronic medical conditions.
- Autism and other medical and psychiatric conditions may share similar genetic factors.
- Medications used to treat psychiatric and neurologic conditions may raise risk for obesity, hyperlipidemia.
How would you rate your knowledge and/or skills in providing care to people with ASD?

- Adult and Family Medicine
- OB/GYN
- Mental Health

Percent

You have adequate tools/referral resources/practice models to accommodate people with ASD in your practice.

Percent
When you suspect ASD in a patient, do you?

- Consult with PCP
- Take care of patient myself
- Inclusive
  - Involve the patient
  - Involve the family
- Kindness
  - Treat them the same as others

Active

Compassionate
When you suspect ASD in a patient, do you?

- I do not work with kids
- I have not encountered ASD
- No Awareness of ASD in adults
- No treatment available
- No treatment authorized
- I don’t do anything
- Patient already receives care
- Treatment as Usual

Open-Ended Interviews with Providers

Medical training, education, resources?

“Zero to none”

Do you make any special accommodations?

“It takes a slow approach”
What are the challenges?

- Routine questions about lifestyle related issues (Drugs, Smoking, Sex)
- Impairment level
- Living arrangements
- Conservatorship
- Social isolation
- Transitions

Summary of Findings

- ASD persists throughout the lifespan
- Increasing numbers of adults with ASD
- High burden of medical and psychiatric conditions in adulthood
- High healthcare utilization, high use of medications
- Low utilization of some preventive healthcare
- Adult healthcare providers are ill prepared

What is Needed

- Integration between mental health and medical departments
- Provider training and resources
- Integration between pediatrics and adult medicine
- Tools to improve patient-provider interaction
- Therapeutic approaches that lower disease burden
- Emphasis on healthy lifestyles from a very young age
- Engagement in all sectors – healthcare, social services, education, employment, community, family
Research Opportunities

- Understand the factors underlying the increased rates of medical and psychiatric conditions
  - Biological
  - Social
  - Health care access
- Understand how physicians investigate and manage chronic disease in adults with ASD
- Develop and test improved strategies for delivering health care to adults with ASD

Acknowledgements

Autism Research Program
Yinge Qian
Jack Collins
Ousseny Zerbo

Autism in Adults Workgroup
ARP Community Advisory Board
Clinical Partners

Fundors
Kaiser Foundation Research Institute
Special Hope Foundation

Children and Adults with ASD and Families

Questions?
Down Syndrome: Updates & Comorbidities

Nancy Roizen, MD
Division of Developmental-Behavioral Pediatrics and Psychology.
Professor of Pediatrics
Case Western Reserve University

Disclosure:
research funded by the Alana Foundation on the use of memantine for improved cognition in Down syndrome

Objectives:
• To be acquainted with the DS Guidelines
• To be aware of the areas of great interest in the field of Down syndrome
• To be aware of the medical issues that might contribute to behavioral and/or developmental problems
Basic DS Stats

- DS: 95% trisomy
- One in 700 births...holding steady or increasing or decreasing
- Life expectancy increase from 12 to 60 yr/60yr
- A whole additional chromosome:
  - Biologically complex: potentially all systems
  - Multiple genes effect cognitive development
  - Complicates interventions

DS: Complicated

Jim is 11 yrs of age with medical problems restricted to hearing loss requiring a hearing aid and glasses and a FSIQ 68 at 6 yrs of age. He has anxiety responsive to fluoxetine (2 mL/d), and ADHD treated with MPH (15 mg BID). Jim was in inclusion setting in a public school through 4th grade with increasing supports and now has on-line modified school program. Pulled out as he was anxious and getting aggressive. He and mother receiving counseling. Mother careful with integration activities such as soccer.

Beware of

DIAGNOSTIC OVERSHADOWING
Hot Topics in DS

- Autism
- Sleep apnea
- Cognitive profiles
- Regression/DS disintegrative disorder
- (Dementia)
- Pharmacological intervention of cognition
- Growth charts
- The family
- Registries
- Adult DS Clinics

ASD/Dual Diagnosis

- **Regression Occurs Much Later**
  - 24 DS w/ ASD:50% autistic regression
  - Loss of language: 61.8 vs 19.7 months controls
  - (Castillo et al. JDBP, 2008)

- **All Areas of Development Poorer & Seizures More Frequent**
  - 20 DS w/ & w/out ASD: 7/21 vs 1/21 seizures
  - (Molloy et al. J Intell Disab Res, 2009)

Risperidone Use ASD/DS

- Improved disruptive/self-injurious behavior
- Sleep
- Hyperactivity
- Stereotypy
- Irritability
- Inappropriate speech
- Lethargy
- Weight gain 2.8 kg over 96 days
- (Capone et al. JDBP, 2008)
Obstructive Sleep Apnea: DS

• Shott (2006): 52 children sleep study at 3 yr
• 50% with OSA
• Parental reports: 60% DS with abnormal sleep studies NO sleep problems
• Guidelines: by 4 years of age sleep study or polysomnogram

Why Treat?

• Study of 38 unreferred children mean age 9y7mo: 19 with OSAS had Verbal IQ 9 points lower (p=0.006) cognitive flexibility lower (p=0.03) (Breslin J et al. 2014)
• Failure to thrive
• Pulmonary and systemic hypertension
• Cardiovascular dysfunction/cardiac failure

How to Treat OSA

• O₂ supplement with CPAP
• Dental appliances; weight reduction; nasal steroids
• T & A: <50% success
• T & A w/ pharyngoplasty: same (Merrell & Shott, 2007)
• Genioglossus advancement & ablation tongue base: 58% (12/19 persisting OSA) success (apnea-hypopnea index decreased and O₂ sat increased (Wootten & Shott, 2010)
• Hypoglossal nerve stimulator
Cognitive/Language Profile

Strengths
- Vineland: Daily living & Socialization
- Visual problem-solving
- Vocabulary comprehension
- Pragmatic language skills

Weaknesses
- Vineland: Communication
- Short-term working memory
- Cognitive flexibility
- Expressive language
- Syntax
- Intelligibility

Memory Issues: McGuire & Chicoine

Positives
- Uncanny memory for people, places and past events like color and type clothing
- Interesting facts: Beatles, sports teams
- Oft find way or direct others to places previously visited
- Rarely forget face or name

Negatives
- Sound letter associations
- Remembering phone # long enough to dial it
- Difficulty linking memories to time
- Tendency to relive past memories
- Self talk (83%) (Mental Wellness in Adults with Down Syndrome, 2006)

Interventions
- EI: consistent benefits in fine motor and adaptive skills
- When leave school, skills in reading, writing, & math
  - 75% skills of a 5 yr old
  - 25% some skills of an 11 yr old
- (Turner & Alborz, 2003)
- Inclusion settings with typical children:
  - Greater mental age gain
  - More reading with comprehension esp girls
  - Intelligibility to strangers 78% vs 56% in sp schools
DS Disintegrative Disorder: Depression vs Autistic Disorder

- Duke: over 10 yrs; n=11; 5-14 yr olds; 64% F
  - ASD deterioration (11)/cognitive decline(10)/new-onset insomnia(9)/tx hypothyroidism(5)
  - Normal: Metabolic work-up/CT or MRI/
  - EEG abn (1); thyroid autoimmunity (11)
  - Followed at 20.7 yrs 73% (8) somewhat better
    - (Worley et al J Child Neuro 2015)

New Growth Charts from CDC!

- Birth-36 months boys and girls:
  - Weight, height, HC, weight-for-length
- 2-20 years boys and girls:
  - Weight, height, head circumference

Mothers & Parents

Skotko et al

<table>
<thead>
<tr>
<th>Organization</th>
<th>Number of Respondents</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post-natal support</td>
<td>1250</td>
<td>• Responses w/ few positive</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Majority anxious/frightened</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Little positive talk but improvement w/time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(Peds,2005)</td>
</tr>
<tr>
<td>Mothers/fathers</td>
<td>2440</td>
<td>• 99% love child</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 97% proud of child</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 79% self outlook more +</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 5% embarrassed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 4% regretted having them</td>
</tr>
</tbody>
</table>
Sibling/Self-perception

<table>
<thead>
<tr>
<th>Organization</th>
<th>Number of Respondents</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sibling</td>
<td>822</td>
<td>• 96% had affection to sib</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 94% older sibs proud</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• &lt;10% embarrassed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• &lt;5% like to trade in</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 88% felt better people</td>
</tr>
<tr>
<td>Self-perceptions</td>
<td>284</td>
<td>• 97% liked who they are</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 96% liked how they look</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 99% happy w/life</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 4% sad</td>
</tr>
</tbody>
</table>

“The DS Advantage”

“The Sibs & parents of children with DS cope slightly better than families with other disabilities”

DS: Disease Burden, Access to Care, & Family Impact

• 2005-6 Survey CSHNC: 98,000 DS
  – Greater number co-morbid condition
  – More likely have unmet needs
  – Faced greater family impacts
  – Less likely to have access to a medical home

  – (McGrath et al. J Pediatr. 2011)
Data Bases & Registries

• DS-Connect: The NIH Down Syndrome Consortium Registry
• Voluntary, confidential, online survey tool to collect basic information about people with DS. Downsindrome@mail.nih.gov
• MGH/Skotko collaboration w/ clinics
• Columbus, OH: Biobank/Colorado
• July 22, 2016 in Orlando, FL

20 Patients with DS

<table>
<thead>
<tr>
<th>Age</th>
<th>%</th>
<th>Check-up</th>
<th>Behavior</th>
<th>Develop</th>
<th>Med</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 1yr</td>
<td>35%</td>
<td>33%</td>
<td>17%</td>
<td>50%</td>
<td>17%</td>
</tr>
<tr>
<td>1-5 yr</td>
<td>25%</td>
<td>14%</td>
<td>43%</td>
<td>28%</td>
<td>14%</td>
</tr>
<tr>
<td>6-12 yr</td>
<td>20%</td>
<td>40%</td>
<td>40%</td>
<td>20%</td>
<td></td>
</tr>
<tr>
<td>13-17 yr</td>
<td>20%</td>
<td>80%</td>
<td>20%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

What are we publishing?

Ovid 100 Articles 2010

• Prenatal testing/genetic: 34%
• CNS and/or dementia: 13%
• Development-behavior: 11%
• Family: 10%
• Heme/oncology: 6%
• Mouse model: 5%
• Other: 21%

Ovid 100 Articles 2015

• Prenatal testing/genetic: 33%
• Cognitive/develop/behavior: 13%
• Cardiovascular: 10%
• Heme/oncology: 7%
• GI: 4%
• Dental: 4%
• Mouse: 3%
• Other: 26%
“Life is not a matter of holding good cards, but of playing a poor hand well.”

Robert Louis Stevenson

**CHANGES:**

- Much more prescriptive
- More discussion state of evidence
- More anticipatory counseling
- Evaluation symptoms
- Added: hemoglobin, sleep study
**Organization of Care for DS**

- **EVALUATION:** cardiac, vision, hearing, sleep apnea, birth TMD
- **MONITOR:** thyroid, hgb, growth
- **SYMPTOMATIC:** atlanto-axial subluxation, celiac, sleep apnea, feeding/swallowing problems
- **VIGILANCE:** arthritis, constipation, diabetes, GE reflux, GI obstruction, leukemia, renal, seizures
- **PREVENTION:** gingivitis, obesity

---

**Congenital Heart Disease**

- **Guidelines:** all ECHO even if fetal ECHO
- **Area of growth:** Adult Congenital Heart Disease Clinic (Majdalany, 2010)
  - Mayo review: 50 patients/57 sx with 15 prior ops
  - 17 repair partial AVC;
  - Valve replacements: aortic (7); mitral (7); pulmonary (3)
  - In hospital deaths (1/1.8%), atrial arrhythmias (14/25%); pulmonary infections (6/12%)

---

**Every 6 Month ENT Visit**

- 48 children with DS <24 mo
- ENT & audiogram q 6 mo
- Follow-up 18 mo – 2 yr later

- **Results:**
  - 40 had PE tubes – 45% x1, 43% x2, 7.5% x3, 5% x4
  - 4/48 – normal audiogram w/out antibiotics or PE tubes
  - 1 abnormal hearing (2%)
  - After 2 years (7% HL)
  - (Shott, SR et al. 2001 Int. J Ped Otol 61:199-205)
Audiology Guidelines
1. NB hearing screen and follow up
2. Audiology eval:
   a. Every 6 mo from 6mo-5yr
   b. Every year 6yr-21 yr
3. Behavioral audiogram & tympanometry until
4. Bilateral ear specific testing possible.
5. Abnormal results refer to otolaryngologist

(Bull. AAP Committee on Genetics. Pediatrics. 2011;128: 393-406)

Monitor: Thyroid- DS
• 1 in 128 newborn screen abnormal
  – (28-54X higher than general population)
• 4-54% with DS; risk increases with age
• Study of 1257 children with DS 10.8% at 1-18 yr of age new prescription with thyroxine after 1 year
• Most frequently: < 3 yr of age & between 12-18 yr -(Carroll et al., 2008)

Thyroid Guidelines:
• Verify results nb thyroid screen
• TSH at 6 mo, 12 mo, & annually

(Bull. AAP Committee on Genetics. Pediatrics. 2011;128: 393-406)
**Special Olympics Changes Rule 2.02: 2014**

- Standard release acknowledge potential impact on an athlete with DS
- Examination required as part of initial registration
- Symptoms of spinal cord compression: can participate if thorough neurological from a physician, qualified to make such a determination, certifies athlete may participate

[http://resources.specialolympics.org/Topics/General_Rules/Article_02.aspx](http://resources.specialolympics.org/Topics/General_Rules/Article_02.aspx)

**HEME GUIDELINES**

- Birth: CBC to r/o TMD & polycythemia

(Bull. AAP Committee on Genetics. Pediatrics. 2011; 128: 393-406)

**Leukemia — DS**

- Transient myeloproliferative disease (TMD) occurs in 4-10% of newborns with DS
- 20% with TMD develops DS-AMKL (acute megakaryocytic leukemia) w/in 4 years
- AML in DS prognosis similar to others
- ALL 20x others with 10 survival numbers less than others

(Alford K et al., Blood. 2011;118: 2222-38)
Discuss:

CAM
How to tell siblings
Support groups, resources, EI
Genetic risk/future pregnancies

Behavior Problems

<table>
<thead>
<tr>
<th>Psychopathology</th>
<th>18-23%</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD</td>
<td>10%</td>
</tr>
<tr>
<td>ADHD</td>
<td>6-8%</td>
</tr>
<tr>
<td>ODD/CD</td>
<td>10-15%</td>
</tr>
</tbody>
</table>

(Dykens, MRDDRR, 2007)

Conclusions

- Diagnostic overshadowing
- Behavior problems: ADHD, ASD, ODD
- Follow the guidelines
- Be a physician: lower your threshold for leukemia, renal diseases, diabetes, arthritis, constipation
- Prepare for transition
Aging, Dementia, and Developmental Disabilities

March 3, 2016
Seth M. Keller, MD
Past President AADMD
Co-Chair National Task Group on ID and Dementia Practices

Nothing to Disclose

Changing US Population Demographics

By 2050, people age 65 and older will equal 30% of the population
U.S. Population (and forecast) by age category and gender

Source: U.S. Census Bureau
Aging and Intellectual and Developmental Disabilities

- In 2002, an estimated 641,000 adults with IDD were older than 60.
- In 2002 about 75% of all older adults with IDD were in the 40-60 year old age range.
- The number of adults with IDD age 60 years and older is projected to nearly double from 641,860 in 2000 to 1.2 million by 2030 due to increasing life expectancy and the aging of the baby boomer generation.

Carter & Jancee, 1983; Janicki, Dalton, Henderson, & Davidson, 1999

- Currently estimated life expectancy of a 1-year-old child with DS is between 43 and 55 years.
- 25% of persons with Down syndrome are still alive at 65 years.


Expected Physical Changes of Aging

- Osteopenia/Osteoporosis - normal aging-related bone loss
- Sarcopenia - progressive loss of muscle mass
- Presbyopia: the lens of the eye becomes stiffer and less flexible – affecting the ability to focus on close objects (accommodation)
- Presbycusis – aging related change in the ability to detect higher pitches – more noticeable in those age 50+
- Gustation (i.e. the sense of taste) decrements become more noticeable beyond 60+
- Olfaction (i.e. the sense of smell), decrements become more noticeable after age 70+
- Somatosensory System - Reduction in sensitivity to pain, touch, temperature, proprioception
- Vestibular – Reduction in balance and coordination
- Cognitive – Reduction in short term memory loss, attention, and, retrieval
**Diversity of the Aging Process**

<table>
<thead>
<tr>
<th>Cognitive Reserve</th>
<th>Plasticity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Susceptibility to disease</td>
<td>Individual organ systems age differently</td>
</tr>
<tr>
<td>Social and cultural factors</td>
<td>Genetic predisposition</td>
</tr>
<tr>
<td>Compensatory behaviors + access to resources</td>
<td>Lifestyle</td>
</tr>
</tbody>
</table>

**Individual Aging Process**

**Gender**

**Lifestyle**

**Successful Aging**

*Optimal Aging*

“A kind of utopia, namely, aging under development enhancing and age-friendly environmental conditions”


**Successful Aging**

- Avoidance of disease and (additional) disability
- Maintaining mental and physical function
- Sustained engagement in social and productive activities


**Modifiable versus Unmodifiable Factors for Successful Aging**

**Unmodifiable**

- Age
- Gender
- Genetics
- Ethnicity
Modifiable Factors for Successful Aging

- Eat a balanced and healthy diet (and supplements)
- Maintain a healthy weight
- Exercise on a regular basis (include weight bearing exercises)
- Manage stress / allow time for relaxation
- Don't smoke (and avoid secondary smoking!)
- Education (promote lifelong learning)
- Occupation (esp. promotes curiosity, or working with people)
- Leisure activities (mental, social, physical)
- Enriching relationships (evolving)
- Living in a nurturing/clean physical environment

Optimizing Successful Aging for Older Adults with IDD

- Health promotion/health prevention - Wellness screenings (e.g. vision/hearing, dental checkups, cancer screenings, mammograms).
- Psychological well-being - advocate to ensure availability of optimal treatments/medications for those with dual diagnosis (e.g. anxiety, depression).
- Important to offer a range of new activities, that may result in continuing personal development and compensatory skill building.
- Effective epilepsy management.
- Avoiding Polypharmacy
- Involve families and support team

Life Course Health Promotion

- A balancing act of guiding philosophies.

Increasing Age

Autonomy & Self-direction  “Duty of Care”
### Leading Causes of Death, Adults 65+ Years, 2010

<table>
<thead>
<tr>
<th>Rank</th>
<th>Cause of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Heart disease</td>
</tr>
<tr>
<td>2</td>
<td>Cancer</td>
</tr>
<tr>
<td>3</td>
<td>Chronic lower respiratory diseases</td>
</tr>
<tr>
<td>4</td>
<td>Stroke</td>
</tr>
<tr>
<td>5</td>
<td>Alzheimer's disease</td>
</tr>
<tr>
<td>6</td>
<td>Diabetic</td>
</tr>
<tr>
<td>7</td>
<td>Influenza and pneumonia</td>
</tr>
<tr>
<td>8</td>
<td>Kidney disease</td>
</tr>
<tr>
<td>9</td>
<td>Accidents (unintentional injuries)</td>
</tr>
<tr>
<td>10</td>
<td>Septicemia</td>
</tr>
</tbody>
</table>


### Cognitive Changes with Aging

- **Normal changes** = more forgetful & slower to learn

- **MCI – Mild Cognitive Impairment** =
  - Immediate recall, word finding, or complex problem solving problems (5% of these folks will develop dementia in 5 yrs)

- **Dementia** = Acquired chronic thinking problems in > 2 areas

- **Deliurium** = Rapid changes in thinking & alertness
  (seek medical help immediately)

- **Depression** = chronic unless treated, poor quality, I “don’t know”, “I just can’t” responses, no pleasure
  can look like agitation & confusion
The Diagnosis of Dementia

- An acquired syndrome consisting of a decline in memory and other realms of cognitive functioning
- At least one of the following deficits
  - Language difficulties (aphasia)
  - Difficulty with common tasks (apraxia)
  - Unable to identify common objects (agnosia)
  - Disturbance in executive functioning
    - Planning, judgment, decision making

Source: Diagnostic and Statistical Manual of Mental Disorders. DSM-IV
Alzheimer’s Disease

- First described by Alois Alzheimer in 1906
- Described pathologic changes
- Emil Kraepelin coined the term Alzheimer’s disease

(1864-1915) Auguste Deter

Alzheimer’s Disease Pathology

Amyloid plaques and neurofibrillary tangles (NFT).

Natural history of Alzheimer’s Disease

- Early diagnosis
- Mild-to-moderate
- Severe

Alzheimer’s Disease in Down Syndrome

- “In not a few instances, however death was attributed to nothing more than general decay—sort of precipitated senility”. Fraser and Mitchell (1876)
- Senile plaques seen in brains of those with DS. Jervis (1948)
- Uncommonly can have rapid progression and death.
- Late onset seizures were evident in 73.9%; with epilepsy dx at mean age of 55.4, and interval of about ½ year following dx of dementia.

<table>
<thead>
<tr>
<th>Age</th>
<th>Percentage with clinical signs of dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>30's</td>
<td>2%</td>
</tr>
<tr>
<td>40's</td>
<td>10-15%</td>
</tr>
<tr>
<td>50's</td>
<td>33%</td>
</tr>
<tr>
<td>60's</td>
<td>50-70%</td>
</tr>
</tbody>
</table>


Hypothetical model of AD pathophysiological cascade

- Diagnosis of I/DD and Dementia

- Suspicion that pathologic decline in cognitive function is occurring; must be aware of prior baseline level of functioning
- Avoid Diagnostic Overshadowing
- Use of early warning screening and EDSD
- Neurocognitive assessments
- Workup and rule out/rule in accurate diagnosis
- Empiric diagnosis; Possible, Probable, Definite
- Usage of Biomarkers
Diagnosis of I/DD and Dementia

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Alzheimer’s Disease Biomarkers

AD Progression

- CSF Abeta42
- CSF tau
- FDG PET
- Amyloid Imaging
- MRI Hipp
- Pre-Symptomatic
- eMCI
- iMCI
- Dementia

- CSF Abeta42
- CSF tau
- Amyloid Imaging
- MRI Hipp
- Pre-Symptomatic
- eMCI
- iMCI
- Dementia
Percent persons with Down syndrome showing evidence of neurofibrillary tangles (NFT) and senile plaques (SP) at autopsy.


Representative Amyloid Scans in DS and AD

Challenges to diagnosis and care

- Individuals with I/DD may not be able to report signs and symptoms
- Subtle changes may not be observed
- Commonly used dementia assessment tools are not relevant for people with I/DD
- Difficulty of measuring change from previous level of functioning
- Conditions associated with I/DD maybe mistaken for symptoms of dementia - Diagnostic overshadowing
- Aging parents and siblings
- Lack of research, education, and training

Realistic Goals of Dementia Treatment

- Attenuate cognitive and functional decline
- Prevent / decrease behavioral and psychiatric symptoms
- Delay nursing home placement
- Lengthen period of self-sufficiency
- Reduce caregiver burden
Community Care Needs of Adults with ID and Dementia

- Dementia is a condition that lessens an individual's ability to self-direct and be left alone – thus long-term living on one's own may not be an option as the disease progresses.
- Aging in Place/In Place Progression/Aging Out
- What are the needs?
  - In home supports (to family caregivers and the person)
  - Advanced planning for alternative care
  - Diagnostic, medical and behavioral health care
  - Support groups for caregivers (family or staff)
  - Dementia capable community housing
  - Day care programs and respite for family caregivers
  - Usage of technology/telehealth

Change in Focus of Supports Provided

- Maintaining skills
- Stabilizing the environment
- Minimizing choices
- Giving reassurance
- Personal care
- Assessing and meetings medical needs
- Meaningful activities

Staff Levels and Training

- Appropriate levels of staffing
- Dementia specific training
- Maintaining and preserving skills vs. learning new skill
- Pain recognition and management
- Addressing concerns about reactions and actions related to the disease
- End of life care, the dying process and grieving for themselves and roommates
Support for Grieving and End of Life Care

- Support teams for staff and roommates
- Pastoral care for families, staff and roommates
- Staff discussions around their beliefs and concerns
- Families values and beliefs around death and dying
- Utilizing hospice and palliative care
- Arrangements for final farewells

Thank You!!
The Toolworks Story
Connecting Ability to Opportunity—Growing up with social enterprise
Presenter: Kristy Feck, CEO

Prologue- How Toolworks’ founder’s crazy idea became a movement

Chapter 1- Social enterprise and the triple net: market, money and mission
http://www.youtube.com/watch?v=gGYXutfUhy8

Chapter 2- Seeing what needs to be done: developing cultural competency to serve the Deaf and hard-of-hearing
http://www.youtube.com/watch?v=3iRmyyQcO2E

Chapter 3- Listening to the experts: increasing capacity through consumer input
http://www.youtube.com/watch?v=2Tn4Gp1UMWw

Chapter 4- Connecting to the community: strategic partnerships to further impact
https://youtu.be/KzwujI7TWQA

Epilogue- The next 40
Mayor’s Office on Disability (MOD)

Carla Johnson, Director
March 4, 2016

Disclosure Statement

I have had no financial relationship with the industry in the last twelve months and have nothing to disclose.

AGENDA

- About MOD
- ADA Basics
- Independent Living
- MOD’s Collaboration with the Community
- Opportunities for People with Developmental and Learning Disabilities
Mission & Objective

Mission: To ensure that every program, service, benefit, activity and facility operated or funded by the City is fully accessible to, and useable by, people with disabilities.

Objective: Ensure that the City is compliant with the Americans with Disabilities Act (ADA) and other federal, state, and local access codes and disability rights laws.

Four Primary Programs:

1. Architectural Access
2. Programmatic Access
3. Disaster Planning for People with Disabilities
4. Supporting the Mayor’s Disability Council

ADA BASICS

- Equal Opportunity
- Full Participation
- Economic Self-Sufficiency
- Independent Living
Independent Living

- Housing
- Transportation
- Continuing Education
- Employment
- Community Connections

Collaboration

- Mayor’s Disability Council
- MUNI Multi-Modal Accessibility Advisory Committee
- Paratransit Coordination Committee
- ADA 25 Celebration

Opportunities

- Disability Access to City Employment Task Force (DACE)
- Internships
- Disability Disaster Planning Committee
- Crisis Intervention Training Work Group
- Technology Council
Contact Information

Mayor’s Office on Disability
1155 Market Street, 1st Floor
San Francisco, CA 94103

Office: (415) 554–6789
FAX: (415) 554–6159
TTY: (415) 554–6799
Carla Johnson Direct: (415) 554–6785
Carla.johnson@sfgov.org
PROMOTING TRANSITION AND MAXIMIZING POTENTIAL
by Heidi Seretan

What is transition?

• A community based program for students 18-22
• Focuses on functional life skills like: money math, budgeting, job training, volunteering, riding Muni and navigating San Francisco, cooking, and creative expression
• Promotes independence and self-determination
• Facilitates students in discovering their passions
• Emphasizes setting goals and following dreams
• Prepares students for a fulfilling and successful future
• Supports students through post-secondary placement in a job or vocational program

Our Mission Statement

AccessSFUSD: The Arc is a community based program for students 18-22 with disabilities. We focus on teaching functional life skills within the community setting.

San Francisco IS our campus.

We strive to help students discover their passions, unlock their potential, and become involved members of the community. We offer an individualized program that works with each student's goals and interests to further develop their skills, gain vocational experience, and to create self-determined individuals who are active in their community.
HOW DO WE PROMOTE TRANSITION & MAXIMIZE POTENTIAL?

PREPARATION STARTS BEFORE STUDENTS EVEN BEGIN

Preparing students for transition before they begin

What is Transition?

Transition is a process of moving from one stage of life to another. It can be

- Learn about health and communities, and about things like

- Learn about treatment plans and the different roles.

- Learn more about the environment and the beauty of life.
Preparing families for what to expect

What is Transition?

Transition is a post-high school program where students participate in functional, community-based training and education. Transition helps prepare students with disabilities to enter adult life with the skills they need to be as successful and independent as possible. Students learn a range of skills, including living, travel, self-care, social, communication, and safety skills. Transition seeks to prepare students to be active and contributing members of their communities.

Transition is for any student in the school district who receives special education services, has an Individualized Education Program (IEP), and will NOT receive a high school diploma upon completing high school. Transition students must be between the ages of 16 and 22.

STUDENT DIRECTED PROGRAMMING

Interest surveys in planning schedule

Student Interest Survey for: 

Please rate your interest in each of the following categories with 1 being your first choice and the highest number being your last choice. Please put an “X” next to any activity that you do not feel comfortable participating in.

Activities

1. Working with kids at a child development center
2. Dining security at a job site
3. Working with teens and helping with activities
4. Retail: Organizing and hanging clothes
5. Grad/Office work, filing, scanning, computer work (independent contractor skill required)
6. Food service
7. Grocery store: cleaning, organizing, packaging bulk items

Volunteer Sites

[Checkboxes for different volunteer sites are listed here.]

[Space for comments or additional information is provided.]
Student Led IEPs

Setting long term goals

KOICHI'S IEP SCRIPT

TRANSITION GOALS:
Upon completion of school I will take classes at City College.
Upon completion of school I will get a job working with people.
Upon completion of school I will help take care of sick dogs.

PRESENT LEVELS:
Strengths: Hip hop dancing, drawing, using the computer, YouTube, picking up clothes at home, math, following a routine at work, following a schedule.

Preferences: I like directions nice and slow. I like routine and to have a set schedule.

RIGOROUS FUNCTIONAL ACADEMICS
Teaching crucial skills for 60-90 minutes per day on site to be reinforced in the community.
Crucial Skill Areas

- Conversation Skills
- Functional Math
- Goal setting
- Personal portfolios
- Functional Reading
- Current Events
- Wellness
- Job Skills
- Social Skills
- Community Building

THE MAJORITY OF EACH DAY IS SPENT IN THE COMMUNITY

Travel Training

Travel Training Checklist

Running Route:
- Use a timer to practice route
- Plan phone or use electronic signs to identify key arrival time
- Vow to smooth reading of schedule/roadmap
- Use a map to practice
- Know all the stops

Setting the Bus Route:
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops

At the Bus Stop:
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops

At the Bus Door:
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops

At the Bus Exit:
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
- Plan for key stops
Internships promote independence

- Teach important life skills
- Offer real world experience
- Learning basic routines helps promote mastery
- Opportunity to work with various mentors and supervisors
- Build on existing strengths
- Promote relationships and increase social interactions with peers and co-workers
- Prepares for future jobs and careers
- Promotes diversity
- Have opportunities to learn from experts in a field

Learning job skills

Contributing to the community
Goals for our students

- Learn valuable job skills
- Increase independence
- Develop relationships
- New passions and interests
- Pride, ownership, and membership as part of the Exploratorium team
- Be prepared for competitive employment

FOSTERING SELF-ADVOCACY SKILLS

Performing at City Hall
Advocating at MAAC and City Hall

Meeting Senator Leno

Speaking at School Board meetings
POST SECONDARY PLANNING IS ONGOING FOR ALL 4 YEARS
What are the post secondary options?

- Competitive employment
- Supported Employment or Training
  - Golden Gate Regional Center (GGRC)
  - Department of Rehab (DOR)
- Adult Day Program
  - Community Based
  - Intensive 1:1 Services
  - Job Coaching
- Continuing Education

Getting to know what post secondary options are out there

Collaboration is key
Family collaboration

- Heavily involved in student’s individual education plan (IEP)
- Visiting adult programs
- Having social worker attend IEP meetings
- Regular communication with the family
- Accountable for goals outside of school

Collaboration with the community

- Having a social worker at every IEP
- Having receiving agency attend IEP in student’s last year
- Getting students on waiting lists and visiting programs
- Creating a personal portfolio for student to take with them to their adult program

FOR FURTHER INFORMATION:

Heidi Seretan
heidiseretan@gmail.com
415-867-9502
WorkLink: Creating meaningful lives for people with disabilities

UCSF Developmental Disabilities Conference
March 4, 2016
Sara Murphy

How do we help people with I/DD to become active, productive members of our communities?

WorkLink’s Services

- Program Goals: 1) Maximize Independence, 2) Build skills, 3) Direct Hire Employment
- A menu of braided services — allows us to build service plans to order
- 100% Community-based
- WORK Focused — value adding
- Individualized, person-centered
What People Want in Life

- Employment (money & self-worth)
- Engagement in community & friends
- A happy home, a sanctuary
- Health
- Choices/options
- Freedom & Independence
- Meaningful lives

Meaningful (adj.): full of meaning, significance, purpose, or value; purposeful; significant: a meaningful wink; a meaningful choice

- Dictionary.com

Community-based Support Services

- Explore interests
- Develop social and professional networks
- Gain independence, self-confidence
- Learn hard/soft skills
- As natural supports are developed, program services fade
Adding Value and Building Skills

Volunteering

Creating Meaningful Lives

Anna

- Employed at GAP 9 hrs a week. Earns $12.53/hr plus stock options
- Learning to cook at Project Open Hand
- Swimming & Zumba @ 24 Hour Fitness
- Volunteers for Save the Redwoods
- Independently travels on bus/Metro all over town
- Loves the Karaoke bars in Japantown

CUSTOMIZED EMPLOYMENT

Our focus is on STRENGTHS, not deficits
Help Wanted


Call for an application.

We must re-frame how we see individuals with disabilities.

See DISABILITY as human variance

Reframing: ROY (aka the Tornado)

What the file said:
- Bombed out of 3 programs/5 jobs
- AD/Hyperactive
- Moderate/severe ID/DD
- Can’t sit still, can’t focus
- Anger management issues, behavior problems
- Limited academic skills
- Low motivation
- Stubborn

What we said:
- Physically active guy
- Very, very outgoing
- Has to move
- Hates getting up in the mornings
- Loves variety
- Can match numbers and use site words
- Opinioned, passionate
- Gearhead-loves expensive cars
Roy's VENN Diagram

Use VENN diagrams to target employment settings based on candidate's unique characteristics.

- Good with his Hands
- Fast Paced, Lots of Variety
- Loves Expensive Cars

Employee of the Year
Divisadero Car Wash

CUSTOMIZED EMPLOYMENT
It Works!
### WorkLink Employment Outcomes

<table>
<thead>
<tr>
<th>2015</th>
<th>Distances</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Number Working</td>
<td>21</td>
</tr>
<tr>
<td>Ave. Hour/week</td>
<td>19 hours/wk</td>
</tr>
<tr>
<td>Range of Hours</td>
<td>4 to 40 hours</td>
</tr>
<tr>
<td>Range of Wages</td>
<td>$12.25 to $22.86/hr.</td>
</tr>
<tr>
<td>Average Wage</td>
<td>$13.65/hr.</td>
</tr>
<tr>
<td>% of Successful Closure (transfer to Habilitation)</td>
<td>95%</td>
</tr>
<tr>
<td>Number of Placements in 2014 &amp; 2015</td>
<td>4</td>
</tr>
<tr>
<td>In Link Development</td>
<td>7</td>
</tr>
</tbody>
</table>

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#### Alvin, Patient Transporter
*Kaiser Permanente/San Francisco*

---

#### Jessie, Development Assistant
*American Conservatory Theater*
Karen, Packer/catering support
*Bi-Rite Markets*

Enrique, Office/lab assistant
*Diadexus*

Delmy, Housekeeping
*Equinox*
Simon, Office Clerk, Phillips, Spallis and Angstadt, LLP

Simon’s Path to Success

• Started in volunteer jobs learning hard & soft skills
• Polished skills in professional setting (Project SEARCH KP)
• Now employed as a clerk at PSA, 18 hrs a week, $16/hr.
• Day Services continue 12 hours/wk: Koret House (laundry & cleaning), Let’s Get Lost (problem solving), POH (initiation & communication)

“The greatest danger may not be that our aim is too high and we miss it, but rather that it is too low and we reach it.”

- Michelangelo
For more information, contact:

Sara Murphy
TransCen, Inc./ WorkLink Program
785 Market Street, Suite 670
San Francisco, CA 94103
415.979.9520
smurphy@transcen.org
www.transcen.org
UCSF Developmental Disabilities Conference
Promoting Transition & Maximizing Potential for Youth & Adults with DD in San Francisco

Kevin Hickey, Director of High School and Bridge Programs

Faculty Disclosure: I have no conflicts to disclose

JVS Overview

- JVS transforms lives by helping people build skills and find jobs to achieve self-sufficiency
- Founded in 1973 – more than 40 Years of Transforming Lives!
- Nonprofit & Non-Sectarian Organization
- Who Do We Serve? San Francisco Bay Area job seekers entry level to executive level with focus on youth with barriers, individuals with disabilities, long term unemployed and other groups

Work Transforms Lives

Career Pathway Programs for Adults

Our most robust programs for adults focus on industries that offer career pathways and a living wage.

- Skills to Work in Healthcare
  - Nursing Refresher, Medical Administrative Assistants, Non-Clinical Hospital Jobs
- Skills to Work in Financial Services
  - BankWork$ for entry-level sales and service positions in the banking industry
- Skills to Work in Technology
  - Salesforce Administrator Training
  - Digital Marketing
  - More to come!
High School and Bridge Programs

- Focus on youth with disabilities, foster youth, and youth at-risk of not graduating high school
- Imbedded in San Francisco Unified School District
- Serve ~600 youth/year
- Achieve ~300 paid internship/job placements per year

High School & Bridge College & Career Framework Goals

- Transition Plan & Supports
- Priority Sectors
  - Early Child Education
  - Building Construction Trades
  - Environmental Technology
  - Customer Service
  - Healthcare

Multiple Entry Points
Multiple Exit Points

Work Transforms Lives

High School & Bridge College and Career Framework

- Placement & Advancement in Priority Sectors
- Early Child Education Certification
- Building Construction Trades Certification
- Environmental Technology Certification
- Customer Service Certification
- Healthcare Certification
- Entry Level Jobs
- On the Job Training
Children and Youth Fund
Prop C, 2014

• In November of 2014, the Children and Youth Fund was reauthorized by SF voters through June 30, 2041. The revamped Children and Youth Fund included several revisions to the original Children's Fund, including increasing the age of eligible youth to 24, an increase in the size of the fund and the establishment of DCYF's Oversight and Advisory Committee.

• DCYF Oversight and Advisory Committee

• Next Meeting Thursday, March 10th at 6pm, 1390 Market Street, Suite 900

For more information:
Kevin Hickey
khickey@jvs.org

www.jvs.org
Supported Employment
City of Seattle
Department of Human Resources

Heather Weldon
Program Manager

TODAY at the City of Seattle

- 97 employees with IDD
- 80% of opportunities are in office settings
- $15.90/hr average wage + benefits

It all started with...

- "Embedded" job developer funded by Vocational Rehabilitation
- 30 jobs for people with IDD in city departments within 18 months
Initial Challenges

1. Funding 30 positions
2. Unions
3. Building partnerships
4. Job title / FTEs
5. Customizing jobs
6. Finding supporters
7. Marketing the idea

What’s the Secret to Seattle’s Success?

Thinking Differently

CREATING A NEW UNDERSTANDING
Reversing Priorities

1. Marketing the idea
2. Finding supporters
3. Customizing jobs
4. Job title / FTEs
5. Building partnerships
6. Unions
7. Funding 30 positions

Marketing the idea
Making the business case:
- Inclusive workplaces
- Cost savings
- Support/training
- Improved workflow
- Team-building
- Reducing turnover of entry-level jobs
Building an “army” of support

- Finding hiring managers who say “yes”
- Building partnerships
- Unions – Labor Relations
- Funding 30 positions

Customizing...

- Job classification/title, customized job descriptions, FTEs
- Interview process
- Onboarding

Philosophical Issues

*It is quick and simple to create impact via mandate, but the outcomes are far more sustainable and meaningful when they are achieved by people reaching a new understanding.*

*The changed mind.*
3 Ingredients for Success

1) Focus on workplace needs

2) Art of Language: How we talk about anything defines it

3) Building an army of support – make it bigger than YOU!

The City Wins...

The Supported Employment program offers city departments a creative and cost-effective approach to meeting business needs while diversifying and expanding the workforce to include people with IDD
Down Syndrome: Transitions

Nancy Roizen, MD
Division Chief, Developmental-Behavioral Pediatrics & Psychology
UH/Rainbow Babies and Children’s Hospital
Professor, Case Western Reserve University CWRU

Disclosure
Research funded by the Alana Foundation on the use of memantine for improved cognition in Down syndrome

GOAL
• To learn about the realities of transition to adult care and adulthood for a person with DS in order to better inform them and their families on how to best prepare for the most positive outcome.
Objectives

• To understand the issues in transitioning to adult care for an adolescent/young adult with SHCN
• To see where we are with transitioning adults with DS to adult care
• To appreciate the employment opportunities for adults with DS
• To add to the picture the social environment for adults with DS

Topics: DS

• Transition Issues & Models
• Medical Transition & Health
• Employment
• Social

TRANSITION ISSUES & MODELS
Transition: To Adulthood

• The purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care system

Who are we talking about?

• Children with Special Healthcare Needs (CSHCN) are defined by the Maternal and Child Health Bureau as: "Those who have one or more chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally" (e.g. asthma, obesity, SCD, CF, DS, developmental and/or behavioral problems).

Be Mindful of Barriers

• 1) Adolescent: feel abandon, time to develop confidence in new doc; anxious adolescent & parents
• 2) Pediatrician: protective; adult colleague insufficient experience
• 3) Internists, Med-Peds, Family Med: not welcome due to lack of training & financial liability
• 4) Transfer may be an event
• 5) Gap in medical education at all levels

(Sawyer et al. 1997; Sharma et al. 2014)
Transition: 112 Internists’ Concerns

- **Patient**: maturity, psychosocial needs, family involvement, family’s hi expectations
- **Providers'** medical competency, transition coordination, lack adolescent training, disability/end of life issues in adolescence & early in relationship
- **Health systems issues**, financial pressures limiting visit time, adult subspecialists

(Per et al. 2009)

Wisdom of Carl Cooley, MD

- “…health care transition to adult care is a systemic problem in our health care system and needs to eventually have systemic solutions that make the handoff a quality measure for pediatricians and for adult providers receiving young adults into their practices…”

Models

- 1) Disease focused subspecialist to adult subspecialist (e.g. CF, SCD,DS)
- 2) Primary care-based coordinated by PCP
- 3) Transfer to adolescent services or transition services and then to an adult provider
Quick Survey of DBPs

<table>
<thead>
<tr>
<th></th>
<th>Dept. wide</th>
<th>Leader</th>
<th>Date</th>
<th>Adult transition</th>
<th>Tr plan</th>
<th>Complex</th>
<th>Special Clincs</th>
<th>Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-N</td>
<td>Tr plan</td>
<td>Med-P</td>
<td>yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-MW</td>
<td>Med-P</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>ASD,CF,SCD, heart</td>
<td></td>
</tr>
<tr>
<td>3-NW</td>
<td>yes</td>
<td></td>
<td></td>
<td>SCD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4-SW</td>
<td>yes</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>ASD,CF,SCD</td>
<td></td>
</tr>
<tr>
<td>5-S</td>
<td>Tr plan</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-MW</td>
<td>Tr plan</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7-MW</td>
<td>Med-P</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>COR, CF, SB</td>
<td></td>
</tr>
<tr>
<td>8-W</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>9-S</td>
<td></td>
<td>X</td>
<td></td>
<td>DS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10-MW</td>
<td>Med-P</td>
<td>yes</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>ASD, CF, SCD</td>
<td></td>
</tr>
<tr>
<td>11-W</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12-MW</td>
<td>Med-P</td>
<td>yes</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

CF Doing this for 20 years

“There are always hiccups, but overall things go pretty well in transitioning CF patients to adult providers. Basically, the transition process begins at diagnosis when we teach the family about CF. Towards the end of our education sessions we go over how our team is constructed in both the adult and pediatric areas. We then explain to the families that we usually transition patients to adult providers between their 18th-23rd birthdays. Starting at about age 13 we discuss transition again once a year at the big visit where they get all of their annual labs and assessments.”

You are an Adult

“Once they turn 18, we go to an adult type appointment. The parents wait in the waiting room if they come to a visit, and I see the patient alone in the exam room. Once we are done, I tell the patient we will bring his/her parents into the room, and I will only divulge the information that the patient wants me to divulge. To be honest, most don’t really care what I tell their parents, but some do. During the last year before transition, the patient will be seen by both my adult colleague and me for a couple of visits to get the patient acclimated.”
Medical Transition & Health

Adults with DS are Living Longer

- 80% adults with DS reach 50th birthday (WHO 2015)
- Life expectancy increased from 12-60 yr/60 yr

Health Care: Significant Factors

<table>
<thead>
<tr>
<th></th>
<th>Total: 205</th>
<th>Adult care: N=99 (48%)</th>
<th>Mixed care: N=106 (52%)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median age: 1st encounter</td>
<td>28 (19-37 yrs)</td>
<td>35 (27-39 yrs)</td>
<td>20 (18-30 yrs)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Cong heart dis</td>
<td>98 (43%)</td>
<td>9 (9%)</td>
<td>80 (76%)</td>
<td>0.001</td>
</tr>
<tr>
<td>Hypothyroid</td>
<td>106 (52%)</td>
<td>50 (51%)</td>
<td>56 (53%)</td>
<td>0.74</td>
</tr>
<tr>
<td>Atlanto-axial instability</td>
<td>15 (7%)</td>
<td>7 (7%)</td>
<td>8 (8%)</td>
<td>0.9</td>
</tr>
<tr>
<td>Annual charges</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No in-patient</td>
<td>$2,305</td>
<td>$2,876</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospitalized</td>
<td>$19,240</td>
<td>$38,301</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Health Care Providers in Adults with DS

<table>
<thead>
<tr>
<th>Primary care Provider</th>
<th>Total: 205</th>
<th>Adult care N=99 (48%)</th>
<th>Mixed care N=106 (52%)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal Med</td>
<td>73 (35%)</td>
<td>48 (49%)</td>
<td>24 (23%)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Pediatrics</td>
<td>21 (10%)</td>
<td>0</td>
<td>21 (20%)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Med-Peds</td>
<td>14 (7%)</td>
<td>6 (6%)</td>
<td>8 (8%)</td>
<td>0.67</td>
</tr>
<tr>
<td>Family Med</td>
<td>93 (45%)</td>
<td>41 (41%)</td>
<td>52 (49%)</td>
<td>0.27</td>
</tr>
<tr>
<td>General Pract</td>
<td>3 (1%)</td>
<td>1 (1%)</td>
<td>2 (2%)</td>
<td>0.28</td>
</tr>
<tr>
<td>Non-Primary Care Specialty</td>
<td>4 (2%)</td>
<td>3 (3%)</td>
<td>1 (1%)</td>
<td>0.3</td>
</tr>
</tbody>
</table>

Jensen et al., 2012

Most Frequently Used Med Sp

- Pediatric cardiology 41%*
- Adult neurology 21%
- Otolaryngology 19%
- Orthopedic surgery 12%
- Ophthalmology 11%
- Adult GI 14%*

*no diff accessing ped cardio(adult=0%; mixed 78%, P<0.001); adult GI (adult=20%, mixed=9%, P=0.02)

Frequency Medical Problems

<table>
<thead>
<tr>
<th>Type</th>
<th>Percentage</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dental</td>
<td>97%</td>
<td>Periodontal/untreated caries</td>
</tr>
<tr>
<td>Obstructive sleep apnea</td>
<td>94%</td>
<td></td>
</tr>
<tr>
<td>Ophthalmic</td>
<td>46-100%</td>
<td>Increase with increased age &amp; decreased IQ</td>
</tr>
<tr>
<td>Hearing loss</td>
<td>64-97%</td>
<td>Increase with increased age &amp; decreased IQ</td>
</tr>
<tr>
<td>Seizures</td>
<td>40%</td>
<td>3rd decade</td>
</tr>
<tr>
<td>Thyroid dysfunction</td>
<td>37%</td>
<td>Hypo/hyper</td>
</tr>
<tr>
<td>Orthopedic</td>
<td>37%</td>
<td>Cervical spondiosis; asymptomatic AAI</td>
</tr>
<tr>
<td>GI problems</td>
<td>Celiac, reflux, constipation</td>
<td></td>
</tr>
<tr>
<td>Mental health</td>
<td>24%</td>
<td>Increased depression; decreased schizoph.</td>
</tr>
<tr>
<td>Cardiac</td>
<td>0.8%</td>
<td>AV canal repairs; mitral regurgitation</td>
</tr>
<tr>
<td>Testicular CA</td>
<td>OR:3.7-4.8</td>
<td></td>
</tr>
</tbody>
</table>

Steingass et al, 2011
Unlike CF We Have Intellectual Disability In the Mix

Cognitive Function: Range 20-70

<table>
<thead>
<tr>
<th>AGE/IQ (Carr, 1988, 2000, 2008)</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 months</td>
<td>Leiter at 30 yrs age equivalent: 5yr 6 mo</td>
</tr>
<tr>
<td>4 years</td>
<td>Mild 41%</td>
</tr>
<tr>
<td>11 years</td>
<td>Moderate 27%</td>
</tr>
<tr>
<td>21 years</td>
<td>Severe 18%</td>
</tr>
<tr>
<td>30 years</td>
<td>Profound 13%</td>
</tr>
<tr>
<td>40 years</td>
<td>Cognitive fx peaks at 50 yrs of age (Mantry, 2008)</td>
</tr>
</tbody>
</table>

DS Adult: Healthy

- Sandy at 40 yrs of age has not had significant health problems. He attended early intervention and graduated from special education at 21 years of age. He lives with his parents and uses public transportation to his full time job as a mail clerk. He is actively involved in his church, plays piano, and swims regularly.
DS Adult: + Med Problems

- Jack who has DS and ADHD was born with feeding problems that resulted in failure to thrive necessitating tube feeding. VSD treated surgically <1 yr and congenital glaucoma corrected at 10 mo. He was recently sedated for much needed ophthalmic and dental exams. At 32 yrs of age, Jack works in a sheltered workshop and 3 years ago after the untimely death of his mom moved to a group home. Then, last year, his dad died. He likes Beatles music and plungers.

EMPLOYMENT

Online Survey Un/employment DS

- NDSC, NDSS, GDSF & national parent support netwks
- 511 survey responses
- Age: 18-61 yrs; 72% 18-30; 22% 31-50; 1%>51
- Current:
  - Paid job 56.6%
  - Volunteer job 25.8%
  - Self-employed 2.8%

(Kumin & Schoenbrodt, 2015)
**Amount of Paid Work**

- Hours/wk  
  - 1-5 h  
  - 6-10 h  
  - 10-20 h  
  - 21-30 h  
  - >30 h  

  - Percentage  
  - 21%  
  - 12%  
  - 26%  
  - 10%  
  - 3%

- **Type:** competitive 65%, 21% sheltered wk, 3% self-employed, 12% other  
  
  (Kumin & Schoenbrodt, 2015)
HOW A PAID JOB WAS FOUND

Parents, friends, family 28%
Rehabilitation agency 24.4%
School district 14.7%
Employment agency 7.9%
ARC/Community organizations 5.6%
Independent 4.1%
Other 3.6%
Sheltered workshop 2.9%
Internship 2.2%
Job coach, post-volunteer, post-secondary training <2%
Newspaper ads, religious groups <1%

(Keunin & Schoenbrodt, 2015)

### Volunteer Work

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Activities</th>
<th>Activities</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>11%</td>
<td>Office/clerical work</td>
<td>Recreation/entertainment</td>
<td></td>
</tr>
<tr>
<td>10%</td>
<td>Schools/childcare</td>
<td>Recreation/entertainment</td>
<td></td>
</tr>
<tr>
<td>9%</td>
<td>Church</td>
<td>Food service/food pantry</td>
<td></td>
</tr>
<tr>
<td>7%</td>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6%</td>
<td>Hospital/medical</td>
<td>Residential homes/elderly</td>
<td>Non-profit</td>
</tr>
<tr>
<td>4%</td>
<td>Janitor/landscape/recycle</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3%</td>
<td>Animals</td>
<td>Library</td>
<td></td>
</tr>
<tr>
<td>2%</td>
<td>Program/agency</td>
<td>Special needs</td>
<td></td>
</tr>
<tr>
<td>1%</td>
<td>Public service</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Social Family Life

Living Arrangements
Social

- **Social Network:** family, community organizations with DD, religious groups
- **Recreation:** solitary, puzzles, watching TV
- **Romance:** 20% dating & 1.6% married/partner
- **Visiting with Family & Friends:**
  - 50% weekly
  - 30% <yearly

Family Life & Living Arrangements

- **Older Sibs Care for Aging Parents & sibs w/DS**
- **DS Advantage:** less family conflict and less burden & stress with caregiving than other disabilities
- **Living arrangements:**
  - 20s and 30s living with parents
  - Older: group homes
  (Steingass et al., 2011)

Summary

- Transition to adult health care is a system issue which requires a system solution
- Adults with DS who have complex medical problems are slower to transition
- More than half of adults with DS have a paid job with 3% working more than 30 hrs
- Social life and family life varies greatly
References


References

- Resource: www.gottransition.org
  www.woodbinehouse.com
UCSF Developmental Disabilities
15th Update for Health Professionals

New Dentistry?

Paul Subar, DDS, EdD - Associate Professor, Dental Practice
Director Special Care Clinic, Pacific Dugoni SOD

Allen Wong, DDS, EdD - Professor, Dental Practice
Director Hospital Dentistry and
AEGD Residency Program, Pacific Dugoni SOD

Disclaimer

- neither speakers are paid by any company or have financial interests in any of the products mentioned
Brief outline

- Overview of the Dental Scenario
- Overview of IDD and Dentistry
- Overview of the New Sciences in Dentistry
- Example of implementation of Prevention
- Review of some cases
- Questions

Overview IDD and Dentistry

- Most unmet need for IDD population?
Overview of Dental Trends (some)

- CAD/ CAM
- ICAT
- Implants
- Sleep Apnea
- Corporate Dentistry
- ACA

People

ADA commissioned strategic plan 2013

- “The population is getting older and more diverse, leading to different disease patterns, care-seeking behaviour and ability to pay.”

- Consumers are more astute purchasers of health care and seek value
Providers

- Increased number of dentists being trained...increase debt load
- Pressure growing for expanded dental team and preventive/ restorative services

Payments

- payment for dental services shifting from commercial dental insurance to public coverage and out of pocket
- Commercial dental plans increase selectivity, accountability and pressure provider to reduce costs
Policies

- ACA pediatric dental benefits will provide millions of additional children with coverage...optional Medicaid expansions
- Public programs, with a growing number of participants will increased accountability from dental providers

Practice implications

- increase demand for value = need for practices to be efficient
- trend toward larger, multi-site practices, increase competition of dentists for patients
- emphasis on outcomes and cost effectiveness of offices/ alternative models of dental care
New Dentistry?

- CAMBRA
- GI
- SN
- SDF

Case Examples

- no pictures for outline
Questions

Thank you!

- Paul Subar:  psubar@pacific.edu
- Allen Wong:  awong@pacific.edu
Exploding Genetic Knowledge in Developmental Disabilities

How to acquire the data and how to make use of it

Elliott H. Sherr MD PhD
Professor of Neurology & Pediatrics
UCSF

Disclosures

- InVitae: clinical advisory board
- Personalis: consultant
- Grants received from:
  - NIH
  - NHMRC (Australia)
  - Simons Foundation
  - John and Marsha Goldman Foundation

The Genetic Principle

- Genome = 3.1 billion letters of DNA
- Genome = 20,000 genes in it
- Gene: stretch of DNA that codes for a protein
- DNA>>>RNA>>>PROTEIN
- Codon: three letter DNA/RNA sequence that codes for a single amino acid
- DNA duplicates by conservative replication of double stranded molecule
The Genetic Principle

The Genetic Code

Autosomal Recessive
Autosomal Dominant: One gene

Mutations: what are they?

- A genetic change that is deleterious
  - Nonsense
  - Missense
  - Del/Dup
  - Other (promoter, 3’ structure, etc)
- Polymorphism
  - A genetic change that may be positive or negative, but of less clinical impact
  - Each of us has ~3,000,000 polymorphisms and probably 10-20 “silent” mutations
- There is overlap between M & P

X chromosome linked inheritance
Nonsense Mutations

Missense Mutations

Polymorphisms

- If polymorphism is a single DNA letter; it is called a SNP (single nucleotide polymorphism)
- Some SNPs are common
  - A = 80%; C = 20%
  - Usually just two choices
  - Can screen for common changes in large numbers throughout the genome easily
  - Common differences each can contribute a small amount to common diseases
- Some SNPs are rare
  - A = 99.9%; G = 0.1%
  - As a collection these are important for disease
  - Tools for assessing these are advancing rapidly
De Novo Genetic Mutations

- Mutation occurs just in that person
  - Can occur during egg or sperm formation or just after fertilization
- Can be single base pair or chromosomal regions
- Occur more commonly in older parents
- Examples of de novo mutations
  - Down syndrome (trisomy)
  - Prader Willi syndrome (small chrom change)
  - Dravet syndrome (point mutation)

Chromosomal Ideograms

SNP Micro-Arrays Detect CNVs
Whole Exome sequencing

Genetics of Neurodevelopment

### Conditions & Identification
- Down Syndrome (1866)
- Neurofibromatosis (1882)
- Fragile X (1943 & 1969)
- Prader Willi syndrome (1956)
- Smith Lemli Opitz (1964)
- Angelman syndrome (1965)
- Costello Syndrome (1977)
- Pitt-Hopkins syndrome (1978)

### Genetic Discovery; Mechanism
- 1959 De novo
- 1990 AD, De novo
- 1995 X-linked
- 1981 De novo
- 1998 AR
- 1987 De novo
- 2005 AD, De novo
- 2007 De novo

Expanding Number of Genetic Disorders
Expanding Diagnostic Yield in DD

Genetics of Neurodevelopment:
Advancing from research to the clinic

Clinical Report
Marinesco-Sjögren Syndrome in a Male With Mild Dysmorphism
Our Patient in 2004

- Born Term, normal BW, Height and OFC
- Developed GTC Sz at 9 months
- At 1 yr had roseola infection and development was reported to decline after this
- MRI at 23 months: hypoplasia of inferior cerebellar vermis cerebral hemispheres
- Follow up scan at 46 months showed worsening brain atrophy, and smaller optic nerves and chiasm
- NCS: 23 months: sensory neuropathy with delayed conduction, amplitudes normal, EMG normal
- Sural nerve biopsy: thinly myelinated and 30% loss of axons
- Loss of milestones, with cessation of speech.
- Phys Ex: mild dysmorphism: hypertrichosis, synophryus, deep-set eyes with epicanthal folds, flat philtrum. Muscles had a doughy texture. Nystagmus with titubation, limb hypertonia, reduced reflexes, but plantar response was extensor.

Diagnostic Eval on Patient C.O.

- Metabolic Testing—negative
  - VLCFA, Phytanic Acid, plasmalogens
  - Lactate, pyruvate
  - Plasma lysosomal enzymes
  - CK, CDG, NCL
- Genetic Testing—negative
  - MELAS, MERRF, NARP, SCA6,7,8; DRPLA, Friedreich ataxia
  - Karyotype, Subtel, Microarray
- ECHO, skeletal survey
- Pause: Focus on clinical management
  - Labeled as MSS—neuropathy variant

Exome Sequencing for C.O. in 2014

- KIF1A
  - R216H, c.647 G>A
  - Zygosity: Het; inheritance: De Novo
  - Kinesin: motor protein that travels on microtubule "tracks"
- NID1
  - T408K, c.1223 C>A
  - Zygosity: Het; Inheritance: De Novo
  - Nidogen: binds extracellular matrix
Progressive Volume Loss In KIF1A de novo Dominant Mutation Carriers

KIF1A: Sites of Mutations

Kinesin moving a vesicle on MT
Gliding assay

https://valelab.ucsf.edu/images/movies/mov-invmtglid.mov

Functional Consequences: Kinesin Mutations

WT
V220I - Polymorphism
A255V - Recessive
T99M - De novo
E253K - De novo
R216C - De novo
MT Speeds in WT and Mut KIF1A

Lab Questions: Autism & Neurodevelopment

Summary
SOCIAL COGNITION IN PEOPLE WITH AUTISM: ROLE OF NEUROPEPTIDES

Karen J. Parker, PhD
Department of Psychiatry and Behavioral Sciences

March 4, 2016

Faculty Disclosure Statement

- Nothing to disclose

Talk Overview

- What is autism?
- Challenges for understanding and treating autism
- Neuropeptide biomarker studies in patients with autism
- Neuropeptide treatment trials in patients with autism
- Monkey model: Naturally occurring social impairments
Autism Spectrum Disorder (ASD)

Core social cognition impairments
- Eye contact, joint attention
- Recognize and respond to emotions in others
- Understand others’ intentions
- Reciprocal social interactions; peer relationships

Three Cases: Same Disease Mechanisms? Same Therapeutics?

IQ of 165
- Math precocious, perfect pitch
- Socially interested – one friend but often bullied
- Comorbid anxiety and depression
- Impaired prosody
- Restricted interests (trains, dogs)
- Adherence to rigid routine

Average IQ
- Socially avoidant
- No friends, impaired social interactions
- Delayed language acquisition
- Repetitive speech
- Restricted interests (computers)

IDD
- Non-verbal
- Severe language delay
- Primitive gestures
- Restricted interests (trains, dogs)
- Hand-flapping, head-banging
- Sensory abnormalities (noise)
- Comorbid epilepsy and aggression

ASD: Challenges and Barriers to Progress

- **Behavioral therapies**: expensive and variably effective
- **Drug therapies**: No effective therapeutic for social deficits
  - Existing drugs treat associated features (irritability); side effects
- **Basic biology of autism not well understood**
  - Difficult to directly study disease biology
  - Human genetic studies will not experimentally unravel mechanisms
  - Few valid animal models
- **Why is biomarker identification important?**
  - Identify subtypes
  - Enable (potentially very) early detection
  - Provide a biological target for drug development
  - Provide a predictor of prognosis or treatment response
Parker Lab Overview:
Social Neurosciences Research Program

Clinical research in children: Biomarkers of social functioning
Drug therapies to treat social deficits

Preclinical research in young monkeys: Monkey model of social impairments
Understand basic biology, test therapeutics

“Back Translation” “Forward Translation”

http://med.stanford.edu/parkerlab.html

Biomarker Discovery for Autism
Neurobiological systems critical for adaptive social functioning are the most promising candidates: OXYTOCIN

“Mother Love: What Turns it on?”
- Klopfer 1971

Oxytocin receptors are highly concentrated in brain areas involved in social behavior

Insel and Shapiro 1992, PNAS
Oxytocin Administration Enhances Social Cognition in Humans

- Gazing at eyes
- Reading the Mind in the Eyes
- Sharing others’ emotional states

Decreased amygdala response to fear-inducing stimuli

“Oxytocin-Deficit” Hypothesis of Autism

Prior Blood OXT Studies:
- 3 studies: OXT levels ASD < Controls
- 1 study: No difference
- 1 study: OXT levels ASD > Controls

Various Limitations:
- Small study cohorts
- Normative data for control OXT levels
- Non-gold standard assay techniques
- Non-gold standard methods for ASD diagnosis
- Did not examine OXT x social behavior
- No sibling analyses to assess “broader autism phenotype”

Genetic variability in OXTR gene: A risk factor for ASD?

- Association studies: Several SNPs/haplotype blocks increase risk for ASD
- Genome-wide scans: 3p25 region may be associated with ASD
- Candidate gene studies: Intronic OXTR SNPs (rs2254298 and rs53576) in neurotypical and various patient populations implicated in social functioning
Study Design and Participant Recruitment  
(with Drs. Hardan, Hallmayer, Phillips)

- *Children ages 3 to 12 years*
  - N=79 with ASD
  - N=52 unaffected sibs
  - N=62 neurotypical controls
- *IQ > 50; In good medical health*
- *ASD:*
  - DSM-IV-TR; confirmed by ADOS and ADI-R
- *Non-ASD:*
  - No history of psychiatric problems
- **Blood collection**
  - OXT levels; OXTR gene variants
- **Social functioning**
  - Vineland, NEPSY-II, SRS

Specific Aims

- **Aim 1: Test the prevalent but not well interrogated “OXT-deficit” hypothesis of ASD**
  - Are blood OXT levels lower in children with ASD? Are sibling OXT levels intermediate?
  - Affected by sex and/or OXTR SNPs?
- **Aim 2: Do blood OXT levels and OXTR SNPs:**
  - H1: Interact to produce ASD social phenotypes?
  - H2: Exert Differential Social phenotypic effects in ASD?
  - H3: Have similar social phenotypic effects independent of disease status?

No Group Differences in Blood OXT Levels

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Parker et al 2014, PNAS
Blood OXT levels: Predict social functioning in all children

Children with autism who have lower oxytocin levels are at increased risk for social deficits

OXTR genetic variants: Predict social functioning in all children

Children with autism who have certain OXTR variants are at increased risk for social deficits

OXTR Numbers: Diminished in Autism and Related to Social Impairments

Parker lab, unpublished data
OXT Biomarker Studies: Summary and Thoughts for Informed Treatment Trials

- Blood OXT levels and OXTR genotypes contribute to the severity of social deficits in children with autism
- Diminished OXTR gene expression is related to ASD and variation in social functioning
- Who is most likely to benefit from OXT treatment?

Six Published OXT Treatment Trials

Stanford Intranasal Oxytocin Treatment Trial

Our study:
- Boys and girls ages 6-12
- N=47 signed consents
- N=30 completed

Aim 1: Does oxytocin treatment enhance social functioning in children with autism?
**Stanford Intranasal Oxytocin Treatment Trial**

Aim 2: Do pre-treatment measurements (e.g., type/severity of social impairments; blood-based biomarkers) predict treatment efficacy?

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**Arginine Vasopressin (AVP; aka ADH): An unexplored ASD biomarker and therapeutic**

**Animal research:**
- AVP vs. OXT selectively enhances social functioning in male rodents
- Selective AVPR1a antagonists impair social functioning even in the presence of normal OXT signaling in mice, rats, and voles
- AVPR1a in primate extended neural amygdala – not oxytocin!

**Human neurotypical research:**
- Enhances memory for happy and angry social information
- Enhances identification of social words
- Enhances cooperative behavior

**Human clinical research:**
- Enhances speech/word formation (post-stroke aphasia)
- Improves short/long-term memory (central diabetes insipidus)

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**Blood vasopressin levels positively predict theory of mind scores in children with autism**

Carson et al 2015, PLOS ONE
First Intranasal Vasopressin Treatment Trial

Our study:
Boys and girls ages 6-12 years
N=50 signed consents
N=20 completed

Aim 1: Does vasopressin treatment enhance social functioning in children with autism?
Aim 2: Do blood-based biomarkers predict treatment efficacy?

ASD: Challenges and Barriers to Progress

- Need better animal models
  - Mouse models (deletion of 16p11.2; duplication of 15q11-13) do not show social deficits
  - Complex social cognition most relevant to ASD simply not present in mice
  - Gene expression and brain anatomy differ significantly in rodents vs. humans and monkeys

Human Genetics Evidence Points to Benefits for Studying “Naturally Occurring” Social Deficits

Genetics of Autism, 2016

Genetic Burden is largely polygenic;
Can engineer a Fragile-X but not a polygenic monkey

Constantino & Todd
Arch Gen Psychiatry. 2000;57(5):524-531
Naturally Occurring Social Impairments in a Rhesus Macaque Population

Monkey social behavior:
- Like humans, stable individual differences in social behavior
- At the extremes: low social vs. high social male monkeys
  - Initiate and receive fewer affiliative interactions
  - Solicit grooming less
  - Spend less time grooming and playing with conspecifics
  - Display more inappropriate social behaviors
  - Diminished social interest and less social competence
- Where and how to rapidly identify extreme monkeys?

Where to Develop the Model?

The California National Primate Research Center Resource:
- 5,000+ rhesus monkeys
- Large cohort = greater number of monkeys at the extremes
- Housed in outdoor ½ acre corrals
- Mixed M/F groups of 90-175 animals
- All ages; study across lifespan
- Bred to preserve genetic heterogeneity
- How to rapidly and accurately identify the extremes?

BBA as a High-Throughput Screening Tool? Predicting the Social Extremes
Proof of Concept Study

- Male monkeys aged 2-5 years selected from BBA database predicted to be high or low social functioning
- Streamlined observations of social behavior (16 focal follows):
  1) Confirm predicted social functioning
  2) Compare groups on candidates biomarkers
- CSF and blood samples from high social and low social monkeys:
  1) Neuropeptides critical for social functioning
  2) Kinase signaling pathways implicated in syndromic forms of ASD

Preliminary Data:
Biomarkers Correctly Classify Monkeys by Group

- Receiver Operating Characteristics
- 93% correct classification

Preliminary Data:
Diminished AVP signaling in low social monkeys

- Table of CSF Concentration
- Oxytocin and Vasopressin levels:
  - Low vs. High:
  - P=0.5481 vs. P=0.0296
Preliminary Data:
CSF AVP predicts socially motivated behavior

![Graph showing correlation between Vasopressin CSF Concentration and time spent social grooming.](image)

Future Directions for Monkey Model

**Behavioral Testing:**
- Create sophisticated social behavior tests to assess type and severity of deficits
- Social behavior tests should assess core features of autism (unlike rodent tests)
- Do females show similar social deficits?
- Can we identify infants “at risk” for poor social outcomes?

**Drug Testing:**
- “Fast Fail” therapeutic screening tool (efficacy and safety) in low social monkeys
- Test long-term safety of candidate compounds in low social monkeys
- Test prophylactic therapies in “at risk” animals

Conclusions

- **Neuropeptide biomarker studies in people with autism**
  - OXT and AVP are biomarkers of social impairments in people with autism and may help identify “types” of autism and “personalized” medications

- **Neuropeptide treatment trials in people with autism**
  - Hold promise; need to identify who responds and why

- **Monkey models**
  - Naturally occurring social impairments, and engineered ones: Indispensable for understanding disease biology and testing novel medications
Acknowledgements

PEOPLE:
Antonio Hardan MD, John Capitanio PhD, Elliott Sherr MD PhD, Joe Garner PhD, Joachim Hallmayer MD, Jennifer Phillips PhD, Carl Feinstein MD, Sonia Partap MD, Annie Penn MD PhD, Alex Urban PhD, Ozge Oztan PhD, Dean Carson PhD, Deb Karhson PhD, Valentina Scalani PhD, Josh Herrington PhD, Jesus Madrid, JoAnn Yee, Laura Del Rosso, Laura Calonder, Robin Libove, Sean Berquist, Shelle Hyle, Erna Tarara, Parker Lab undergrads, CNPRC staff, patients and families

FUNDING:
http://med.stanford.edu/parkerlab.html
Maternal Depression & Health: Impact on Child Development: Putting Research into Practice

Carol D. Berkowitz MD FAAP
2016 Developmental Disabilities: Update for Health Professionals
March 4, 2016

• I have no conflicts of interest or financial disclosures.

Postpartum Depression: The image in the media
Perinatal Maternal Mental Health: Learning Objectives

- Prevalence and spectrum of perinatal mood and anxiety disorders (PMADs)
- Number of infants affected by PMADS
- Effect of PMADs and parental toxic stress on infants and children
- Role of pediatricians in the evaluation and care of families with PMADs and toxic stress
  - Screening
  - Trauma-informed care

Broadening the Focus: Not Just Post-Partum Depression

- Perinatal: Expand the time
  - Preconception period
  - Pregnancy
  - First year of infant’s life
- Mood Disorders: Expand the conditions
  - Depression
  - Anxiety
- PMADs: Perinatal Mood and Anxiety Disorders
- Other mental health problems

Perinatal Maternal Mental Health: Depression

- Incidence varies with the population studied
- WHO: Depression 4th leading cause of disease burden
- Estimated rates range from 5-25%
  - Fewer than 1% identified
- Higher in certain groups: 40-60%
  - Low-income women
  - Pregnant and parenting teen-agers
  - Mothers of multiple births
- Peak incidence for major depression: 6 weeks
- Peak incidence for minor depression: 2-3 months
- Second peak at 6 months
Perinatal Maternal Mental Health: Depressive Symptoms

• “Baby blues”: 50-80% of new mothers
  – First days after delivery
    • Resolves in 1-2 weeks
    • No DSM V categorization
    • Doesn’t impair function
    • May predict later depression
  – Tearfulness
  – Mild sadness
  – Anxiety
  – Irritability for no reason
  – Increased sensitivity
  – Fatigue
  – Mood swings

Perinatal Maternal Mental Health: Depressive Symptoms

• Post-partum depression (PPD)
  – Meets criteria for depression in DSM V
    • Deep sadness, crying spells, hopelessness
    • Social withdrawal
    • Changes in appetite and sleep
    • Excessive worrying and fears
    • Irritability or short temper, mood swings
    • Feeling overwhelmed, very emotional
    • Decreased concentration, difficulty making decisions
    • Mixed emotions about the baby
  Doesn’t recognize as separate entity, only as specific onset
  – DSM V TR Must begin within 4 weeks of delivery
  – At risk for up to 1 year

Perinatal Maternal Mental Health: Psychosis

• Post-partum psychosis (PPP)
  – Affects 1-3/1000 deliveries
  – First 4 weeks after delivery
  – Infanticide rates 4%
  – Severe impairment
    • Paranoia
    • Mood shifts
    • Hallucinations
    • Delusions
    • Suicidal and homicidal ideation
    • Usually requires hospitalization
    • May have pre-existing bipolar disorder
Peripartum psychosis:
The Headlines

LA Times May 2014

• Carol Coronado, the woman accused of killing her three young daughters inside her West Carson home, pleaded not guilty Thursday to three counts of murder and one count of attempted murder

• Local
  • Mom Accused Of Throwing Infant Son Off Garage Pleads Insanity
    • January 2, 2013 1:03 PM

Perinatal Maternal Mental Health: Mood Disorders

• Postpartum depression with anxiety
• Panic disorder
• Postpartum post traumatic stress disorder
• Postpartum obsessive/compulsive disorder
  – 5%: intrusive thoughts of harming the baby
• Post partum bipolar disorder

Maternal Mental Health: Risk Factors

• Can affect anyone!!
• Medical: infertility history, birth trauma or complications, substance abuse, perinatal loss
• Psychiatric: personal or FHx; loss of mother
• Social: IPV, poverty, homelessness
• Populations: adoptive moms, recent immigrants, military, LGBTQI, single or teen moms
Maternal Mental health: Adoptive Mothers
- Stress and anxiety during the adoptive process
- Fears about genetic or environmental (drugs) factors
- Biologic mom may take the baby back
- Issues related to prior infertility
- Less support from family (failure to provide a biologic grandchild)

Prior Infant Loss (Miscarriages, Perinatal, SIDS)
- Timing of the loss
  - 1st trimester vs 3rd trimester
  - Did you name the baby yet?
- Timing till the next pregnancy
  - Normal grief and mourning
- Guilt about factors surrounding the death
  - Genetic disorders
  - Co-sleeping death

Intimate Partner Violence
- IPV more likely during pregnancy than at any other time
- Violence more likely than hypertension or diabetes
- Homicide is the leading cause of death during pregnancy
- Toxic stress for the mother
Military Families

- PPD reported in 50% of military mothers
- Increased risk of depression and anxiety in military fathers
- Preterm delivery (5X more common in active military women)
- Frequent moves
- Extended spousal absence
- Limited social support
- Stigma of seeking mental health services

Perinatal paternal depression

- Increasingly recognized
- May be more difficult to recognize
  - Covert or masked depression
- Men less likely to seek help
- Men less likely to have access to healthcare providers in an on-going basis

Perinatal Paternal Depression: Manifestations

- Lowered stress threshold
- Increase aggression
- Burnt out, feeling empty
- Irritable, restless, frustrated
- Workaholism
- Withdrawal
- Feeling excluded from mother-infant relationship
Maternal Mood Disorders:
The infant/child

- 400,000 infants born to mothers who are depressed
- Potential adverse effect on infant development
  - Attachment
  - Bonding
  - Impairment of social skills
  - Developmental delay
  - Changes in MRI of brain
  - Adverse effects can be avoided with early recognition and intervention
  - May persist through ages 4-8 years, and beyond

How does maternal mental health affect their infants and children?

- Mirror neurons: reciprocal relationships
- Adverse childhood experiences
- Cumulative toxic stress
- Unintentional neglect

The role of relationships

- Humans fundamentally depend on relationships
- Humankind has spent 99% of its history living in small, intergenerational groups
- The impetus for relationships is biological
- Biologically humans are interdependent not independent
- Relationships are critical in crafting how we respond to stress: *Mirror neurons*
Importance of Maternal Responsiveness

- The persistent absence of responsive care disrupts brain development
- The brain is experience dependent
- Skill begets skill
- Serve and return serve

Peripartum depression: The infant/child

- Language development
  - Language acquisition related to number of words spoken by family
  - Fewer words/fewer interactions in family with depressed mom
  - Look at depressed mom less
    - Classic findings of FTT infant
    - "Infant becomes apathetic and fails to thrive"

Peripartum depression: The infant/child

- Attachment disorders
  - Insecure attachment
  - Risk of later conduct disorder
  - Risk of later behavior disorders
Peripartum depression:

The infant

- Increased child cortisol level at school entry
  - Internalizing behaviors
    - Anxiety
    - Wariness
    - Withdrawal

Adverse Childhood Experiences

- Questionnaire sent to 13,494 adults: 9,508 responded: Had undergone medical exam at Kaiser
- > 50% had at least 1 ACE
- 25% had >2 ACEs
- Increased ACEs, increased health risks
  - > 4: 4-12 x alcohol, drug abuse, depression, suicide
  - 2-4 X smoking, poor health, >50 sexual intercourse partners, STIs


Adverse Childhood Experiences: ACEs

- 7 categories of specific childhood events
  - Psychological abuse
  - Physical abuse
  - Sexual abuse
  - Violence against mother
  - Substance abuse in household
  - Mental illness or suicide in household
  - Incarcerated household member(s)

Adverse Childhood Experiences: (ACEs)

- alcoholism and alcohol abuse
- chronic obstructive pulmonary disease (COPD)
- depression
- fetal death
- health-related quality of life
- illicit drug use

- ischemic heart disease (IHD)
- liver disease
- risk for intimate partner violence
- multiple sexual partners
- sexually transmitted diseases (STDs)
- smoking
- suicide attempts
- unintended pregnancies

So what can you do as a pediatrician???
GET THE CONVERSATION STARTED!
Peripartum Maternal Mental Health: Screening for PMADss

- Screening felt to be within the scope of pediatric practice
  - Moms comfortable with being asked
  - Rate of screening <50%
  - Concern re diagnosis and management
  - Concern that the parent is not the patient
    - Can I bill?
  - Peds see moms sooner and more often than ob-gyns
    - Ob-gyns not comfortable dx’ing depression
    - (Ob-gyn 2006;107:642-7)
  - Screen at least at 2 weeks and at 6 months (maybe more often)

Peripartum depression: The role of the pediatrician

- Characteristics of pediatric practices supportive of screening
  - Older pediatricians
  - Provider child mental health services in practice
  - White patients
  - Use ≥ 1 method to address maternal depression
  - Practice in Midwest
  - Believe important to the child’s well-being
  - Do at Kaiser in Northern California at every WCC visit


Parent Health Questionnaire: Getting the Conversation Started

- Depression is a common but treatable condition that occurs more often among parents. Many parents who experience depression don’t realize they have a medical condition and could benefit from treatment.
Edinburgh Post-Partum Depression Scale: EPDS

- Developed 1987
- 10 question screen completed by the mother
- Maximum score 30
- Score ≥10 indicates risk of depression
- Question 10: suicidality: positive screen
- In public domain; free; downloadable: English and Spanish
Parent Health Questionnaire: The Questions

• For this reason, please take a minute to respond to the 2 statements below. We'll then take a look at your responses together during the visit.
• Over the past 2 weeks, you have felt down, depressed or hopeless (true or false).
• Over the past 2 weeks, you have felt little interest or pleasure in doing things (true or false).
• If true, have you felt this way for (several days, more than half the days, or nearly every day)?

Screening for Postpartum Depression in the PED

• Compared EPDS with 3 question version of EPDS (Bronx, NY)
  – Mothers (N=194) of infants < 6 months
  – 23% full EPDS
  – 34% 3 question EPDS
  – + screen associated with number of children < 5 years in home
  – + screen associated with food/housing concerns

  – Arninghem et al. Pediatr Emerg Care 2011;27:796-800
Preventing PMADs: Dried Placenta!!

Really??

• We are the only mammals who do not eat the placenta.

Value of Home Visitation

• Supportive figure
• Potential for screening
• New moms or all moms?

Peripartum Depression:
Other Points to Ponder

• Reimbursement for screening of parents
  — More states providing incentives (IL, NJ)
• Does screening lead to any difference in outcome?
  — Only if you have access to resources
• Is there medical liability related to screening?
  — The infant not the mother is the patient
• Should women continue SSRIs during pregnancy?
  — Who’s knowledgeable enough to decide?
• Should women with a prior history of peripartum depression start SSRIs immediately after delivery if breast-feeding?
Peripartum Maternal Mental Health: What to do with a Positive Screen?

- **Referrals**
  - Studies suggest that intervention (meds, referral) often lacking
  - Obstetrician: refer back to them for care
  - Mental health providers
    - May not have access because of insurance
    - Primary care doctors: helpful if the mom has a physician
    - Community mental health services
    - Crisis intervention for suicidality or high Edinburgh score

Move toward team-based care

- Have a mental health clinician co-located in the primary care clinic or the office
  - Consider having a social worker or case manager at a minimum
- Eisner model at LAC USC
  - Social worker and psychiatrist present in family medicine clinic

Use of Psychopharmacology

**Pregnancy**

- No anti-depressants specifically FDA-approved for use during pregnancy
- All anti-depressants cross the placenta (never Category A [no risk])
- Non-teratogenic in animal studies
- Risk of untreated depression vs SSRIs
Use of Psychopharmacology

Potential risks

• Paroxetine (Paxil) – CHD (RV outflow tract)
  – Increased risk of septal heart defects from 0.5 to 0.9% (any SSRI)
• Increased risk of pre-term delivery
  – Increases from 6% to 22%
  – Untreated maternal depression increases the risk to 20%

Use of Psychopharmacology

Potential Risks

• Poor Neonatal Adaptation (PNA; Neonatal Abstinence Syndrome)
  – Respiratory distress, irritability, jitteriness, hypotonicity, poor latching and feeding seizures (rare)
• Persistent Pulmonary Hypertension
  – Increased from 1/1000 to 6/1000
• Increased risk of Autism Spectrum Disorder
  1% (study not yet replicated)

Use of Psychopharmacology

Breastfeeding

• Low levels get into breast milk
• Levels undetectable in infant blood
• Most experience with sertraline (Zoloft) and paroxetine (Paxil)
• If mother stable on another medication, recommendation is to continue that medication (visit medication website)
NOT JUST PMADS, BUT TOXIC STRESS

Adverse Childhood Experiences

• How does a high parental ACE score impact on parenting and health of the child?
• Should parents complete an ACE questionnaire when their child is being seen for the first time?
• Would this represent “trauma-informed care”?
• At what point should children/adolescents complete an ACE questionnaire?
• 2 generational approach to ACEs: cumulative toxic stress

ACEs and Toxic Stress

• Positive Stress
  — Tough test at school

• Tolerable Stress
  — Death of a loved one

• Toxic Stress
  — Sexual abuse, physical abuse
  — Living with a terrorist
Consequences of toxic stress

- Hypothalamic-pituitary axis
  - Dyregulation by ventral tegmental area, reward center
- Immunologic
  - Increased interleukin, TNF α, interferon gamma
  - Altered microbiome
- Endocrine
  - ↑ cortisol, adrenaline
- Epigenetic
  - Short telomeres (early aging)
- Circulatory
  - ↑ plasma vascular endothelial GF, total peripheral resistance
  - Biomarkers for stress in the saliva and blood

Pediatrics and Trauma-Informed Care

- Recognize the “invisible” baggage of families
- Consider using screening tools as part of routine practice
- Identify toxic stress
- Promote resilience
  - AAP Center on Healthy, Resilient Children
- America’s Promise
  - Grow up with the help and guidance of a caring adult
  - Healthy childhood
  - Safe surroundings
  - Effective education
  - Opportunities to serve

Pediatrics and Trauma-Informed Care

- Getting a conversation going as a pediatrician
  - Listening is therapeutic
  - When something becomes speakable, it becomes tolerable
  - “Since the last time I saw you and your child, has anything really scary or threatening happened to you or your child?”
  - “What have you done for fun since the last visit?”
  - “How are you and your partner getting along?”
Pediatrics and Trauma-Informed Care

• Focus on the symptoms and not the history
  – Rule something out, not in
  – When something bad happens, you have 3 choices:
    • You can let it destroy you.
    • You can let it define you.
    • You can let it strengthen you.
• Notion not of referral but of collaboration
• Trauma-informed care defined by the actions taken
• Need to include parents: Parent Management Training

Peripartum Maternal Mental Health: What to do next

• Include infant/child in treatment plan
  – Circle of Security
    • Video-based intervention; attachment theory; strengthen caregiver giving
  – Parent-Child Interactive Therapy
  – Parent-Child Psychotherapy
    • Increase attachment

Peripartum Depression; Resources

• Parental Depression Screening for Pediatric Clinicians: An Implementation Manual: Ardis Olson M.D.
  – www.cmwf.org
• Depression During and After Pregnancy: A Resource for Women, Their Families and Friends
  – www.mchb.hrsa.gov/pregnancyandbeyond/depression
• Reducing Maternal depression and its Impact on Young Children
  – National Center for Children in Poverty
  – www.nccp.org
Welcome. Postpartum Support International is dedicated to helping women suffering from perinatal mood and anxiety disorders, including postpartum depression, the most common complication of childbirth. We also work to educate family, friends and healthcare providers so that moms and moms-to-be can get the support they need and recover. You are not alone. You are not to blame. With help, you will be well.

Peripartum Depression:
Resources: www.postpartum.net
1-800-944-4PPD

www.postpartum.net

- Go to site
- Click on get help
- Click on map for location
- Click on “email” for region
- You will get a reply in 24 hours

Pediatrics and Trauma-Informed Care

- It is unlikely that a pediatrician would be the sole therapist
- Many referral possibilities
- Many on-line sites/programs
- National Child Traumatic Stress Network (NCTSN.org): established by Congress
- The California Evidence-Based Clearinghouse for Children (www.cebc4cw.org) Children and families in the child welfare system
Enhancing Early Intervention: Putting Research Into Practice To Serve Infants, Toddlers & Their Families

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Keck School of Medicine
University of Southern California
Children’s Hospital Los Angeles

Disclosures

Nothing to Disclose!

California Families
Infants & Toddlers: Birth to Three

- 1,500,000 babies birth to three
- 34,000 Early Start families with babies with special needs
California Early Start State Eligibility
Infants & Toddlers: Birth to Three

33% Developmental Delay:
- motor
- communication
- cognitive
- adaptive
- social or emotional functioning

Established Risk: Probability of delay

California Early Start State Eligibility
At Risk: 2 Biomedical Factors
- Low birth weight
- Assisted ventilation
- Small for gestation
- Asphyxia
- Prenatal exposure
- Neonatal seizure
- CNS lesion
- Failure to thrive

California Early Intervention Services Act
Early Start

Family service system for infants, toddlers and their families that coordinates health, developmental, educational and social services that are culturally competent and responsive to family-identified needs.

--- CEISA, Title 14, §95001
California Early Start Families
Infants & Toddlers: Birth to Three

- Audiology
- Nursing
- Nutrition
- Occupational Therapy
- Physical Therapy
- Psychology
- Social Work
- Speech & Language
- Family Training
- Family Counseling
- Service Coordination
- Transportation
- Vision Services
- Assistive Technology
- Health Service
- Medical Services

Part C Federal Requirements
California Early Start Program

- $53 million federal support, with $256 M from state general fund = $309,000,000
- Federal mandates, including Performance Plan and Annual Report on 10 indicators of compliance
- 2014 Added Requirement of a State Systemic Improvement Plan addressing an outcome for high interest but low performance indicator

State Systemic Improvement Plan (SSIP)
2020 Achievable Measureable Result

- Improves outcomes for infants and toddlers and their families
- Based on State data and Stakeholder input
- Recommended by the State Systemic Improvement Plan Task Force
CA State Identified Measurable Result
Social and Emotional Development By Three

- Turns to caregivers for TLC, solace, attention & guidance
- Manages emotions & behaviors to developmental expectations
- Has the initiative to explore, discover, learn & make friends

State Identified Measurable Result
Social and Emotional Development

- Stakeholder Input
- State Data
- Critical preschool inclusion indicator
- Infant brain research

State Identified Measurable Result
Social and Emotional Development

- Infant brain research: mother-infant relationships play a crucial role in long-term outcome
1997 White House Conference
Brain Development in Young Children
Insights on Early Mother-Child Nurturing Relationships

- Influence how the intricate circuitry of the brain is wired
- Influence extremity and frequency of stress levels of cortisol
- Interpersonal interaction, not sensory stimulation, as the key to healthy development

Infant/Family Mental Health
Relationship as the Centrality of Development

Maternal Emotional Availability
Infant Emotional Availability
Mother-Infant Relation-ship

Early Caregiving
Relationships Matter!

- Every child needs a close intimate bond with at least one person who is sensitive to his needs and responsive to his cues.
Infant/Family Mental Health
Relationship as the Centrality of Development

- Infant Emotional Availability
- Mother-Infant Relationship

Infant Emotional Response Vulnerability
Neurobehavioral Sensitive Status

- Prematurity
- Low birth weight
- Substance exposure
- Special health care needs
- NICU experience
- Antenatal depression

NICU Infant Experience
Neurobehavioral Impacts

- Sensory over-stimulation
- Repeated medical procedures
- Pain
- Parental separations
- Multiple caregivers
Antenatal Depression, Trauma & Anxiety
Neurobehavioral Sensitive Status

- Prenatal distress acts through the placenta to alter fetal development
- Prenatal distress predicts increased behavioral reactivity and cortisol in response to novelty in infants.
  --- Monk et al, 2012

Infant Emotional Availability
Neurobehavioral Status that Influence Relationships

- Organization of engagement behavior
- States of arousal
- Sleeping regulation
- Crying consolability

Infant/Family Mental Health
Relationship as the Centrality of Development

Maternal Emotional Availability
Mother-Infant Relationship
Mother as Regulator

- Requires regulation of own emotional state
- Requires understanding/attunement to infant’s internal state
- Requires positive social supports

Motherhood is NOT an Innate Skill

- Survey of new mothers .......
  - 46% found it hard to care for their baby
  - 61% found motherhood harder than expected
  - 20% believed their babies had the motivation to be angry with them

- Motherhood is learned from a community of moms & home support!
Social Capital

- Benefits derived from personal social relationships that influence parenting
  -- Desmond Runyon, 1998

Social Capital that Supports Parenting Adapted

- Presence of 2 parents or parent-figures
- Social support for maternal caregiver
- Number of children relative to family emotional resources
- Neighborhood support
- Regular church/synagogue/mosque attendance by the family

Where is the Community of Moms and Home Support!

Life in the 21st Century

- Smaller families of origin
- Single parenthood
- Separation from families of origin
- Neighbors in the workforce
- Down church, temple, mosque attendance
**How Do Infants Learn Healthy Crying, Sleeping and Feeding Patterns?**

- Parents play an important role in setting up the neural circuitry that helps infants learn to regulate their behavior.  
  — Bruce Perry

- Who is helping the mothers with sensitive babies with special needs?
- Who is helping the overwhelmed, anxious, depressed mother?

---

**Mothers of Babies with Delays, Disabilities and Biomedical Risks**

- May be first time moms
- May be experiencing anxiety or depression
- May be alone
- May be worried about family circumstance
- May be experiencing birth-related posttraumatic stress disorder

---

**Maternal Psychosocial Stressors: Family Stability and Family Harmony**

- Economic worries: shelter, food, health care
- Family discord
- Family illness
- Family separation
- Ethnic discrimination
- Community violence
Maternal Stress/Trauma Circumstances

Risks to Post Traumatic Stress Disorder

Living in Fear!

- Undocumented status
- Domestic violence
- NICU experience

"Trauma causes an emotional concussion to the brain"

California’s Challenging Family Circumstances

- 24% live below federal poverty level
- 46% babies live in low income families
- 32% live in single parent families
- 45% babies born to foreign-born mothers
- 10-15% on new mothers experience postpartum depression

California’s Challenging Family Circumstances

- 19% of mothers did not finish high school
- 12% live in families with parents who are unemployed
- 23% of babies experience high mobility
- 65% of babies have at least one risk factor known to increase the chance of poor health, school & developmental outcome
Maternal Depression/Anxiety/Trauma
Prolonged Effects if Severe & Complex

- The notion of CUMULATIVE RISK asserts that the greater the number of biological and social-environmental negative circumstances, the greater is the risk for negative developmental outcomes for mother & infant.

Maternal Depression/Anxiety/Trauma
Severe Effects with Multiple Stressors

- History of depression
- Poverty
- Single, isolated parenthood
- Stressful life events
- Conflictual relationship with baby’s father
- Infant health & development problems

- Impact of maternal depression, anxiety and trauma on infant – mother relationships
Maternal Emotional Availability
Infant Emotional Availability

Mother-Infant Relation-ship

Infant/Family Mental Health Relationship as the Centrality of Development

- Sad, under-stimulating & withdrawn
- TLC devoid of affect
- Tense facial expressions and handling
- Inconsistent caregiving rituals & routines
- Less gentle touching & stroking
- Lack of contingent responding to infant cues
- Blunted brain response to crying baby

Patterns of Depressed Parenting Responses to Cries and Cues

Consequence of maternal depression
- Infants withdrawn and less active
- Infants become fussy
- Infants with shorter attention
- Elevated heart rates and cortisol levels
- 75% with less frontal brain activity
- Greatest risk between 6 and 18 months

--- Dawson, 1994; Fields, 2010
Infant Brain-Behavior Relationships

- What does infant brain research tell us about child neurobehavioral sensitivity, family discord, stress, distress proneness & the regulation of behavior?

Behavior is Communication!

- Infants who experience antenatal stress may have more sensitive & reactive nervous systems
  ---- Monk et al., 2012

- Infants and young children who chronically experience stressors within the home may have more sensitive and reactive nervous systems!
  ---- Jack Shonkoff,
  Early Childhood Summit, 2010

Stress Raises Cortisol Levels
Toxic Stress
Increased Levels of Cortisol

- Destroys brain cells & connections between brain cells
- Affects: impulse modulation, emotional regulation, behavioral control

Chronic Stress Becomes Toxic
Can Effect Architecture of the Brain

Impact of Toxic Stress on the Brain

Persistent Stress Changes Brain Architecture

Normal

Toxic

Prefrontal Cortex and Hippocampus

Source: Buhle et al., 2001; Bock et al., 2000
Behavior is Communication!

- Infants and toddlers may respond to chronic stress with inconsolable crying, night awakening, noncompliance, & temper tantrums.

Distress Proneness

- Long periods in high or low arousal states.
- Repeated experiences encoded in implicit memory as expectations of what the world is all about.
- Cortisol leads to altered development of CNS
- Perceived threat overloads the brain’s ‘stress management’ system

Normal and Chronic Stress

- Alarm
- Relaxation
- Chronic Stress
Infant Mental Health Development Project

Impact of Mismatched Caregiving

- Inadequate Caregiver Responsiveness
- Patterns of neglectful and explosive experience
- Elevated stress hormone
- Child behavioral over-reaction
- Neurobehavioral vulnerability
- Toxic stress
- Patterns of hyperarousal
  - easily upset
  - irritable
  - over-sensitive
  - problems sleeping
  - poor concentration
  - clingy
- Surge of stress hormone
- Overinterpretation of non-verbal cues of potential threat
- Brain wired on 'hair trigger' alert

Surge of stress hormone

Maternal Anxiety & Depression Minimized Risk with Protective Factors

- Healthy well nourished baby
- Social capital: Family, faith, friends
- Family resilience: Problem solving
- Parenting self-confidence
- Concrete needs met

Brain-Behavior Relationships Pathways to Infant Mental Health
Roots of Social-Emotional Development
Responsive Meaningful Caregiving

- **Promotion:**
  - Anticipatory Guidance

- **Preventive Intervention:**
  - Special Caregiving Strategies

- **Intervention/Treatment**
  - Mother-Child Dyadic Intervention

- **Family supports**

---

Infant/Family Mental Health Support
For Mothers and Babies

When baby shows...........

- Excessive fussiness & sleep deprivation
- Feeding problems with low weight gain
- Lack of initiating with mom
- Lack of responding to TLC
- Pervasive sadness or withdrawal
- Long & frequent toddler tantrums
- Extreme non-compliance in toddlers
- Overly active with disinterest in play

---

Dyadic Intervention

- Most efficacious treatment approaches will be those that address the needs of the mother, child and their relationship: reduce mother's symptoms and increase her understanding of her infant's internal experience.
Dyadic Interventions

- Infant Massage
- Floortime
- Interaction Guidance
- Parent-child Psychotherapy

Interaction Guidance
Susan McDonough

- Relationship-based approach for “hard to reach” over-burdened mothers
- Assist mothers in gaining
  - enjoyment from their child, and
  - an understanding of child’s development & behavior
- Through an interactive play experience
- Videotaped mother-infant/toddler dyadic play and review with mother

Interaction Guidance
Relationship-based Approach

- Partner with mother: working alliance
- Build on parenting strengths: focus on mother-infant relationship
- Clarify interpretation of infant/toddler cues
- Provide developmental guidance
- Model a supportive, nurturing and caring interactive style with mother
- Respond to request for concrete assistance
Mother-Child Psychotherapy

- For mothers who are struggling with emotional conflicts related to parenting that need to be addressed.
- Internal preoccupations prevent attention to their babies.
- Search for ‘ghosts in the nursery’ that preoccupy mother’s psyche

‘Double Whammy’ Crisis
Maternal Depression & Colicky Baby

- “A fussy baby doesn’t make you sad, it makes you mad.”
- “I just want to open the door, keep running and not come back.”
- “I don’t even know if I like this child.”

Mother-Child Psychotherapy

- Aims at understanding how mother interprets baby’s crying, sleeping, feeding and play behavior.
- Aims at understanding the connection between mother’s experience of her infant and her own relationship experiences, current and past.
Mother-Child Psychotherapy

- The mother's subjective experience of herself as a mother and of herself as a child is explored.
- Observed interactions of mother with her baby in the sessions are used to discuss mother’s affective responses.
- Negative attributions of infant and self are challenged sensitively.

Mother-Child Psychotherapy

- Belief that mother’s behaviors change as her perceptions of self and infant change.
- Used when mother has pressing internal conflict about her situation, displays intense interpersonal affect toward the child, and has the capacity for insight.

Risk is Not Destiny!

- Many perinatal risks decline over the course of development.
- Dyadic interventions play critical roles in helping infants build resilience.
- Focusing on dyadic relationship can improve outcome even if maternal depression/anxiety remains.
Seminal References


Dual Diagnosis: Assessment, Diagnosis, and Treatment

Michael S. Marcin, MD, MSCR
Associate Clinical Professor, UCSF
Assistant Medical Director, AIP LPPi
March 4, 2016

Financial Disclosure:
I have nothing to disclose.

Gratitude:
- Patients, families and caregivers
- Andrew Booty
- Gemi Collins-Bride
- Jim Bourgeois
- Clarissa Kripke
- Gaelen Lombard
- Matthew State
- My Colleagues at GGRC and ARC
Comments about Presentation

• We have a discussion panel following this, which is a great time to ask more involved questions. Please ask if a slide needs clarification.
• Most of the data for the many studies presented are based in the DSM-IV not the DSM-5.
• Nearly all of this presentation is based on other people's hard work. Please see the slide-by-slide Reference Handout provided today. Readability of slides was my main goal for this PPT.

Presentation Outline

• Working Assumptions
• What is Dual Diagnosis?
• Problem Behaviors vs. Psychiatric Disabilities/Disorders
• Why are We Talking about Dual Diagnosis?
• Assessment Tools
• Somatic Treatment Options
Working Assumptions

- Individuals with Dual Diagnosis are INDIVIDUALS
- Seeing persons with DD as anything other than entire persons leads us astray
- Individuals, Providers and Caregivers are doing the best they can on a daily basis
- Looking at available, high quality research data provides an anchor in decision making
- There is a lack of this data across the spectrum of persons with ID as well as persons with PD and especially for those with both, DD.
- Yet, progress is being made

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Defining Dual Diagnosis (? + ? = DD)

- Intellectual disability in DSM-5 involves mental impairments that affect adaptive functioning in three domains impacting completion of everyday tasks:
  - Conceptual domain: skills in language, reading, writing, math, reasoning, knowledge, and memory.
  - Social domain: “empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.”
  - Practical domain: “self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks.”
Defining Dual Diagnosis (? + ? = DD)

- Psychiatric Disability/Disorder: Clinically significant disturbance in cognitive, emotional regulation, and behavior that represents a disturbance in mental functioning that leads to struggles with work, school, family or other social arenas. (DSM 5, American Psychiatric Association, 2013, p. 20)
- Neurodevelopmental Disorders: Intellectual Disabilities + Communication Disorders + Autism Spectrum Disorder + AD/HD + Specific Learning Disorder + Motor Disorders + Other Neurodevelopmental Disorders
- Basically: PD = All DSM 5 diagnoses – some Neurodevelopmental Disorders but keeping others
- Now, you know why everyone is so confused

Defining Dual Diagnosis (? + ? = DD)

- "Dual diagnosis is a conceptualization of comorbidity in adults with an intellectual disability. Co-morbidity refers to the presence of at least two distinct and separate disabilities or pathologies in the same individual. First utilized in the US during the 1970s, dual diagnosis was used to describe mental health problems in adults with an intellectual disability. The term dual diagnosis specifically refers to coexisting intellectual disability and mental disorder."
- Dual Diagnosis = ID +/- Autism + other DSM 5 non-Neurodevelopmental Disorders

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Defining Problem Behaviors AKA Challenging Behaviors (PB/CB)

- People with intellectual disabilities are at higher risk for developing behavior problems.
- Studies have reported that 7–15% of individuals with ID who receive services have severe behavior problems. Thus, 85–93% of people with ID do not show severe behavior problems, regardless of what level of their ID.
- Types of PB/CB are: “aggression towards others, temper tantrums, screaming or shouting, and self-injury.”
- Several authors have suggested that behavior problems may be indicators of psychiatric disorders in individuals with intellectual disability.
- There is a higher incidence of PD in persons with ID who also have PB/CB compared to those without challenging behavior.

<p>| Table 3 |
|----------------------|----------------------|----------------------|----------------------|
| Number of participants in the group with behavior problems and in the comparator group who scored above cut-offs |</p>
<table>
<thead>
<tr>
<th>N</th>
<th>Group with behavior problems</th>
<th>Comparator group</th>
</tr>
</thead>
<tbody>
<tr>
<td>General psychopathology</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bone Screen</td>
<td>70</td>
<td>49 (69.9%)</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>70</td>
<td>9 (12.9%)</td>
</tr>
<tr>
<td>Depressive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bone Screen Depression (H)</td>
<td>71</td>
<td>0 (0.0%)</td>
</tr>
<tr>
<td>Psychiatric Depression (P)</td>
<td>71</td>
<td>11 (15.5%)</td>
</tr>
<tr>
<td>Mood Axis-II</td>
<td>71</td>
<td>2 (2.8%)</td>
</tr>
<tr>
<td>Major</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mood Axis-II</td>
<td>71</td>
<td>12 (16.9%)</td>
</tr>
</tbody>
</table>

Note: These are not cut-off scores for the 75 participants who were assessed with the ADOS. 

" p < 10.85
" p < 10.86
Other Correlations: Level of ID, Symptoms of PD and PB/CB

- More symptoms of PD in those with mild and moderate than those classified as severe and profound ID.
- Those classified as mild/moderate had more symptoms of psychosis and depression than those classified as severe/profound, while other symptoms of PD were more evenly distributed regardless of classification of ID.
- Interesting Correlation Between PD and PB/CB:
  - anxiety → tantrums
  - mania → tantrums, aggression and screaming
  - weakest correlation: self-injurious behavior (SIB)
  - depression → aggression, tantrums and screaming in those classified as severe and profound
  - depression → tantrums and SIB, mild and moderate ID

Hypotheses of Link

- PB/CB may have the same roots that express itself differently sometimes as PD
- Challenging behavior may be an expression of mental illness
- Challenging behaviors may occur in an attempt to stop aversive experiences in PD
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Why focus on Dual Diagnosis?

- Average life expectancy of people with ID is around 60 years. But, for those individuals with mild ID free of comorbid PD, their lives are as long as neurotypical individuals.
- Many studies show that for children and adolescents with ID between 30 and 50% have comorbid PD with a relative risk of having PD with ID of 2.8–4.5.
- The mental well-being of parents of children with ID is more affected by their children’s severity of PD than that of the severity of ID.
- Adults with ID experience comorbid PD at higher rates than other adults; point prevalence is approximately 40% with annual incidence at about 8%.

Why focus on Dual Diagnosis?

- The 1995 Welsh Health Survey found that persons with ID had a higher rate of psychiatric illness (32.2%) than the general population (11.2%).
- People with ID disproportionately contribute to total psychiatric morbidity. Emerson and Hatton in 2007 estimated that the 3% of British children with ID account for 14% of total child and adolescent psychiatric morbidity.
- “Psychosocial masking”
- “Cognitive disintegration”
Examples of Specific Psychiatric Disabilities/Disorders Rates

- 2005 Australian Study looking at the ‘Disability, Ageing and Carers Survey’, 1998 comprising data on 42,664 adults living at home or in care facilities. The prevalence of ID was 1.25%. Rates for disabling comorbid PD were: 1.3% psychosis, 8% depression, and 14% had an anxiety disorder. (E9)
- Two more studies reported a point prevalence of 3% and 2.7% respectively for schizophrenia compared to 0.4% in the general population.
- Interestingly, in another study the point prevalence of depressive disorder ranged up to 3.7%, which is just over a fourth in the general population.
How Does Ageing Affect Those with Intellectual Disability?

- Londoners with ID who are 65 and older showed PD in 74% of those surveyed.
- Those with Down’s Syndrome have higher rates of dementia. In those 65 years or over, 18.3% had dementia, which is 3.9x higher than general population.
- Down’s Syndrome and dementia is associated with more frequent and severe PB/CB
- Dementia progression in people with Down’s Syndrome was demonstrated to be: 45 "to 49 years – 16.6%; 50–54 years – 17.7%; 55–59 years – 32.1%; 60 years plus – 25.6%.
- Increased mortality in those with dementia (44.4%) compared with those without dementia (10.7%).
Dual Diagnosis in Autism

- Higher parent and teacher ratings for ADHD, ODD, aggression, anxiety, and depression compared with neurotypical students.
- Preschoolers through young adults: elevated behavior problems, anxiety, depression, irritability compared to control group. Individuals without ASD but with ID had lower rates of same behaviors when compared with individuals with autism.
- Hurtig et al. (2009) reported greater anxiety, depression, and attention problems in 43 adolescents with HFA/Asperger’s disorder than controls.

A study of 177 children with autism showed elevated scores: 26% depression, 25% anxiety, 25% ADHD, 16% conduct disorder, and 15% oppositional-defiant disorder.

Youth with autism (combining results from two studies):
- 8-44% for specific phobia, 29% social anxiety disorder
- 8-37% for OCD
- 10% panic disorder, 8% agoraphobia
- 2-13% for generalized anxiety disorder
- 28-31% for ADHD
- 13% for depression
- 12% for separation anxiety disorder
- 7-28% for oppositional-defiant disorder
- 3% conduct disorder

| Table A: Percentage of children with ADHD and HFA (n=177) who have specific, oppositional-defiant, and conduct disorders.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific phobia</td>
<td>8-44%</td>
</tr>
<tr>
<td>Social anxiety</td>
<td>29%</td>
</tr>
<tr>
<td>OCD</td>
<td>8-37%</td>
</tr>
<tr>
<td>Panic disorder</td>
<td>10%</td>
</tr>
<tr>
<td>Agoraphobia</td>
<td>8%</td>
</tr>
<tr>
<td>Generalized anxiety</td>
<td>2-13%</td>
</tr>
<tr>
<td>ADHD</td>
<td>28-31%</td>
</tr>
<tr>
<td>Depression</td>
<td>13%</td>
</tr>
<tr>
<td>Separation anxiety</td>
<td>12%</td>
</tr>
<tr>
<td>Oppositional-defiant</td>
<td>7-28%</td>
</tr>
<tr>
<td>Conduct disorder</td>
<td>3%</td>
</tr>
</tbody>
</table>

Some children may have more than one diagnosis.
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What is an Ideal Assessment?

• Avoid “Diagnostic Overshadowing”
• Use multi-method approach evaluating mood, personality, social skills and aberrant behavior
• Review of the client/patient’s records: medical information, illnesses, injuries, recent trauma events, past effective interventions
• Interviews with the individual, parents, teachers, and caregivers asking baseline/changes in adaptive functioning: changes in interpersonal skills, relationships, or communication skills, as well as in daily functioning.
• Observations—frequent behaviors vs. infrequent behaviors. Two methods for infrequent behaviors: Antecedent Behavior Consequence (ABC) and the scatterplot (formal and Calendar Method)
• Use Rating Scales

<table>
<thead>
<tr>
<th>TABLE 2. Properties of Somatic Experience During Life Span</th>
<th>% of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living with the sudden death of a family member or loved one</td>
<td>50%</td>
</tr>
<tr>
<td>Being physically, sexually, or emotionally abused or neglected</td>
<td>55%</td>
</tr>
<tr>
<td>Being threatened, assaulted, or beaten by someone within the family or someone being killed, restrained, or left alone</td>
<td>45%</td>
</tr>
<tr>
<td>Being sexually assaulted by someone not in the family</td>
<td>10%</td>
</tr>
<tr>
<td>Being shown a dead body</td>
<td>67%</td>
</tr>
<tr>
<td>Being exposed to a death or death in another</td>
<td>37%</td>
</tr>
<tr>
<td>Having an attempted rape or sexual assault</td>
<td>1%</td>
</tr>
<tr>
<td>Being physically, sexually, or emotionally abused</td>
<td>5%</td>
</tr>
<tr>
<td>Being in a military conflict or a war zone</td>
<td>2%</td>
</tr>
<tr>
<td>The somatic experiences</td>
<td>7%</td>
</tr>
<tr>
<td>None</td>
<td>25%</td>
</tr>
<tr>
<td>1</td>
<td>15%</td>
</tr>
<tr>
<td>2</td>
<td>10%</td>
</tr>
<tr>
<td>3</td>
<td>20%</td>
</tr>
<tr>
<td>4</td>
<td>30%</td>
</tr>
</tbody>
</table>
Rating Scales: The Gold Standards for Self and Caregiver Reports

- **PIMRA**: The Psychopathology Instruments for Mentally Retarded Adults
- **DASH II**: The Diagnostic Assessment for the Severely Handicapped Scale
- **ADD**: Assessment of Dual Diagnosis
- **RSMB**: The Reiss Screen for Maladaptive Behavior
- **RSCDD**: The Reiss Scales for Children’s Dual Diagnosis
- **CBRF**: The Nisonger Child Behavior Rating Form
- **DBC**: The Developmental Behavior Checklist
- **PAS-ADD Checklist**: Psychiatric Assessment Schedules for Adults with Developmental Disabilities Checklist

---

### TABLE 1. Proportion of Sample Exposed to Life Events During the Last 12 Months

<table>
<thead>
<tr>
<th>Life Events</th>
<th>% of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death of first-degree relative</td>
<td>10%</td>
</tr>
<tr>
<td>Death of close family member or relative</td>
<td>17%</td>
</tr>
<tr>
<td>Moving house or residence</td>
<td>6.4%</td>
</tr>
<tr>
<td>Serious illness or injury</td>
<td>0.7%</td>
</tr>
<tr>
<td>Separation or divorce of a mate</td>
<td>5.6%</td>
</tr>
<tr>
<td>Breakup of steady relationship</td>
<td>5%</td>
</tr>
<tr>
<td>Serious problems with spouse, friend, or relative</td>
<td>3.4%</td>
</tr>
<tr>
<td>Unemployed or seeking job</td>
<td>0.6%</td>
</tr>
<tr>
<td>Sexual problems</td>
<td>4.5%</td>
</tr>
<tr>
<td>Problems with police or other authority</td>
<td>1.7%</td>
</tr>
<tr>
<td>Alcohol problems</td>
<td>1.3%</td>
</tr>
<tr>
<td>Problems with illegal drugs</td>
<td>1.1%</td>
</tr>
<tr>
<td>Lost affiliated from work</td>
<td>0.1%</td>
</tr>
<tr>
<td>Major financial crisis</td>
<td>0.1%</td>
</tr>
<tr>
<td>Separation or divorce</td>
<td>0.0%</td>
</tr>
<tr>
<td>Retirement from work</td>
<td>0.0%</td>
</tr>
<tr>
<td>% life events</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>49.6%</td>
</tr>
<tr>
<td>1</td>
<td>26.4%</td>
</tr>
<tr>
<td>2</td>
<td>12.8%</td>
</tr>
<tr>
<td>&gt;2</td>
<td>6.2%</td>
</tr>
</tbody>
</table>

---

### TABLE 2. Typology of ICD-10 Diagnosis

<table>
<thead>
<tr>
<th>Diagnostic Category</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No ICD-10 disorders</td>
<td>110</td>
<td>62%</td>
</tr>
<tr>
<td>ICD-10 disorders</td>
<td>67</td>
<td>38%</td>
</tr>
<tr>
<td>F00–F02 Schizophrenic, schizotypal, and delusional disorders</td>
<td>16</td>
<td>24%</td>
</tr>
<tr>
<td>F10–F9 F02 Mixed (affective) disorders</td>
<td>23</td>
<td>31%</td>
</tr>
<tr>
<td>F30–F49 Neurotic, stress-related, and somatoform disorders</td>
<td>23</td>
<td>31%</td>
</tr>
<tr>
<td>F50–F59 Behavioral syndromes associated with physiological disturbances and physical factors</td>
<td>4</td>
<td>6%</td>
</tr>
<tr>
<td>F84 Perinatal and perinatal disorders</td>
<td>5</td>
<td>8%</td>
</tr>
</tbody>
</table>

*Sample values were excluded due to their non-clinical nature.*
Rating Scales: The Challengers to the Gold Standards

- CBCL: Child Behavioral Checklist
- GDS-LD: The Glasgow Depression Scale for people with a Learning Disability
- CDI: The Children’s Depression Inventory (CDI)
- BDI: Beck Depression Inventory
- GAS-ID: Glasgow Anxiety Scale for people with an Intellectual Disability
- ADAMS: Anxiety, Depression and Mood Scale

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- Working Assumptions
- What is Dual Diagnosis?
- Problem Behaviors vs. Psychiatric Disabilities/Disorders
- Why are We Talking about Dual Diagnosis?
- Assessment Tools
- Somatic Treatment Options

Outline for Somatic Treatments

- General guidelines for Somatic Treatments
- Need to acknowledge that there is evidence for medication treatment of PD
- But need to recognize that most of the recent evidence-based treatments for DD have come from studies of youth with ASDs and mostly targeting PB/CB not formal PD in DD
- Following is a series of slides that summarizes most of the recent relevant somatic treatment studies in youth with ASD
- Also follows is an additional series of slides that identify common somatic treatments with sufficient evidence to support treatment of DD
Somatic Treatment of PD in DD

- Know what you are treating
- Know what you want to happen with treatment
- Use Scales to help identify PD and response to treatment
- Use Scatterplot, Calendar Method, or ABC graphs to understand targets of treatment
- First line treatment should involve behavioral and environmental interventions
- If you need to use medications:
  - Watch for side effects
  - Only use evidenced-based treatments when you can.

Psychotropic medications...have side effects that [may] be harmful to the physical health of the individuals who take them, such as gait disorder, tardive dyskinesia, diabetes mellitus, tics, hair loss, acne and weight gain. The recognition of side effects is especially challenging because of the cognitive and self-awareness limitations of many individuals.”


Brief Summary of Evidence in Autism Spectrum Disorders

- Atypical Antipsychotics can be used to treat irritability (aggression, self-injury, and severe tantrums), stereotypies, and hyperactivity: risperidone and aripiprazole are best.
- Methylphenidate, atomoxetine, clonidine and guanfacine are effective in reducing ADHD symptoms
- SSRIs are not effective in reducing repetitive behaviors
- Anti-epileptic drugs (AEDs) have mixed results
- N-acetylcysteine (NAC) found to be helpful in improving irritability in children with ASD
Treatments Currently Under Investigation with RDBPCT

- Oxytocin
- Glutamatergic agents
- Vasopressin
- Donepezil
- Oxidative stress pathways:
  - Sulforaphane,
  - terahydrobiopterin,
  - L-carnitine and
  - methyl-B12
Insomnia Is a Problem in ID

- ASD (50-80%): see melatonin study
- Angelman Syndrome (20–80%): likely sensitive to GABAergic agents
- Cerebral Palsy: pay attention to sleep apnea, possible role for melatonin
- Rett Syndrome (80%): hard to treat due to medical complications
- Williams Syndrome: significantly more daytime sleepiness
- Smith-Magenis: possible role for melatonin

In a survey of Child and Adolescent Psychiatrists, 30% of those with ID were being treated for insomnia
<table>
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<tr>
<th>Table 3: Other Hematologic Findings in bone marrow of patients with metastatic tumors</th>
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A Closer Look at Specific Somatic Treatments

Class: Antipsychotics

- **Generic Name:** Risperidone
- **Known for:** Irritability in autism, class problems with weight gain, movement disorders, lipid issues, metabolic syndrome/diabetes; increased prolactin levels
- **FDA Approvals:** Adult and child Schizophrenia and Bipolar I Disorder, acute manic/mixed; Irritability associated with Autism in children and adolescents
Class: Antipsychotics

- **Generic Name**: Risperidone (continued)
- **Evidence for DD**: (RDBPCT)
- High doses effective for reduction in irritability, stereotypy, and hyperactivity in ASD
- Long-term effects maintained in ASD
- Combo of risperidone/parent-training more effective in ASD
- Risperidone and aripiprazole are equal in ASD
- Tryer et al. in an RPCT showed placebo to be better than risperidone and haloperidol in reducing aggression in non-psychotic adult patients with DD.
- Risperidone was safe and remained effective after one year in disruptive behavior disorders in children with low IQs who did not have ASD.

Class: Antipsychotics

- **Generic Name**: Aripiprazole
- **Known for**: Irritability in autism, class problems with weight gain, movement disorders, lipid issues, metabolic syndrome/diabetes
- **FDA Approvals**: Adult and child/adolescent for Schizophrenia, Bipolar I Disorder (manic/mixed); Adult treatment for Major Depressive Disorder (adjunctive treatment); and child/adolescent for irritability associated with ASD, Tourette Syndrome
- **Evidence for DD**: (RDBPCT)
- Reduced irritability, stereotypy, and hyperactivity in ASD
- Long-term effect maintained in ASD
- Increased weight, dyslipidemia, and aggression were common, especially in antipsychotic-naïve youth with baseline weight issues
- Risperidone=aripiprazole in ASD

Class: Antipsychotics

- **Generic Name**: Olanzapine
- **Known for**: Large amount of weight gain in addition to typical class concerns
- **FDA Approvals**: Adult Schizophrenia, Bipolar I Disorder (manic/mixed/agitation/acute depression), Major Depressive Disorder, acute treatment resistant. In children/adolescents approved for Bipolar I Disorder (manic/mixed) and Schizophrenia
- **Evidence for DD**: (RDBPCT)
- Was effective in improving aggressive behavior in ASD, but with large amount of weight gain
Class: Antipsychotics

- **Generic Name:** Haloperidol
- **Known for:** Highly potent and specific to D2 receptors; movement disorders and associated class side effects
- **FDA Approvals:** Adult and child and adolescent psychosis and Tourette Syndrome; child and adolescent severe behavioral problems
- **Evidence for DD:** (RDBPCT)
  - Improved aggressive behaviors but higher risk than risperidone and aripiprazole
  - Tryer et al. in an RPCT showed that placebo was better than both risperidone and haloperidol in reducing aggression in non-psychotic adult patients with DD.

Class: Antipsychotics

- **Generic Name:** Quetiapine
- **Known for:** Sedation, orthostatic hypotension in addition to other class side effects
- **FDA Approvals:** Adult and child/adolescent treatment for Schizophrenia and Bipolar I Disorder (mania); also adult approved for Bipolar I Disorder (depression)
- **Evidence for DD:** (Open label studies)
  - Poor efficacy and poor toleration of side effects in ASD

Class: Antipsychotics

- **Generic Name:** Ziprasidone
- **Known for:** More weight neutral in adults, but need to pay attention to QTc
- **FDA Approvals:** Schizophrenia, Bipolar I Disorder (manic/mixed)
- **Evidence for DD:** (Open label studies)
  - In one retrospective naturalistic study 49% responders on Clinical Global Impressions-Improvement Scale (CGI-I) for ASD
  - Another small study had 75% responders on CGI-I for ASD
  - Another small open label study had 60% responders on the Maladaptive Behavior Scale and they lost weight gained from other meds
### Class: Antipsychotics
- **Generic Name:** Clozapine
- **Known For:** Can have amazing results in Schizophrenia. Many worrisome side effects including collapse of the immune system; requires weekly labs for a year to check white blood count
- **FDA Approval:** Adults with Refractory Schizophrenia and Schizophrenia-associated Suicide Prevention
- **Evidence for DD:** Inconclusive at best for managing aggression in adults with ID

### Class: ADHD Medication
- **Generic Name:** Methylphenidate
- **Known for:** One of most effective ADHD tx, common side effects: weight loss, anger, poor sleep
- **FDA Approvals:** Adult and child/adolescent ADHD, Adult Narcolepsy
- **Evidence for DD:** (RDBPCT)
  - Only stimulant studied in ASD
  - Effective for ADHD treatment in youth with ASD
  - Less effective than in typically developing children with ADHD
  - Aman et al. analyzed three studies demonstrating that children with ADHD and ID have significant improvements in children, less so with lower IQs

### Class: ADHD Medication
- **Generic Name:** Atomoxetine
- **Known for:** Non-stimulant. Also helpful for ADHD + anxiety
- **FDA Approvals:** ADHD in both adults and youth
- **Evidence for DD:** (RDBPCT)
  - Effective in ADHD in those with ASD
  - Atomoxetine plus parent training was more effective than med or parent training alone in ADHD in those with ASD
Class: HTN Meds for ADHD
- **Generic Name:** Clonidine and Guanfacine (similar meds)
- **Known for:** Alpha 2-agonist. It can also treat tics, insomnia, Tourette’s, agitation. Also, lowers blood pressure, sedating, rebound hypertension
- **FDA Approvals:** Adult Hypertension; Adult and child and adolescent Severe Cancer-Related Pain, adjunctive treatment; Children and adolescent ADHD
- **Evidence for DD:** (RDBPCT)
  - Effective for ADHD symptoms in children with ASD

Class: SSRI Antidepressants
- **Generic Name:** All SSRIs (Selective Serotonin Reuptake Inhibitors)
- **Known for:** Black Box warning for Suicidal Ideation, some weight gain, activation of mania or aggression
- **FDA Approvals:** Numerous for depressive/anxiety disorders in both adults and youth
- **Evidence for DD:**
  - For core symptoms of ASD ineffective and possibly activating and aggression inducing (RDBPCT)
  - Aman et al. in a review of many open label studies that these meds were indeed useful in anxiety and depression in DD.

Class: SSRI Antidepressants
- **Continued from prior slide**
- **Evidence for DD:**
  - Open label citalopram study found 60% of patients with ID and depression improved on the Clinical Global Improvement Scale (CGIS)
  - In an open retrospective study of adults with DD, Ulzen and Hughes demonstrated an overall rate of 12.3% activation into hypomania compared to the general population rate of 0.5–1%.
Class: Non-SSRI Antidepressants
- **Generic Name:** Clomipramine
- **Known for:** Gold Standard for OCD, lots of potential side effects
- **FDA Approvals:** Adult and child and adolescent OCD
- **Evidence for DD:** (RDBPCT)
  - In youth with ASD, not well tolerated and not enough evidence to use
  - In adults with ASD, effective for stereotypes, anger, compulsions/ritualized behaviors, and hyperactivity

Class: Mood Stabilizer
- **Generic Name:** Lithium
- **Known For:** Classic treatment for mania. Side effect profile that is well-understood.
- **FDA Approval:** Bipolar Disorder I (mania, acute and maintenance) for both adults and children
- **Evidence for DD:**
  - Two studies dating back to 1987 and 1993 showing up to a 77% response rate in individuals with both ID and Bipolar Disorder (RCT & RDBPCT)
  - Retrospective chart review found lithium to be 43% to 71% effective in children who had ASD and mood disorder symptoms

Class: Anti-Epilepsy Drug (AED)
- **Generic Name:** Divalproex Sodium
- **Known for:** It is used commonly in seizure control, Bipolar Disorder and aggression. More worrisome in females of child-bearing age.
- **FDA Approvals:** Seizures in both adults and youth; Adults only for Bipolar I Disorder (manic), and Migraine
- **Evidence for DD:** (RDBPCT)
  - Maybe? in treatment of irritability in ASD
  - Kotsasitis reviewed 17 open label studies showing that 77% of patients’ manic/aggressive behavior responded
Class: Anti-Epilepsy Drug (AED)

- **Generic Name:** Topiramate
- **Known for:** It is used commonly in seizure control and migraine treatment. May help with weight gain when on antipsychotics, but with other complications
- **FDA Approvals:** Adults and youth for Seizures and Migraine prophylaxis
- **Evidence for DD:** (RDBPCT)
- In combination with risperidone it may help with PB/GB in children with ASD

Class: NMDA receptor modulators and antagonists

- **Generic Name:** N-acetylcysteine (NAC), amantadine, riluzole and memantine
- **Known for:** Tylenol overdoses, Trichotillomania, OCD, ADHD?, flu, ALS, dementia and Parkinson’s Disease treatment
- **Evidence for DD:** (RDBPCT)
- NAC found to be helpful in improving irritability in children with ASD
- Amantadine, riluzole and memantine ineffective as single agent in several trials
- Yet, may be effective in combo with antipsychotics in improving behavioral measures in children with ASD

Class: Alzheimer’s Dementia/Cholinesterase Inhibitor

- **Generic Name:** Donepezil
- **Known for:** Alzheimer’s treatment
- **FDA Approvals:** Alzheimer Dementia
- **Evidence for DD:** (RDBPCT)
- Two trials with mixed results in core features of ASD
- Ongoing trials currently
Class: Opioid Antagonist
- **Generic Name:** Naltrexone
- **Known for:** Treatment for Substance Abuse disorders
- **FDA Approvals:** Opioid Addiction and Alcohol Dependence
- **Evidence for DD:**
  - No good clinical trials to support treatment of SIB in those with ASD
  - But, Roy et al, reviewed 10 RDBPCT and reported that there may be evidence for improvement for hyperactivity and restlessness in children with ASD

Class: Sedative Hypnotic
- **Generic Name:** Melatonin
- **Known for:** Effective with sleep; some experience possible nightmares, Non-FDA regulated OTC supplement
- **FDA Approvals:** Circadian Rhythm Sleep Disorder in Blind Children and adults
- **Evidence for DD:** (RDBPCT)
  - Melatonin plus CBT found to help with insomnia (better than CBT alone)
  - See Slide 55 for three more trials

Class: ECT Treatment
- **Indications:** Severe/Resistant Depression, Severe Mania, Catatonia, PB/CB in people with Dementia. Useful in pregnant patients when medications are considered unsafe
  - Kessler [32] reviewed 16 case reports between 1968 and 2001 of ECT in patients with ID and a variety of PD.
  - The treatment was successful despite failures on all prior medication treatments
  - No significant complications
  - No cognitive decline from the treatment
Dual Diagnosis: Assessment, Diagnosis and Treatment

Michael S. Marcin, MD, MSCR

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Turgay et al. Long-Term Safety and Efficacy of Risperidone for the Treatment of Disruptive Behavior Disorders in Children With Subaverage IQs. Pediatrics; 110(3); 2002.
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**Total Number of Attendees for MOC16001: 188**
## UCSF Laurel Heights Area Restaurant List

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<thead>
<tr>
<th>Number</th>
<th>Name</th>
<th>Type</th>
<th>Address</th>
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<tr>
<td>1</td>
<td>The View Cafe</td>
<td>Cafeteria</td>
<td>2nd Floor - Laurel Heights Building</td>
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<tr>
<td>2</td>
<td>Beautifull</td>
<td>Organic</td>
<td>3401 California St.</td>
<td>415-728-9080</td>
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<tr>
<td>3</td>
<td>Artesano</td>
<td>Latin Food</td>
<td>3415 California St.</td>
<td>415-221-5500</td>
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<tr>
<td>4</td>
<td>Ella’s</td>
<td>New American</td>
<td>500 Presidio Ave.</td>
<td>415-441-5669</td>
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<tr>
<td>5</td>
<td>Café Luna</td>
<td>American</td>
<td>3313 Sacramento St.</td>
<td>415-346-7900</td>
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<tr>
<td>6</td>
<td>Rigolo</td>
<td>French</td>
<td>3465 California St.</td>
<td>415-876-7777</td>
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<tr>
<td>7</td>
<td>Noah’s Bagels</td>
<td>NY Deli</td>
<td>3519 California St.</td>
<td>415-387-3874</td>
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<tr>
<td>8</td>
<td>Trader Joe’s</td>
<td>Grocery</td>
<td>3 Masonic Ave.</td>
<td>415-346-9964</td>
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<tr>
<td>9</td>
<td>Bryan’s Market</td>
<td>Grocery/Deli</td>
<td>3445 California St.</td>
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<td>10</td>
<td>Starbucks</td>
<td>Coffee Shop</td>
<td>3595 California St.</td>
<td>415-387-2249</td>
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<tr>
<td>11</td>
<td>Cal-mart</td>
<td>Grocery/Deli</td>
<td>3585 California St.</td>
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<tr>
<td>12</td>
<td>AG Ferrari</td>
<td>Italian Deli</td>
<td>3490 California St.</td>
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<tr>
<td>13</td>
<td>Magic Flute</td>
<td>Cal-Italian</td>
<td>3673 Sacramento St.</td>
<td>415-922-1225</td>
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<tr>
<td>14</td>
<td>Sociale</td>
<td>Italian</td>
<td>3665 Sacramento St.</td>
<td>415-921-3200</td>
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<tr>
<td>15</td>
<td>Bistro SF Grill</td>
<td>American</td>
<td>2819 California St.</td>
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<tr>
<td>16</td>
<td>Eliza’s</td>
<td>Chinese</td>
<td>2877 California St.</td>
<td>415-621-4819</td>
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<td>17</td>
<td>Food Inc.</td>
<td>Italian Deli</td>
<td>2800 California St.</td>
<td>415-928-3728</td>
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