



15TH ANNUAL CONFERENCE OF THE AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

4TH ANNUAL CONFERENCE
OF THE NATIONAL TASK
GROUP ON INTELLECTUAL
DISABILITY AND
DEMENTIA PRACTICES

June 2-4, 2017

University of Texas Health Science
Center at Houston (UTHealth)





Dear Colleagues,

I am very pleased to welcome you to The University of Texas Health Sciences Center at Houston (UTHealth) School of Dentistry (UTSD), our host, and to the 15th Annual Conference of the American Academy of Developmental Medicine and Dentistry (the AADMD)! Howdy Y'all!

This year's conference heralds a significant milestone in the history of the AADMD, as it marks the 15th anniversary of its founding. In 2001, then-Surgeon General David Satcher provided the impetus and challenge to the field of developmental disabilities' medical care to not only recognize that healthcare needs were going unmet and that great disparities existed, but to do something about it. The AADMD, created directly from this strong message to the Academy's founders, continues to be inspired by Dr. Satcher's challenge. What started out as a small grass roots effort among medical care leaders grew to become the Academy and its mission.

Dedication and heart were never in short supply as the AADMD defined its mission of expanding awareness about the healthcare needs of children and adults with intellectual and developmental disabilities. Each year the AADMD expands its reach and reputation by tackling national healthcare concerns including the medically underserved population status initiative, restrictions on transplant recipients, neuropathologies, as well as the need to engage inter-professional education and training on specialized medical and dental care issues. The AADMD, with the support of Special Olympics, created and fostered healthcare student chapters. These further energized the organization to broaden its scope and desire to partner with advocacy, governmental, parent-based, and other community support organizations – all to close the gap and enable those persons with intellectual and developmental disabilities to achieve parity in healthcare access and quality care.

I am very proud and pleased of the Academy's growth over the years and its successes in becoming an influential health care association striving to fulfill Dr. Satcher's vision. With this year's conference, we have organized the broadest program in our history. I trust you will join me in actively participating in our 15th conference and that you find your experience both rewarding and enjoyable!

/s/

David F. Fray, DDS, President
Associate Professor, Department of General Practice and Dental Public Health
UTHealth School of Dentistry

PROGRAM

15TH ANNUAL CONFERENCE OF THE AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

Friday, June 2, 2017

Time	Event					
7:00 AM	Registration and Continental Breakfast					
8:00 AM	UTSD Dean Valenza: Welcome and Keynote 1.1 Jim Brett, President's Committee for People with IDD					
9:15 AM	Keynote 1.2 Mary Davis, SOI, Exec Director					
10:00 AM	BREAK					
10:30 AM	Plenary 1.3 Joe McBeth, NADSP, Exec Director					
11:00 AM	Panel 1.4 Role of the DSP in Healthcare Panel					
11:45 AM	LUNCH					
1:00 PM	Breakout Sessions 1.1					
	Use of the 'Practice Without Pressure' model to eliminate restraint Deborah A Jastrebski, BS, MPS, CHL, Hope Thomas-Glavin, Janet Yellowitz, DMD, MPH, FASGD, DABSCD	National Curriculum Initiative in Developmental Medicine (NCIDM) Report Priya Chandan, MD, MPH	Nutrition care for children and adults with intellectual and developmental disorders Dawna Torres Mughal, PhD, RDN, LDN, FAND and Janice Scott, MS, RD, CSP, LD	E-Consults to improve the primary care of adults with Down syndrome Carl Tyler, MD, MSc, ABFP, CAQ-Geriatrics and Michael Wells, BA	Actions speak louder than words: Common behavioral presentations of medical conditions in people with IDD Craig Escude, MD and Sherry Neal, RN-BC, CDDN	Drill or Not to Drill: Caries Management with Silver Diamine Fluoride Cynthia L. Wong, DMD, MS
2:00 PM	Breakout Sessions 1.2					
	Panel on Behavior Approaches Drs. Jeter, Perlman, Thomas-Glavin, Yellowitz, DD Council	Interprofessional Virtual Grand Rounds: AADMD Case Study Forum Michael Tarr	Vitamin D Adequacy and comorbidities in persons with IDD Sunil J. Wimalawansa, MD, PhD, MBA	Medication Management by people with IDD and their support network Steven Erickson, Pharm.D.	Next generation collaboration in Electronic Health Record Adam Bauer, MBA, PMP and Ashley Purdon	Dental Van Care Shazia Khattak, DMD and Jenelle Fleagle, DDS
2:50 PM	BREAK					
3:20 PM	Breakout Sessions 1.3					
	The Eyes have it: Brain basis of social cognition in ASD Cameron Jeter, Ph.D.	Healthcare Inadequacies A Call to Action and MUP Strategies in your State Rebecca Lech, OMS III	Dental Treatment Planning and Dental Materials Jack I. Joseph, DDS Reactors: Michael Miller, DDS and Alan Wong, DDS	Interdisciplinary Professional Education in I/DD Clinic Directors Symposium Lynne M Taiclet, DMD and Cynthia Peacock, MD	Developing a healthcare transition process for young adults with IDD Judy Lu Kim, MD and Elisha Acosta, MD	Protective Stabilization: The Good, The Bad and The Ugly Gary R. Badger, DDS, MS
4:15 PM	POSTER SESSION					
6:00 PM	Adjourn for day					

NTG	FRIDAY	1-4 PM
Community Forum: Aging ID HOST: Seth Keller Contact: Katie Scott 6055 S Loop East Houston, TX 77087		

15TH ANNUAL CONFERENCE OF THE AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

Saturday, June 3, 2017

Time	Event					
7:00 AM	Registration and Continental Breakfast					
8:00 AM	Welcome: Maria Town, Dir. Mayor's Office for People with Disabilities and AADMD Vice-President Sulkes and Keynote 2.1					
	Jennifer Howse, March of Dimes					
8:40 AM	Panel 2.2					
	Building Bridges Panel					
9:30 AM	Plenary 2.3					
	Jim Balamaci, SO Alaska Exec Director					
10:00 AM	BREAK					
10:20 AM	Plenary 2.4					
	Down syndrome and Alzheimer's disease: Common pathways and potential treatment avenues - Lotta Granholm-Bentley					
11:00 AM	Panel 2.5					
	Nothing About us without us! Self Advocate Panel - Michlle Cornnachia MD - Host					
11:45 AM	LUNCH					
	Keynote: Rick Rader					
1:00 PM	Breakout Sessions 2.1					
	Caries Risk Assessment (CAMBRA), MID and Silver Diamine Fluoride Allen Wong, DDS, EdD, DABSCD and Paul Subar, DDS, EdD, FACD	The NTG-EDSD: An administrative tool that supports healthcare decision-making Lucille Esralew, Ph.D.	Specialized supportive services model for aiding caregivers of individuals with ID and dementia Sandra L. Fournier, MSN, RN, CDDN, CBIS	A Special Olympics young athletes healthy athlete programs Sandra S. Block, OD, M Ed, MPH and Alice Lenihan, MPH, RD, LDN	Polypharmacy and its Consequences Nanette R. Wrobel, RPh	Education and Advocacy for persons with I/DD Desire K. Christensen, MD, MS, Jessica Prokup
2:00 PM	Breakout Sessions 2.2					
	End of Life Decision Making and developmental disabilities: Issues, challenges and approaches Stephen Sulkes, MD	Scotland International Summit on ID and Dementia - Issues and Recommendations Seth M. Keller, MD and Matthew P. Janicki, Ph.D.	Telemedicine: Bringing Care to Those Who Need it Most James Powell, MD	Alternative approach to surgical caries management Keon Ahghar, DDS, David McMullan, DDS and Sarah Usher, DMD	Health care advocacy: the family perspective Jadene S. Ransdell	Special needs comprehensive eye exams Kassandra Johnston, OD, FAAO
2:50 PM	BREAK					
3:20 PM	Breakout Sessions 2.3					
	Living while dying: End-of-life considerations for people Kathy Service RN, MS, FNP-BC, CDDN	Coping with forensic issues among persons with intellectual and developmental disabilities Andrew W. Griffin, Ph.D.	A new model for care management in state supported living centers Jacque Waller, RN, BSN, Rosalind Bader, MSW, Gretchen Golladay, LMSW, and Vera Dampthey, RN, BSN	Care Management in the digital age: Integrated human service solutions Douglas Golub	Ten Tips for successful transition of adults with I/DD Samuel Garcia, LMSW, LCDC and Tiffany Castenell, LMSW	Oral ID: Pathology Dx Tool for Docs (Hands on Workshop) June Sadowsky, DDS, Ben Warner, DDS, MD, Ashley Clark, DDS, MS and David Fray DDS, MBA
7:00 PM	2017 AADMD GALA Dinner- Marriott					

15TH ANNUAL CONFERENCE OF THE AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

Sunday, June 3, 2017

Time	Event			
7:00 AM	Registration and Continental Breakfast			
8:00 AM	Welcome and Keynote 3.1			
	Jack Dillenberg (MUP presentation)			
8:50 AM	Keynote 3.2: Neurodiversity and How I Came to Be Founder of DifferentBrains.com			
	Harold "Hackie" Reitman, M.D.			
9:45 AM	Breakout Sessions 3.1			
		Mortality in Medical Home Settings for Patients with I/DD Ellen Fremion, MD		
11:00 AM	Breakout Sessions 3.2			
	Perception of Dentists on learning and treating persons with IDD Dr. Nameeta Kaur	Mortality Reporting by State IDD Agency to improve Health Outcomes Jeffrey Okamoto, MD and David Fray DDS, MBA		
12:00 PM	Adjourn			

AADMD Institute
8:00 AM - 12:00 PM

NTG Business Mtg
10:00 AM -
12:00 PM

Special Meetings and Events

Thursday, June 1

7:00pm – 9:00pm	AADMD Board Meeting and Dinner	Marriot Medical Center Hotel
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Friday, June 2

8:00am – 8:15am	Welcome: John A. Valenza, UTSD Dean; Maria Town, Houston Mayor’s Office; David Fray, President, AADMD	Cooley Center
1:00pm – 4:00pm	NTG / Baker-Ripley Public Forum on Dementia and Intellectual Disabilities	Greater Houston Alzheimer’s Association
4:15pm – 6:00pm	Posters and Award Reception	Cooley Center Fullerton Room - #4310

Saturday, June 3

8:00am – 8:15am	Welcome: Cathy L Rozmus, Vice Dean, UTHealth School of Nursing; Steve Sulkes, Vice-President, AADMD	Cooley Center
5:00pm – 5:30pm	Tours of Various Departments	UTHealth School of Dentistry

Sunday, June 4

8:00am – 12:00pm	Institute in IDD Certificate Track	Cooley Center
10:00am – 12:00pm	NTG Business Meeting	Cooley Center

Monday, June 5

9:00am – 5:00pm	NTG Workshop on Dementia and Intellectual Disability	Cooley Center
9:00am – 4:00pm	IASSIDD Academy Workshops	Marriott Medical Center Hotel

Tuesday, June 6

9:00am – 5:00pm	NTG Workshop on Dementia and Intellectual Disability	Cooley Center
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Wednesday, June 7

9:00am – 5:00pm	NTG ‘Train-the-Trainer’ Workshop	Cooley Center
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American Academy of Developmental Medicine and Dentistry Institute on Intellectual and Developmental Disabilities

Sunday, June 4, 2017 8:00am-12:00pm

The Denton A. Cooley, MD & Ralph C. Cooley, DDS University Life Center, UTH

Orientation on the Context of Intellectual and Developmental Disabilities Health

Dr. Rick Rader - 60 min

This session will introduce Institute scholars to the complex landscape of IDD Health by Medical Futurist, Dr. Rick Rader, who has devoted most of his career to improving the lives of individuals with IDD.

How to Create an Intellectual and Developmental Disabilities-Friendly Career

Dr. Seth Keller – 60 min

This session will include ideas and advice on how to develop a career that includes patients with IDD including the logistics of loans, management of a practice, and career development.

The Big 5: Essential Concepts About the Most Common Conditions in Intellectual and Developmental Disabilities

Dr. Matt Holder – 60 min

This session will describe a basic thinking construct with respect to the care of patients with IDD. Dr. Holder will discuss the most common diagnoses found in this field and how they interrelate. He will also provide tips for providing patient care learned over more than a decade of working with patients with IDD in an interdisciplinary capacity.

Interdisciplinary Care: A Case-Based Discussion on Comprehensively Meeting the Complex Needs of People with Intellectual and Developmental Disabilities

Panel Discussion – 60 min

A panel will demonstrate through a case-based discussion that close collaboration of diverse healthcare team members is essential for determining and addressing primary causes of distress or ailment in individuals with IDD and coordinating appropriate care.

Certification:

Scholars must take an initial and post-Institute assessment of their knowledge of Intellectual and developmental disabilities healthcare topics. All scholars will receive a certificate of participation in the AADMD Institute upon completion of the assessment.

PLENARY SPEAKERS

James T. Brett is the President and Chief Executive Officer of The New England Council. In addition to Mr. Brett's day job, his passion and mission has been working as an advocate for people with intellectual disabilities. He served as the Chairman of the President's Committee for People with Intellectual Disabilities and continues to serve as a member. In 2016, Congress appointed Mr. Brett to the National Council on Disability. He is also Chairman of the Massachusetts Governor's Commission on Intellectual Disability and serves as the Chairperson of the Massachusetts Disabled Persons Protection Commission. Mr. Brett served as a member of the Federal Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities.

Mary Davis is the Chief Executive Officer of Special Olympics International. She has been a life-long leader within the Special Olympics movement, beginning after college as a volunteer and coach with Special Olympics Ireland. Davis has served in many leadership roles, helping create Special Olympics' first-ever Regional games, the 1985 Special Olympics European Games, working to build a powerful national Program as CEO of Special Olympics Ireland, and helping globalize the movement as CEO of the first Special Olympics World Summer Games held outside the US. Since 2009, Davis has served as the Managing Director and Regional President of Special Olympics Europe Eurasia, overseeing the growth and development of Special Olympics across 58 countries in Western Europe, Eastern Europe and Central Asia.

Ann-Charlotte "Lotta" Granholm-Bentley, DDS, Ph.D. is the founding executive director of the Knoebel Institute for Healthy Aging at the University of Denver, where is also a research professor in the Department of Biological Sciences. Dr. Granholm-Bentley was previously the director of the Center on Aging at the Medical University of South Carolina. She is also guest professor in neurosciences at the Karolinska Institute in Stockholm, one of the largest and most prestigious medical universities in the world. She is author of numerous publications on neuroscience and brain research related to Alzheimer's disease, including recent work on Alzheimer's disease biomarkers in Down syndrome.

Jennifer Howse, Ph.D. is a national leader in health and science, having served as President of the March of Dimes Foundation for more than two decades. She was instrumental in launching national campaigns to expand newborn screening, promote folic acid education, and prevent preterm birth. Dr. Howse has held high-level public service appointments overseeing services for persons with developmental disabilities, including serving as a commissioner of the developmental disabilities agencies in Pennsylvania and New York. She has served on many boards, including the Salk Institute for Biological Studies. In recognition of her many achievements, she was elected to the prestigious National Academy of Sciences Institute of Medicine and received the Jimmy and Rosalynn Carter Humanitarian Award from the National Foundation for Infectious Diseases.

Joseph MacBeth is the Executive Director at the National Alliance for Direct Support Professionals (NADSP) and has worked in the field of intellectual and developmental disabilities for some 30 years. Mr. Macbeth is recognized as a leader in the advocacy and advancement the direct support profession and has assisted more than 500 direct support professionals advance their college education through the "Disability Studies Certificate". He is a member of the boards of the American Network of Community Options & Resources (ANCOR) Foundation, the Alliance for Full Participation (AFP), the Council on Quality and Leadership (CQL), and the College of Direct Support (CDS) National Advisory Board.

Harold "Hackie" Reitman, M.D. is an entrepreneur, philanthropist, children's activist, and neurodiversity advocate. He is also a retired orthopedic surgeon and a former professional heavyweight boxer who currently serves as the CEO of Fort Lauderdale, Fla.-based PCE Media, LLC, the multi-platform production company he founded in 2004. Dr. Reitman's mission is to achieve excellence in creating family-friendly content that will effect positive social change. Dr. Reitman wrote, produced and co-directed the full-length independent film, *The Square Root of 2*, the story of a college student with various challenges and a seizure disorder. He is Fellow of the American Academy of Orthopedic Surgeons, the American College of Surgeons, and the International College of Surgeons. Dr. Reitman is the founder of the neurodiversity site www.DifferentBrains.com. He is also a contributor there, including hosting the interview show "Exploring Different Brains."

ABSTRACTS

[Index for presenters found on page 20]

AHGHAR, Keon, **MCMULLAN**, David, **USHER**, Sarah
Private Practice, Roswell, NM
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A modern, alternative approach to surgical caries management for patients with developmental disabilities

Abstract: Traditional restorative materials and techniques provide less than ideal treatment options for high risk patients, especially patients with intellectual and developmental disabilities (IDD). Such materials are highly technique sensitive and are a poor restorative option when treating dental caries in patients with IDD. Advances in glass ionomer products offer a material that melds the best qualities of traditional materials. Modern glass ionomers (GI) give practitioners a material that is strong, esthetic, and minimally affected by oral environment moisture, and less technique sensitive than traditional materials. It enables minimal caries removal techniques, chemically bonds to tooth structure, provides a reservoir of fluoride/mineral release, arrests caries in affected dentin, and is usable without need for anesthesia. Utilization of modern advances in GI materials for direct restorations in surgical caries management offers a superior alternative for patients and practitioners. To appreciate the utilization of GI restorative materials in surgical caries management for patient with IDD, the authors explored ways to understand partial caries removal techniques and related CAMBRA methodologies.

ASPELUND, Laura & **VAN DEN BERG**, Rain
University of Alaska – Anchorage, AS
[laura.aspelund@gmail.com]

Partners in health: communication tips for working with people with intellectual and developmental disabilities event kit

Abstract: In the United States, approximately 3 percent of people are diagnosed as having an intellectual disability or developmental disability (IDD). Individuals with IDD have a significantly more difficult time accessing quality preventative health care, and thus experience higher rates of chronic health conditions. Evidence suggests that the greatest barrier to accessing quality health care for individuals with IDD is communication. The Alaska LEND developed a training video for providers to learn strategies to improve effective communication with people who experience IDD. The strategies covered in the training are research-based, and have been proven to be effective in enhancing communication between persons with IDD and their healthcare providers. The UAA AADMD Student Chapter developed a training event kit so this video can easily be facilitated in classrooms and other learning venues. The UAA AADMD Student Chapter has piloted this training with nursing students, occupational therapy students, dental hygienists, health care students, and others. Evaluation of the training has shown that it is effective at teaching key concepts related to improving communication and inclusion of patients with IDD. Facilitator feedback has been positive that the event kit is easy to use to hold an event. Copies of the kit are available from the authors. (POSTER)

BALAMACI, James D. & **KELLER**, Seth M.

Special Olympics Alaska, Anchorage, AK
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Senior athletes – inclusion into Special Olympics

Abstract: Individuals with Intellectual and developmental disabilities (IDD) are now living longer. Age-related decline associated with normal aspects of aging, as well as age-associated conditions and illnesses (including dementia) increase with age have an impact on their quality of life. Participation in health promotive activities, as well as in sports as they age, has been of great interest to a growing number of organizations, including Special Olympics International (SOI). Participation in athletics and exercise can promote needed conditioning, raise spirits, and provide companionship and a valuable social outlet. Studies have shown the value of such exercise, but have also shown that self-directed exercise falls short of commitment and continued engagement. Other aspects also affect participation in exercise programs by older individuals' with IDD, such as demographics, lack of exercise facilities, and other complications affecting participation. The possible solution for continued engagement and participation lies in the value of forged community and state partnerships that provide targeted exercise and competitive athletic programs. One such partnership is the engagement of older athletes in Special Olympics, via the "Senior Athletes" program. The efforts by Special Olympics Alaska and its success with the Disability and Aging Summits held in Anchorage serve as a prototype and platform for other state Special Olympics programs to emulate and provide a viable and sustainable exercise program that can help promote healthy ageing among older adults with IDD. Such a platform can help bring perspective, guidance, and goals to SOI and to broaden healthy aging in national plans in general. (PLENARY)

BAUER, Adam & **PURDON**, Ashley
Deloitte Consulting, Austin, TX
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Next generation collaboration: Electronic health record success approaches for the developmental disabilities field

Abstract: Savvy developmental disabilities provider agencies recognize that selecting an electronic health records (EHR) vendor is only the beginning of their journey to technology-enabled operations. Leading software in today's market is flexible, responsive, and highly configurable to the unique needs of each organization – so how do you take an "anything's possible" platform and arrive at a system that delivers the specific impact and return on investment you envision? The process of evaluating and selecting an EHR vendor includes examining the critical considerations for staffing an effective project team, and exploring innovative, cross-functional design approaches to achieve efficiency and operational effectiveness through technology. Through an active approach to blending experience, knowledge, and perspectives from resources inside and outside of the agency, provides can effectively drive standardization and best practices through the value of collaboration. Such lessons are of value to executives, technology professionals, and clinical or programmatic managers with a vested interest in the success of their agency's EHR future.

BASSANO, Alicia & BOSEMAN, Charita
Westside Regional Center, Culver City, CA
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Improving physician knowledge and family support around the diagnosis of intellectual disability: A Special Olympics International (SOI) collaboration

Abstract: Parents recall years later with great accuracy the exact words physicians use when giving the diagnosis of intellectual disabilities. Families who receive timely resources from an informed physician with a positive prognostic outlook describe improved outcomes and less distress. Despite this, physicians receive little training on giving this diagnosis or supporting families. Thus, targeting physicians for training and providing parent resources should be priorities. Special Olympics is uniquely positioned to provide outreach and education on intellectual disabilities among physicians and families of newly diagnosed children. Thus, the authors developed a community-academic partnership between Special Olympics International (SOI) and UCLA Mattel Children's Hospital to increase physicians' knowledge, skills and self-efficacy on intellectual disability support for families and determine the feasibility of a Resource Guide to improve family understanding of the diagnosis and resources. In collaboration, we developed and utilized three strategies as a single-site demonstration project: (1) recorded "Grand Rounds" educational session on diagnosis, prognosis and delivering the news (2) visual educational poster in breakrooms/ residency offices (3) family Resource Guide for newly diagnosed children. We evaluated the intervention using online surveys to physicians and requested parent feedback on the Resource Guide. Results showed that (1) Fifty-six participants attended the teaching intervention and 39 completed evaluations. Of those, 85% agreed that the intervention increased knowledge and that the intervention could improve practices, including better preparation, increased family support and knowledge of resources. (2) Eight representatives of residencies and offices completed evaluations of the poster. They all described increased knowledge, cultural sensitivity to disabilities, and 62% showed increased comfort with guidelines. It was concluded that a brief educational intervention can increase physician's knowledge and self-reported ability to give an intellectual disability diagnosis and provide supports to families. Further studies should focus on the effects on measurable changes in practice from the physician and family perspectives. (POSTER)

BLOCK, Sandra S. & LENIHAN, Alice
Illinois College of Optometry, Chicago, IL
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Special Olympics Young Athletes Healthy Athlete Programs: A means to ensure that health care services reach individuals with developmental disabilities early to ensure better outcomes

Abstract: Special Olympics (SO) is a global program focused on ensuring that individuals with intellectual and developmental disabilities achieve optimum quality of life. The organization shifted from solely sports to sports for athletes age 8 and older to sports and health promotion for those children 2½-7 years old as Young Athletes (YA). How this occurred is of interest, as the integration of YA into the SO Healthy Athlete family shows the shift from only diagnosis/treatment to prevention with diagnosis

and treatment. The literature states early intervention has positive impact on health. Examples include identification and intervention of risk factors to prevent amblyopia and better nutrition supports normal growth/ development. Health promotion, which focuses on nutrition, bone health, sun safety, tobacco avoidance, hygiene and physical activity, uses interactive educational tools/displays, motivational literature and demonstrations to heighten the healthy behaviors. The screening includes a height and weight health habits survey to identify health challenges that may need additional education and follow-up. The screening offers a forum for discussing health challenges seen, data from global screening exams and examples of education tools, and opportunities for health professionals to participate in Health Promotion activities in their community. In addition, the "Opening Eyes YA Program" examines the types of visual problems prevalent in this younger athlete group, including refractive errors, strabismus, amblyopia and eye health problems more commonly seen in Down syndrome, Zika virus, autism, and fetal alcohol spectrum. The three goals of the YA are to focus on providing quality services, educate the family about the health issues that their child may face and how to intervene, and train more health providers to ensure that access in the community.

BRETT, James T.
President's Committee for People with Intellectual Disabilities, Washington, DC
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From the heart: my journey as a leading advocate for quality of life issues for children and adults with intellectual disabilities

Abstract: Covered were the speaker's personal observations of being an advocate within various federal councils and other entities and reflections how to approach social change. [PLENARY]

CARTER, Alison & STONEY, Minshew
Transition Medicine Clinic, Houston, TX
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Team-based care coordination

Abstract: The care of adults with intellectual and developmental disabilities (IDD) is often complex, involving sub-specialists, insurance changes, family resources, and social supports. Without appropriate care coordination, patients are often lost in the healthcare system, leading to insufficient care or follow up. A team-based care coordination model in use at the Transition Medicine Clinic (TMC) involves all members of the healthcare team: physicians, registered nurses, medical assistants, medical social workers, and insurance plan service coordinators. This model allows each team member to practice at the highest level of their degree, ensures there is no role confusion, and gives the patient higher quality care. By implementing this model, the Transition Medicine Clinic has taken the appropriate steps to provide the care coordination needed to follow through on complex, medical plans of care. After implementing the TMC's Team-Based Care Coordination model, the number of hospital and emergency room visits decreased and the number of quarterly follow up visits increased. Involving physicians, nurses, medical assistants, medical social workers, insurance service coordinators, and participating sub-specialists' leads to improved health outcomes in patients in a medical home. (POSTER)

CHANDAN, Priya
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A report on a national curriculum initiative in developmental medicine

Abstract: The National Curriculum Initiative in Developmental Medicine (NCIDM) is the result of a partnership between Special Olympics International (SOI) and the American Academy of Developmental Medicine and Dentistry (AADMD). The goal of the NCIDM project is to provide training to medical students in the field of developmental medicine—the care of individuals with intellectual and developmental disabilities across the lifespan. The NCIDM’s specific aims are to (1) develop a standardized set of Goals and Objectives, (2) develop a standardized knowledge assessment tool that ties to the Goals and Objectives, and (3) over 5 years, recruit 12 total medical schools (3 per year) to participate as Medical School Partners. To address Aims 1 & 2, experts in developmental medicine were invited to take place in an NCIDM Working Group meeting in January 2017. The first Medical School Partner cohort is completing project activities for 2017-2018, including a variety of methodologies, such as Photovoice, OSCEs, and Elective Creation. Each project activity also had a corresponding evaluation plan, utilizing the knowledge assessment developed in the Working Group and/or an attitudes assessment. Because each medical school, among the partners, is unique, intervention designs and implementations varied. Outcomes to date show what kinds of activities can be implemented.

CHEETHAM, Thomas
Tennessee Department of Intellectual and Developmental Disabilities, Nashville, TN
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Drinking from a firehose: My experience as an ‘accidental’ bureaucrat

Abstract: Few clinicians begin their career with a plan to become an administrator; however, many will find themselves in this role throughout their working life. The presenter reviewed his personal perspective as a clinician who transitioned to an administrator and reflected on the process of evolution to an administrator and the lessons learned along the way to inform other “accidental” bureaucrats. [PLENARY]

CHRISTENSEN, Desire K.
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Intellectual disability curriculum in medical education

Abstract: Patients with intellectual disabilities face numerous barriers to healthcare access that have contributed to health disparities and shorter lifespans. Negative attitudes and behaviors of healthcare providers have been identified as significant obstacles to health services in this population. Curriculum interventions have been shown to improve medical student attitudes and skills towards individuals with disabilities. To date, there has been limited curriculum development designed to address the attitudes, knowledge and skills of medical students in regards to care for patients with intellectual disabilities. Curricula development in a medical education

setting followed a six-step approach: general needs assessment, specific needs assessment, goals and objectives, educational strategies, implementation, and evaluation. The curriculum was designed to span the four years of medical education in a variety of learning environments, including didactic, small group, case-based learning, clinical experiences and community settings. The proposed curriculum requires collaboration across multiple departments and course directors. Exposure to patients with intellectual disabilities is common in healthcare settings. Healthcare professionals require learned attitudes, knowledge and skills to care for patients with intellectual disabilities. The process of curricula development in a medical setting identified limited formal instruction on the healthcare needs of patient with intellectual disabilities. Implementation of intellectual disability curricula into medical education is deemed an important step towards reducing health inequities in this population.

CORNACCHIA, Michelle & TBA
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Nothing about us without us! Self-advocates discuss their experiences navigating this ‘crazy healthcare system’

Abstract: Self-advocacy is “...one form of advocacy, occurring any time people speak or act on their own behalf to improve their quality of life, effect personal change, or correct inequalities” (Concunan-Lahr and Brotherson, 1999). Individuals with intellectual and developmental disabilities (IDD) are a medically underserved population, although not recognized as such by the US federal government. This is despite the Health Resources and Services Administration stating that a population can be considered medically underserved if its Index of Medical Underservice (IMU) score is less than 62. According to the AADMD leadership, the IDD score is 54.1, which would qualify for consideration. Also, the 2001 US Public Health Service blueprint, “Closing the Gap”, notes that persons with IDD have higher rates of preventable deaths and chronic conditions and less access to preventative care and health promotion than their non-disabled peers, which further highlights the gaps in their care compared to the general population. To improve health care outcomes and quality of life for this population, individuals in health care and policy need to hear from individuals with IDD to better understand their needs and what can be done to improve their health care. Therefore, a panel of 2-3 self-advocates discussed their experiences navigating the medical/dental systems, medical etiquette while working with adults with disabilities, and solutions for their concerns using their personal stories as a guide. The goal of this panel was to provide first-hand information to health care providers on patients’ with IDD perspectives on the current health care system and how they can improve to provide better care for this population.

DAVIS, Mary
Special Olympics International, Washington, DC
[mdavis@specialolympics.org]

‘40 Years A Growing’: Perspectives on the Special Olympics journey of transformation

Abstract: The speaker addressed the transformation of Special Olympics International and spoke to the

changes that have occurred in behavior and attitudes over the past 40 years and the effect this transformation has had on leading health clinicians to become more involved with SOI athletes, supporting and enhancing their health and personal welfare. [PLENARY]

DILLENBERG, Jack
Arizona School of Dentistry & Oral Health, Mesa, AZ
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Being an AADMD Ambassador

Abstract: The role of an AADMD Ambassador was discussed in the context of the Academy's mission and significant activities.

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Risk factors for fracture in a population of cerebral palsy patients with disuse osteoporosis

Abstract: The Baylor Transition Medicine Clinic is a medical home for 712 adults with intellectual and developmental disabilities (IDD), including 155 with cerebral palsy (CP). A large cohort of the patients with CP is non-ambulatory and at risk for disuse osteoporosis (i.e., disuse osteoporosis refers to reduced bone mineral density due to inability to bear weight). Though common in adults with CP, the evaluation and management of disuse osteoporosis remains poorly defined. Our aim was to identify those patients at risk for disuse osteoporosis and identify risk factors for fractures. We identified 155 non-ambulatory patients with CP (with Gross Motor Function Classification System score of 4 or 5). We performed a retrospective chart review of these patients' DEXA scores, fracture history, and common osteoporosis risk factors. Eighteen patients (11.7%) had a history of fracture. There was a statistically significant correlation between fracture history and DEXA z-scores at hip and femoral neck sites. Patients with fracture history had lower mean DEXA z-scores compared to patients without reported fracture history (hip z score -3.491 vs. -2.348, femoral neck z score -3.933 vs. -2.623). We found no correlation between fracture history and other osteoporosis risk factors including: calcium and vitamin D levels, anti-epileptic drug use, contraceptives, or chronic steroids. Osteoporosis diagnosis and management has been defined in the ambulatory geriatric population, and treatment offers the potential to prevent fractures and preserve mobility. This framework, however, is not appropriate for younger, non-ambulatory patients. Although we found a statistically significant correlation between fracture history and z-scores of the hip and femoral neck, much remains unknown about the clinical significance of fractures in non-ambulatory patients and effectiveness of treatment. A larger cohort is needed to further define the diagnostic criteria and management goals in this group. (POSTER)

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Medication management by people with intellectual and developmental disabilities and their support network

Abstract: Medication management is a complex process for persons with intellectual and developmental disabilities. Some of the factors that place the person with intellectual and developmental disabilities at high risk for medication related problems include polypharmacy-complex medication regimens, having multiple health care providers prescribing, and reliance on caregivers to assist in the medication management. The medication management process is composed of a series of steps which, if all are completed correctly, leads to safe and effective use of medication. The process begins with the prescriber being able to obtain accurate and complete information from the patient and to rationally prescribe a medication. The patient then acquires the medication from a dispenser, typically a pharmacy. The medication is taken home and stored until such time that the patient determines it's time to take it. Monitoring tasks may be necessary to determine if to take or how much to take of the medication, as well as the effect of the medication after administration. The patient then must reorder medication when long term therapy is prescribed. Extensive literature reviews and studies of medication issues for people who have intellectual and developmental disabilities show that this group is at risk for medication-related problems. Future work is warranted to examine individual as well as system-related interventions focusing on appropriate prescribing, dispensing, and administration of medications. Further research is also necessary to follow-up on the issues of medication training both for person with intellectual and developmental disability as well as for caregivers.

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Actions speak louder than words: Common behavioral presentations of medical conditions in people with intellectual and developmental disabilities

Abstract Many people with intellectual and developmental disabilities communicate pain and other ailments through their behavior. To the unaware provider, this may result in treatment of a perceived behavioral issue rather than the underlying medical issue that may be the cause of the behavior. Common behaviors that should prompt a medical evaluation include hand-mouth behavior, self-injurious behavior, rapid eye blinking, covering one's eyes or ears, aggression, refusing to eat and many others. These behaviors often point to a group of medical conditions. Understanding those connections can help healthcare providers perform an appropriate exam and identify potentially harmful or painful conditions that can be treated providing better care and improving the quality of life of people with intellectual and developmental disabilities.

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The NTG-EDSD: an administrative tool that supports healthcare decision-making

Abstract: Although we know that individuals with Down syndrome are at higher risk for early dementia, beginning in their 50's, we know less about individuals with other developmental disabilities regarding age related cognitive, behavioral and adaptive skills changes.

These age-related changes are most likely to be observed by family and professional caregivers well in advance of any formal diagnosis related to dementia. In response to the need for an administrative tool to advance care of all adults with disabilities and aging changes, the National Task Group (NTG) developed an administrative rating scale, published in 2013, so that family and professional caregivers could capture their observations of change and communicate this to health practitioners and service providers. The National Task Group Early Detection of Dementia Screen (NTG-EDSD) has been used internationally since its publication and has become a strategy to collect relevant data, track changes and inform discussion, and support healthcare decision-making that advances best practice care for aging adults regardless of the etiology of their developmental disorder. This administrative rating tool, easily used by family caregivers or agency staff, can be used to support informed healthcare decision-making and to advance care through discussion with healthcare professionals. Knowing about the tool and how the data have been collated can be useful to health providers when communicating with examinees and their caregivers.

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Mercy Health Youngstown pipeline for dental care in the rural health setting

Abstract: In many areas of the United States there is a shortage of dental care for persons who are uninsured or are insured Medicaid patients, especially those with special needs. To pilot reaching out to this group of individuals we developed a plan at Mercy Health Youngstown Hospital in Northeastern Ohio to use mobile dental vans to provide a pipeline for our rural area, specifically in two counties. The targeted populations include the following: low income drug abusers, elderly, veterans, Hispanics, Amish, uninsured, pediatric, and Medicaid patients unable to find a provider. A program formulated in 2014 allowed for 1) placement and education of our dental residents in these areas to increase the rural dental workforce and 2) serving the communities we recognized as having high vulnerable populations due to metrics drawn from increased emergency department visits, lack of dental care, high drug abuse, and socioeconomic status. To illustrate the process, we reported on our work with a special needs patient with autism spectrum disorder (ASD). The process involved movement from initial evaluation to desensitization and then to eventual dental care provision in an operating room setting to address the dental infection and mitigate the patient's aggressive behavior. By creating a rural oral pipeline through our mobile dental vans, many individuals considered most vulnerable were reached and provided with dental care, referred to primary care physicians, and social work when needed. Education was provided to our dental residents on the importance of providing care in these communities, especially within the drug abuse epidemic areas and to our area's population of persons with special needs, such as ASD.

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Specialized supportive services for caregivers of intellectual and developmental disabilities and Alzheimer's and other dementias

Abstract: In Rhode Island, education and supports to professionals and caregivers has not addressed the needs of individuals with intellectual and developmental disabilities and Alzheimer's disease and other dementias. There is a strong interest in improving quality of service delivery in both the healthcare and human services industries which includes support to both paid and unpaid caregivers. The work has shown that there is a strong interest among professionals in healthcare, human services and educational systems to improve their efforts toward meeting the needs of the population and caregivers. Differences were noted in the approaches necessary to engage the intended audiences. (POSTER)

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Specialized supportive services model for aiding caregivers of individuals with intellectual disabilities and dementia

Abstract: The clinical aim of the Seven Hills Rhode Island Caregiver Assistance Project, funded via a development grant from the US Administration on Community Living was to develop a more dementia capable system of care in Rhode Island and to help individuals with intellectual and developmental disabilities (IDD) affected by dementia remain in community settings. The approach was to ensure that both paid, and unpaid caregivers have access to the necessary education and training that will be utilized to support the progressive nature of dementias. The clients of this project were paid and unpaid caregivers of individuals with IDD affected by dementia. The project organized and provided free training through multiple levels of availability to ensure that access is not limited to one resource in the state but rather is available in both private and public settings. The model's premise is that by developing partnerships with various community organizations, and joining forces with regulatory bodies, the work will remain sustainable. To date many services have been offered, including person and family centered care and training. We've observed improvements in the quality and effectiveness of programs and services dedicated to individuals aging with IDD at risk of developing dementia and enhanced delivery of behavioral symptom management training and consultation to family caregivers.

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Mortality among patients with developmental disabilities in medical home settings

Abstract: Individuals with developmental disabilities (DD) are known to have decreased life expectancy and increased risk of death due to preventable causes. Seizures, aspiration, constipation, and dehydration, termed 'the fatal four', are common etiologies of potentially preventable death for individuals with DD. Best practice strategies in preventing these complications as well as discussing life expectancy with patients and family need further development. We sought to identify causes of death and associated risk factors for patients established with a medical home specifically for adults with DD living in the community. The patient registry for a

medical home for patients with physical and intellectual disability to chronic childhood conditions from 2008-2017 was reviewed to identify the most common causes of death and associated underlying diagnoses. We found that 46 (6.1%) deaths were recorded out of 750 patients. 27 (58.7%) were male and the average age of death was 27.4 (range 17-54). The most common cause was sepsis (total 17, 5 due to pneumonia, and 3 due to urinary tract infection) followed by respiratory and neurological etiologies. The most common primary diagnoses for deceased patients were genetic syndromes followed by cerebral palsy. 50% of these patients had underlying seizure disorders, were wheelchair dependent, and were gastrostomy tube dependent. Like other mortality studies of individuals with DD, death due to respiratory, nervous, and genitourinary systems was common in this population and patients who were more technology dependent were more likely to have early death. The medical home setting offers an opportunity for population-based health care including best practices for discussing life expectancy and intervention for preventable causes of early death for patients with DD.

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Utility of a health care transition feedback survey

Abstract: Special needs patients face many challenges, and transitioning from pediatric to adult care can be especially daunting. Many patients and their caregivers report not being sufficiently prepared for this transition. To help guide professional and community outreach efforts in our Transition Medicine Clinic, we administered the "Got Transition" Health Care Transition Feedback Survey to 29 young adult special needs patients and 69 caregivers of patients who were unable to complete the survey themselves. Regarding previous experience, respondents reported that: their pediatric providers had explained things understandably (90.8%); listened carefully (90.8%); provided a medical summary (81.4%); explained legal and insurance changes to expect (77.6%); informed them about the age of transition (76.5%); helped identify an adult care provider (62.2%); and provided a copy of medical records for the adult provider before the first visit (50.0%). Regarding their own feelings, 58.2% reported feeling very (23.5%) or somewhat (34.7%) prepared for transitioning to adult care. Three physician behaviors correlated with patients feeling prepared for transition: actively working with patients to think and plan for the future in general ($p=.024$), to gain healthcare self-management skills ($p=.003$); and to talk with patients without the parent/guardian in the room ($p=.003$). Percentages of respondents who reported these experiences were respectively 59.2%, 60.2%, and 34.6%. Preparing for successful transition to adult health care must begin proactively during the time of pediatric care. In this study, the individualized and personalized physician-patient interactions that help patients the most reportedly occurred the least. Numerous tips and resources are available to facilitate better transition. The challenge is not to discover what helps but rather how to translate what is known into practical standards of care that will help special needs patients to address their adult life and health care needs. (POSTER)

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Ten tips for successful medical transition of adults with developmental disabilities

Abstract: The goal of transition in healthcare for young adults with special needs is to maximize lifelong functioning and potential through the provision of high-quality, developmental appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood. (Pediatrics. 2002. 110-1304-1306). Medical transition is invaluable for young adults with special needs. When applied appropriately, it gives individuals the opportunity to access the services they need and reach their fullest potential. With a patient population of approximately 700 (and growing), the Baylor College of Medicine & Texas Children's Transition Medicine Clinic has gained much experience and expertise - since its inception in 2005 - in the treatment of patients with complex medical conditions and disabilities who have transitioned from pediatric to adult care. Over the years, their social work team has identified specific areas that are of utmost importance for young adults who are transitioning. This led to the development of the "Ten Tips for Successful Medical Transition." By focusing on these ten tips, young adults with special healthcare needs can experience smoother transition and better quality of life.

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Person-centered care: Five strategies to drive empowerment, inclusion, and outcomes

Abstract: As states draft transition plans to comply with the new Centers for Medicare and Medicaid Services rules on home and community-based services and implement conflict-free case management under the Balancing Incentive Program, provider organizations serving individuals with developmental disabilities must implement new service-delivery models, support strategies, and potential structural changes – all amid a turbulent political backdrop and uncertain future for Medicaid funding. One way to address this is to follow five-data driven strategies, which include (1) improving communication among providers, individuals, and their circles of supports – strategies to eliminate barriers and empower individuals to drive their services; (2) delivering cost-effective and time-efficient case management – exploring new, integrated delivery channels and opportunities to maximize braided funding for optimal outcomes; (3) effectively engaging individuals in the person-centered planning process – from assessments to individual service plans, tools and tactics to improve collaboration among individuals, providers, and circles of supports; (4) measuring, monitoring, and improving outcomes and quality in community-based setting – solutions for tracking and sharing qualitative and clinical information among team members in real-time, and (5) moving beyond compliance to advance the principles and practices of self-determination and discussing 'optimal service delivery' and what that means to various stakeholders. The authors conclude that in today's landscape, effectively delivering case management and person-centered supports requires new tools and strategies to balance compliance, outcomes, community inclusion, and cost-efficacy. (POSTER)

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Care management in the digital age: Integrated human service solutions for real-time monitoring, alerting, and reporting

Abstract: Individuals with intellectual and other developmental disabilities have complex health care needs, which often include an increased occurrence of physical and mental health comorbidities as well as a higher rate of hospitalizations compared with population averages. The human services field has been advocating a shift to new service delivery models that focus on the integration of physical, behavioral, and long-term services and supports (LTSS), including the development and expansion of home and community-based service (HCBS) alternatives to institutional care. This shift, coupled with a focus on further integration into the community, promises to increase the number of providers working with each individual and expand the settings of care or support. The authors undertook an evaluation of current and proposed service delivery models to identify how proposed technology solutions would be used to meet goals of improving outcomes and reducing costs. Where appropriate, strategies were compared with more established initiatives and/or best practices in traditional healthcare delivery to determine effectiveness. The evaluation demonstrated the role of electronic record systems as essential in coordinating care for the individual in the digital age, with a specific need for interoperability among disparate provider systems. The authors note growing trends in LTSS/HCBS delivery modeled after strategies employed in traditional healthcare delivery. These include a focus to integrate disability and social data with state health population-level data collection and the role of “big data” in outcomes tracking and program design.

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Down syndrome and Alzheimer’s disease: Common pathways and potential treatment avenues

Abstract: Down syndrome (DS) is a developmental genetic condition caused by trisomy of human chromosome 21. DS occurs in approximately 1 in 600 to 1000 live births world-wide, and is estimated to involve more than 300,000 people in the USA. Neuropathological and clinical features of Alzheimer’s disease (AD) present in the fourth through sixth decade of people with DS, and include neurofibrillary tangles (NFTs), amyloid plaques, neuronal cell loss, inflammation and dementia resembling AD. The prevalence of AD in DS rises steeply with age. In contrast to the normosomic population, people with DS have almost complete penetrance of AD pathology in those that survive long enough. Biological mechanisms and potential biomarkers of DS in AD have not been investigated until recently. Several research groups are now examining mechanisms underlying the onset of AD pathology and the relationship to cognitive decline in the population with DS. Our research group explored the use of neuron-derived exosomes purified from blood samples to determine when during the life cycle these extracellular vesicles which are secreted from nerve cells in the brain start expressing AD biomarkers. Amyloid and

phosphorylated Tau levels, which are two common biomarkers for AD, were highly increased in exosomes already at 8 years of age in DS, and continued to increase during the life span. In addition, we found that those with DS and dementia expressed even higher levels of phospho-Tau, but reduced amyloid levels in neuron-derived exosomes. Our studies indicate that interventions reducing AD pathology should be initiated early in life in DS, and may indicate a window of opportunity for treatment or life style changes that can impact dementia onset and/or progression. (PLENARY)

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Coping with forensic issues among persons with intellectual and developmental disabilities

Abstract: Issues associated with forensic evaluations for persons with intellectual and developmental disabilities cover a range of areas, and as health workers increasingly encounter them, more knowledge can help mitigate potentially problematic situations. It is increasingly important for persons working with this population to understand the forensic process to assist and prepare their clients for courts, and to maintain proper records to assist the courts in their decisions. The courts bear an enormous responsibility in cases involving persons with cognitive and developmental disabilities, and there are many difficult decisions to be made in the court process. In addition, judges, lawyers and others associated with the courts may not fully understand the complexities associated with assessment, competency, mental health, and related issues for this population. It is important for persons working with this population to understand the forensic process to better assist the courts as well as the persons in their care. For example, it is not unusual for an adult with no clear history of assessment or services to be referred for assessment with a question if he or she is a person with an intellectual or developmental disability. In forensic situations, appropriate diagnosis, documentation and assessment are extremely important to fairly adjudicate persons with intellectual and developmental disabilities. Health workers should know the issues associated with the determination of a diagnosis for the courts of intellectual and developmental disabilities, along with the issues of competence to stand trial, responsibility for conduct, and the possibility of malingering.

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Tackling health disparities and implementing a ‘best practices’ health care model for people with intellectual disability

Abstract: Disparities in health care and treatment of people with intellectual disability lead to increased morbidity, mortality, and costs, and decreased quality of life. A recent ‘Partnering to Transform Healthcare with People with Disabilities Conference’ enabled self-advocates across disability communities (intellectual, physical, sensory and mental) to partner with national experts (providers and policy makers, executives, insurers, regulators and others) to synthesize current innovations and improvement efforts in health care with people with disabilities, reach consensus on best practices, propose needed services development and policies, develop action

plans, and create a research agenda. The speakers discussed the findings from the conference with respect to implementable solutions, consensus on best practices and research, and the policy agenda recommendations for people with intellectual disability.

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Building bridges to health equity: Parable and paradox

Abstract: As in the parable of the mustard seed, the smallest bridge can become the most significant passage over an obstacle. Despite groundbreaking and positive shifts in the last three decades in public attitudes, available resources, and established legal rights for persons with intellectual and developmental disabilities, significant health disparities remain. How can the AADMD and its friends be a pivotal catalyst to allow our nation to reach the goal of health equity for all? Explored was this question and as well a reflection upon the current human rights framework which can support this goal and some real challenges to the full integration of health services -- including the critical role of preventive services and the essential place of individual leadership. In the end, it is quality, character, demands, and rewards. [PLENARY]

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Use of the 'Practice Without Pressure' model to eliminate restraint and reduce sedation in delivery of medical, dental, and personal care

Abstract: People with intellectual and developmental disabilities (IDD) are often restrained or sedated for care. Sedation and restraint cause negativity cycles to be created. This care approach is one that most clinicians are not comfortable performing, so referrals are made to the small number of clinicians who specialize in restraint and sedation. It causes waiting lists of sometimes years before care can be rendered. It is often assumed by clinicians as well as caregivers that these individuals cannot participate in their own care. The Practice Without Pressure (PWP)[™] philosophy of care assumes that people with IDD can participate in their own care without the use of restraint, and with minimal to no sedation. PWP operationalizes this philosophy with the PWP Process Model[™]. The model includes working with the individual, caregiver and clinician with strategies developed by PWP in intentional, positive ways that break the negativity cycle and build capacity in the individual. PWP intervention allows people who have had care only under sedation or restraint in the past to experience, and participate in, care without either. The PWP approach, when used from a young age, removes the need to break the negativity cycle, as it is never created. The PWP Process Model has been used successfully with over 700 individuals with IDD to participate in their own care. A data analysis of 90 adults with IDD showed a reduction of sedation after PWP intervention of 76% for a medical or dental procedure. Over a three-year time frame the reduction rate held at 70%. The author concluded that the PWP Process Model builds capacity over time in the individual, caregivers, and the clinician.

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The eyes have it: Brain basis of social cognition in autism spectrum disorder

Abstract: Individuals with autism spectrum disorder (ASD) have difficulty interpreting the minds, intentions, and nonverbal cues of others (i.e., theory of mind). This strong, self-referential focus in ASD is reflected in abnormal brain development and function. The specific aims of this program are to 1) describe deficits in theory of mind, 2) discuss eye gaze patterns in face and emotional processing and 3) examine the neural correlates of social cognition exhibited by individuals with ASD. Studies of autistic deficits in theory-of-mind primarily employ false belief tasks and eye tracking. Neuroimaging of brain development and function are coupled with these measures. Individuals with ASD are unable to discern the mental states of others (mind-blindness). Rather, they prefer to focus on their internal thoughts or inanimate external stimuli and routines. The mechanism for this is their tendency to avoid eye gaze. Whereas neurotypical controls preferentially view the eyes of a face, those with autism tend to watch the mouth. This affects their ability to infer intention and emotion. This abnormal perception is tied to abnormal brain size and function. Anatomical studies show that patients with ASD are born with small head circumference, but that growth quickly outpaces their peers. Simultaneously, key brain areas are reduced in volume and impaired in function. This is true of the amygdala, fusiform face area, superior temporal sulcus, and medial prefrontal cortex – all structures associated with person perception. ASD is a complex and heterogeneous set of developmental disorders with impaired performance on tasks of mentalization. Because these individuals cannot accurately detect the thoughts, intentions and emotions of others, they have difficulty experiencing and expressing empathy. These deficits in social cognition are challenging to amend, as they are rooted in neuropathology.

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Behavior Approaches Panel

Abstract: Following a session describing behavioral approaches to avoid the use of protective stabilization, experts in neuroscience, psychology, and behavior management served as panelists during a discussion representing multiple viewpoints.

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Effects on dental treatment of vitamin D deficiency in autism

Abstract: Vitamin D deficiency is a prevalent issue affecting the health of people with a developmental disability with contributing genetic and environmental factors. The effects of the deficiency can have a considerable impact on how dental and medical

professionals treat these patients in conjunction with their developmental disorders. People with developmental disabilities are more likely to have vitamin D deficiency and its effects compared to the neurotypical population. Certain medications can also augment the lack of vitamin D in these individuals. This population with a vitamin D deficiency is impacted with impaired bone metabolic and dental diseases such as osteoporosis, periodontal disease, and edentulism. Patients with a vitamin D deficiency and neurodevelopmental disorders may need to be treated in a healthcare setting with more care and patience than those without these disorders. (POSTER)

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Applications of comprehensive eye examinations for special needs populations

Abstract: Most younger pediatric special needs patients are provided with appropriate ocular health care by either an optometrist or ophthalmologist. As the population ages, there are fewer eye care specialists who are willing to integrate and perform complete eye exams on patients with special needs. The UT/H Special Needs Adult and Pediatric Service (SNAPS) and well as our other pediatric and binocular vision clinics accept patients of any age and of a wide variety of abilities and disabilities. The SNAPS clinic specifically has no age limit. We perform as much of a comprehensive eye exam as possible on every patient. In addition to providing this service to our patients, we are also a university and teaching institute where we are educating future optometrists. The student clinicians in our service are gaining priceless experiences and tools to be able to integrate this training into their future practices. Our clinic is equipped with many materials to be able to assess the patient's level of vision, binocular vision status, and ocular health, as well as gain insight into their contrast, color, and depth perception. Many binocular vision and refractive error corrections are more common in a special needs population. Understanding their visual demands is imperative to helping them use all abilities at the highest level. This information is typically useful in understanding the patients' visual needs in school, therapies, or for typical activities of daily living. Patients of all ages with special needs should be provided with the same potential for continued eye care as their classmates, friends, and family members. We have many goals for our clinics and hope that we can not only set an example to the community of the potential to serve this population as well as providing training to future eye care professionals.

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Dental management and treatment planning for the aged compromised patient

Abstract: The success of dental therapy and treatment, as with other interventional specialties, relies heavily on the cooperation and understanding of the patient being treated. The aged compromised patient, who is physically or mentally compromised, or both, poses many challenges to fulfillment of the practitioner goals due to the lack of comprehension or cooperation. It

therefore becomes critical for the practitioner to be able to assess the patient's physical limitations, as well as cognitive ability. Based on that assessment, appropriate treatment can then be attempted. Using Alzheimer's disease as an example, assessment can be complicated. Alzheimer's disease progression is broken down into seven stages (in one system), which can be arbitrary depending on the evaluator's perspective, but nevertheless can be a helpful guide in making the practitioner's final evaluation. The number of Alzheimer and adult dementia studies and associations has grown significantly from when "The 36 Hour Day" (by Mace & Rabins) came out. As with many other area of studies, the more that becomes evident, the more questions are asked, so it become incumbent on the practitioner to be as knowledgeable as possible and proceed to treatment with forethought and patience.

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An overview of dental informatics: What, where, and how

Abstract: Dental Informatics is a specialization within health informatics, a multi-disciplinary field that seeks to improve healthcare through the application of health information technology and information science to health care delivery, health information management, health care administration, research, information gathering and synthesis, and knowledge sharing. Dental Informatics has application in all the areas of dentistry whether it is dental practice, research, education or management. One of its applications, tele-dentistry, can have a significant impact on the society especially for the lower socio-economic community, children with special needs and disabilities. Results have shown that this field of dentistry has a huge role in securing patient's health information and data integrity which has significantly improved the access and enhanced the quality of the care. Imagine a dentist with clinics in multiple locations and with the help of the electronic record, information is uniform and attainable at any location which helps the associate dentist retrieve full medical and dental history, including radiographical information. The result is reducing the cost and ameliorating the care. Computerized data mining tools and analysis are used in the field of research for various epidemiological studies which have helped many scholars to share their results and supplement in decision making. Dental Informatics can similarly be a helpful asset for improving the quality care and enhancing patient access.

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Addressing oral health among adults with intellectual disability and dementia

Abstract: It is generally known that people with dementia have significant problems with oral health and that these problems can affect self-esteem, self-confidence and social communication. Equally, substandard oral health can lead to a toothache and tooth loss that can impact their quality of life and has eloquent effect on the functional, communal and mental well-being of a person. People with intellectual disability, who also

have a progressive neurodegenerative disorder, such as Alzheimer's disease, Parkinson's disease, Wernicke-Korsakoff syndrome, or other similar condition, are likely to compromise their oral health due to further intellectual impairment – thus increasing the risk of oral disease. Dementia patients may be on multiple medications that cause undesirable effects such as xerostomia, vomiting, gingival overgrowth or tardive dyskinesia. Moreover, a medication for dementia has the capacity to cause an unfavorable response when incorporated with drugs used in the dental clinic, including anesthetic and antimicrobial agents. Dental treatment for a patient with dementia is generally based on patient's level of independence, cooperation, cognitive state, and physical impairment. The aim of the treatment is to improve the quality of life in persons with dementia by providing preventive and therapeutic dental care and educating the patients and their caregivers about the importance of oral hygiene and its role in the overall health. Adults with intellectual disability, when in early stages of dementia, can retain the capability of maintaining good oral hygiene practices if they are provided with sound dental care and supported with guidance on maintaining oral care. Further, frequent dental exams can lower tooth loss, earlier recognition of oral cancer, lessen oral pain, and reduce intraoral infections. (POSTER)

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Perception of dental professionals and caregivers towards treatment of individuals with intellectual disability - A qualitative study

Abstract: Oral health has a significant impact on holistic health. As individuals with intellectual disabilities (ID) may be difficult to treat, there is a risk that the disability may constitute a barrier preventing them from receiving good treatment. The provision of timely and appropriate preventive and therapeutic oral health care is beset with problems. This study describes the challenges, perception, understanding and knowledge of dental care professionals and their caregivers in treating and dealing with individuals with intellectual and developmental disabilities in the Delhi NCR Region. Purposive sampling was undertaken of four dental professional providers and four caregivers who had been working in the special care dentistry clinic at one institution. In depth interviews were carried out. These were analyzed in open and focused coding processes in accordance with grounded theory. We found two core categories, which we labelled variability in treatment with the dimensions, *professional uncertainty* and *professional commitment*. Variability in procuring oral health care could be described as forming a continuum between two end points captured in the dimensions. The dental teams' treatment of persons with ID could be placed anywhere in the continuum. Providers most often noted that communication barriers and complexity of social and medical situations limited their ability to effectively deliver care. Most adults gave no specific reason as to why the care providers did not visit the dentist but it was surmised that it was due to high cost, fear, and lack of time. Discussions gave participants an opportunity to share their experiences, which will be useful for training of dental professionals. There is need for more educational opportunities, better financing, and more support at the university level. Obstacles can be overcome by sensitizing students and oral health professionals, encouraging home-based preventive services, and facilitating access of patients and caregivers to the clinic. Seamless integration of care at all levels may be achieved by building up the workforce. (POSTER)

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Transitioning from pediatric to adult neurologic care for individuals with intellectual and developmental disabilities

Abstract: Individuals with intellectual and developmental disabilities (IDD) frequently have neurologic complications including medically refractory seizures disorders, spasticity, and movement disorders, all of which may be complicated by challenging behaviors and difficulties with communication. Many of these complications begin in childhood and continue throughout the lifespan. The healthcare supports for these individuals most often begins in childhood and is provided by trained specialists in pediatric neurology for which education and a training curriculum are well established. Transitioning to adult care services typically occurs after age 18. Access to qualified adult neurologists who specialize in IDD is not uniformly seen. Adult neurologists typically receive only 3 months of general pediatric training in residency and specific aspects salient to IDD within training may or may not be a part of the program. There are no current standardized neurology care guidelines for adults with IDD and neurologic complications, nor are there any established curriculum, CME courses, or board examination questions. There is also a paucity of research in this area. To stimulate discussion and potential actions, a roundtable was held discuss and tackle these continuing issues during the April 2017 annual conference of the American Academy of Neurology in Boston, Massachusetts. The participants included leaders in child neurology, adult neurology, advocates, IDD nurses, as well as the Massachusetts Department of Developmental Services, and regional support agency leaders. Managed Healthcare was represented in the conversation to help flesh out the questions and concerns about reimbursement and coverage of services that can have an impact upon access and quality of neurologic care and services. (POSTER)

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National Task Group Business Meeting

Abstract: The National Task Group business meeting covered annual updates, a discussion of introducing memberships to the NTG, preliminary planning for the Seattle 2018 program and planning NTG activities for the balance of 2017 and into 2018. The meeting was open to NTG members.

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A conversation about the International Summit on Intellectual Disability and Dementia: Issues, commentary, and recommendations

Abstract: The International Summit on Intellectual Disability and Dementia held in Glasgow, Scotland, October 13-14, 2016, was hosted by the University of Stirling and co-sponsored by National Task Group on Intellectual Disabilities and Dementia Practices (NTG). The Summit was composed of individuals and representatives

of several international and national organizations with a stake in various issues related to adults with intellectual disability affected by dementia. The summit was discussion-based and designed to produce a summative report on a number of issues with recommendations for public policy, practice, and further research. Working groups were assigned *a priori* tasks to produce discussion summaries on several topics. The discussion topics encompassed three main conceptual areas, including (1) human rights and personal resources (applications of the Convention for Rights of People with Disabilities and human rights to societal inclusion, perspectives of persons with intellectual disability), (2) personalized services and caregiver supports (advancing and advanced dementia, post-diagnostic support community, dementia-capable care practice, end-of-life care practices, support for family caregivers), and (3) advocacy and public impact (nomenclature/terminology, and inclusion of persons with intellectual disability in national plans). To date, several discussion summaries have been converted to published papers in peer-reviewed journals and a summative report has been produced. Information was offered about the various outputs and their main themes and recommendations. The various papers, the summative report, and the recommendations have become international resources, guidance for practices, and the impetus for advocacy on behalf of people with intellectual disability affected by dementia, as well as their families.

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A patient review of a young adult male with autism with a need for oral care

Abstract: Providing care to patients with autism spectrum disorder (ASD) can be challenging because each patient presents with a unique set of symptoms requiring individualized behavioral management. Patients with ASD generally react favorably in routine environments and with familiar people. Factors outside their normal routine can cause stress and lead to anxiety, meltdowns and aggressive behavior. Thus, identification and elimination of stressors can help the patient better cope with stress. In this case, the patient seen was a non-verbal 21-year-old male with ASD, obesity, and a history of aggressive behavior. On initial presentation to the dental clinic the patient would not exit the vehicle for examination despite pre-medication for anxiety. On visual examination through car window it was determined that the patient needed dental care. This case presented an example of a unique challenge to healthcare providers due to the patient's weight (350lbs/158.7 kg), history of aggressive behavior, reluctance to leave the vehicle, and limited ability to communicate. Together with the dental team, a picture chart was incorporated into the patient's home routine to identify and help acclimate the patient to the dental clinic. Regular drive-by visits to the dental clinic with patient's mother were scheduled to familiarize the patient to the clinic's lobby. After 6 weeks of behavior guidance, the patient would open the car door, but still refused to exit the vehicle. Use of a ketamine dart was previously discussed with the family to ensure that the patient safely exited the vehicle, but was not administered. The patient was scheduled for dental care after undergoing general anesthesia (GA). The patient was met at the emergency room lobby by emergency, anesthesia, and dental teams. Security was also present. He was administered Versed elixir (midazolam) car-side by t anesthesia team adjacent to the emergency department (ED). Patient willingly walked into ED and was transported

via gurney to operating room where he received dental care while undergoing GA. (POSTER)

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Developing a healthcare transition process for a heterogenic group of adults with intellectual and developmental disabilities

Abstract: We aimed to improve the patient/caregiver experience of healthcare transition planning by establishing a patient-centered Transition Readiness Program (TRP) run by an interdisciplinary transition team at the Texas Children's Special Needs Clinic (SNC). The users of the clinic include primary care pediatric/adolescent patients with complex, chronic medical conditions (most with profound intellectual disability) receiving care at a tertiary medical center. Office visits were conducted with patient/families consisting of a multidisciplinary team dedicated to transition planning. A transition statement was developed for review with patients/families and office visits were structured so that a care plan could be developed together with the family, and could be shared with the patient's new adult provider. Additionally, other members of the healthcare team supported families via discussions regarding medicolegal, funding, and scholastic/workforce transitions. Preliminary data indicates successes (improvement in patient's having a clearly documented and easily-accessible care plan) and challenges (no good measure of patient satisfaction) experienced in implementation phase of a novel Transition Readiness Program. Further studies and practice modifications will be derived from the outcomes from our internal reviews.

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Health care inadequacies faced by adults with intellectual and developmental disabilities: A call to action

Abstract: The most easily remediated barriers to health care access that impact individuals with intellectual and developmental disabilities (IDD) involve both a lack of training for medical students and a lack of recognition of the persons with IDD as a distinct medically underserved population (MUP). The largest barrier to health care for the IDD population is lack of education and training of their current and future physicians, which consequently causes lack of trust toward the clinician by the patient and/or the family, discomfort for the provider, and medical consequences for the patient that include overmedication, mismanagement, misdiagnosis, inability to recognize the unique ways common problems present, lack of screening, and lack of proper access to care. Additionally, the IDD population is not federally recognized as a MUP because the Health Resources and Services Administration (HRSA) defines a MUP as a specific sub-group of people living in a defined geographic area with a shortage of primary care health services. Since this geographic criterion is not met, the IDD population is excluded from targeted public health efforts, HRSA's many training and scholarship programs for health professionals, NIH program requirements for research on health disparities, and grants from NGOs and states. Training solutions include proposed curricula for medical schools that encompass didactic instruction,

patient panels, standardized patient encounters, clinical experience, formative exams, and home visits/community service. Advocacy solutions include continued efforts on the part of medical organizations and societies and petitioning of the governor's Exceptional Medically Underserved Population (EMUP) designation state by state. Medical students, residents, and practicing clinicians can further advocate by speaking to their curriculum committees to petition that IDD training be included into didactic and clinical education. Further, advocacy groups should use resources provided by the AADMD and other organizations and complete online modules/Continuing Medical Education (CME) lectures available online to enhance their own knowledge and awareness. (POSTER)

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Emerging roles and changing expectations of the direct support workforce

Abstract Examining this topic offers us a chance to reflect on the current direct support workforce crisis and the evolving role and expectations of Direct Support Professionals. Many of these changes are driven by the Centers for Medicare & Medicaid Services (CMS) and its Federal Home and Community-Based Services Community Rule. This is a radical departure from which we are accustomed and will ultimately create an emphasis on 'personal autonomy', greater access to 'integrated settings,' and helping people to make 'informed choices'. This presentation addressed and stimulated discussion on several important aspects of the CMS Rule, including: How do we support people with disabilities to make informed decisions? What is the direct support professional's role in this process? What are the workforce demographics and projections to fulfill these expectations? Do direct support professionals currently possess the tools, resources and skills to uphold this responsibility? Ultimately, can we find new methods to implement change and address the workforce crisis with new public policy initiatives? (PLENARY)

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Correlation between periodontal disease and Alzheimer's disease

Abstract: The older population is progressively including more adults from the baby boomer generation. This is altering the demographics in the US population with an increase in the number of people over the age of 65. As this population ages, Alzheimer's disease (the most common cause of dementia) is increasing and there is evidence suggesting a relationship between oral health problems and patients having Alzheimer's type dementia. Etiology of Alzheimer's disease involves gram-negative bacteria from brain infection. Current studies have depicted the presence of Chlamydia pneumonia in cells of an affected Alzheimer's brain which research has shown to be a biologically attainable pathogenic oral bacterium that propagates via the bloodstream. The human body's line of defense against bacterial and viral pathogens is through inflammation. Genetics play a large role in the chronic inflammation progress. Alzheimer's disease and periodontal disease both have a similar underlying genetic

factor (variants in the interleukin 1 gene family) which provides insights into their pathogenesis. While poor oral health has an impact on patients with dementia, recommendations for prevention are similar to those for patients without dementia. It is crucial to practice early prevention and detection to maintain oral health. Patients with Alzheimer's disease have lowered cognitive and mental skills; thus, they often have significant issues with oral health, predominantly due to periodontal disease. The absence of supervision and guidance to maintain oral health may lead to increased inflammation which not only accelerates periodontal concerns, but also influences Alzheimer's disease, further declining overall health. (POSTER)

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Nutrition care for children and adults with intellectual and developmental disorders

Abstract: Children with intellectual and developmental disabilities (IDD) have a variety of feeding difficulties beginning at birth and extending to old age. Their challenges include sensory problems, gastrointestinal and pulmonary issues, mobility and orthopedic problems, mental and behavioral concerns, side effects of medication, and changes in energy and nutrient needs. These and other issues associated with specific disability and social and environmental factors affect food intake and assimilation of nutrients thereby increasing individuals' risks for chronic malnutrition, slowed growth and development, and compromised overall health and premature mortality. Throughout their life course, the individuals' ability to consume or receive adequate calories and nutrients is crucial to maintaining health and supporting growth of young children and youth. As individuals with IDD age, the age-associated functional and cognitive decline and exposure to other health problems (e.g. obesity, cardiovascular diseases, diabetes) magnify the complexity of meeting their nutritional needs. Like the general aging population, their risks for developing Alzheimer's dementia also increase. It is widely recognized that a healthful diet, along with other health-promoting lifestyle factors, can help improve the nutritional health and well-being of this group from birth to old age. It is important to have a sound grounding in select common nutritional concerns of individuals with IDD and practical nutrition strategies for reversing these concerns. These occur at significant points along the lifespan in which nutrition needs demand careful consideration and nutrition intervention makes a difference.

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Reviews of the deaths of clients in the state of Hawaii developmental disabilities system

Abstract: Sub-optimal care resulting in premature death and impairment of people with intellectual and developmental disabilities (IDD) still occurs even with home and community based systems. An important quality assurance tool is mortality reviews. The State of Hawaii Department of Health has analyzed several years of reviews. Mortality data collected on all individuals served by DDD that died revealed that the average age of death for people with IDD is much lower than the average US or Hawai'i life expectancies. Additionally, the average age of death recorded by Hawai'i's IDD system is on the

lower end of the range reported by state IDD systems nationally. A paper looking at select states showed adults with intellectual disability tend to have a lower life expectancy at birth ranging from 58.7-62.0 years. In reviewing causes of death in Hawai'i, cardiac complications and cancer were common causes of death for both the general state population and those with I/DD. However, compared to the general population, deaths attributable to pneumonia and septic shock ranked higher among those with IDD. People with IDD are often vulnerable because of poor or absent skills in communication. They may have problems telling those around them that they do not feel well and have a problem that requires medical care. They are at a higher risk for chronic medical conditions such as dysphagia, aspiration pneumonia, and decubitus ulcers and require special supports to thrive in home and community settings. Conducting mortality reviews for people with IDD enables systematic identification of challenges in effective medical care for this population, leading to recommendations that have the potential to result in improved length and quality of life for this vulnerable population.

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Telemedicine and adults with neurodevelopmental conditions: An innovative means of bringing care to those who need it most.

Abstract: As part of an innovative grant through the New York State Department of Health, a program sent urgent care teams to the homes of over 2000 enrolled individuals with neurodevelopmental and intellectual disabilities. The goal of the grant was to provide access to care to reduce emergency department (ED) visits and hospitalizations. The early success of the grant allowed us to implement a process of using telemedicine. The use of a newly constructed portable telemedicine bag allowed the providers to use diagnostic equipment to treat individuals in the comfort of their home. The value of this program was demonstrated by the cost savings noted during the term of the program. Using grants to develop and implement the telehealth process show that the goals for ongoing use of the equipment and a demonstration of the equipment with a remote patient in New York can be an effective process. Such an effort demonstrates how the rate of ED visits can be reduced. This reduction of ED visits lowered costs to the oversight agencies and insurance companies, as well as returned patients to normal activities sooner. This specialization approach allows for the use of equipment as well as demonstrates how this approach augers well for the future of medicine so that it can help those who need it most.

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Training medical students to care for patients with disabilities: a pilot program at the Ohio State University College of Medicine

Abstract: Leadership Education in Neurodevelopmental Disabilities (LEND) faculty and fellows collaborated with The Ohio State University College of Medicine (OSUCOM) to develop a clinical experience to educate third year medical students in caring for patients with

developmental disabilities. OSUCOM's curriculum lacked structured and deliberate practice interacting with this unique population. Our objective is to assess the efficacy of this experience with the long-term goal of implementing a more permanent and standardized Formative Objective Structured Clinical Examination (FOSCE). Twenty-six volunteers with developmental and other disabilities were recruited to serve as patients for the practice encounter. Students were given reading materials to prepare for their interaction. The student was given 15 minutes to complete a social history, followed by direct feedback from the patient volunteer and their caregiver, if present. After completion of the interview and feedback, students participated in a group debriefing session led by a faculty member. Attitudes and comfort caring for patients with disabilities were assessed using a post-encounter survey. It was expected that students would perceive this as a positive experience and report feeling more comfortable and competent to care for patients with disabilities. Both quantitative and qualitative survey data were used to assess these outcomes. Medical schools in the U.S. must do more to incorporate disability education into the undergraduate medical curriculum. Providing medical students with direct practice interacting with patients with disabilities may improve their competence and comfort caring for this population. It is anticipated that our work with OSUCOM will serve as a model for other medical schools.

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Foundations in developmental medicine: The contributions of Sir Ludwig Guttmann

Abstract: This is the fifth installment of Foundations in Developmental Medicine; where physicians, who have made lasting and significant contributions in laying down the values, skills, insights and 'eureka's' that have guided the AADMD and developmental medicine are described and applauded. This year we share the story of Sir Ludwig Guttmann who revolutionized the treatment of patients with spinal cord injuries. Guttmann incorporated sports into the treatment of paralyzed British World War II soldiers and found it played a key role in their rehabilitation. These games became the Paralympics and pioneered a new frontier in the lives of patients with a previous life expectancy of six weeks. Many of the lessons learned in the modern Special Olympics regarding normalization and engagement were formulated by Dr. Guttmann over 75 years ago. [PLENARY]

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Health care advocacy: the family perspective

Abstract: Do you have patients with intellectual and developmental disabilities (IDD) whose families are filled with questions and concerns that are difficult to address? Do you have family caregivers asking questions that aren't related to your specialty? When family caregivers tell you that their loved ones are showing declines in skills and report other significant changes, what can you do to help them uncover the causes of these changes? If you have patients whose family caregivers are stressed and burning out, do you know how you can help them? Do you have patients who have suddenly started to refuse to come

into your office or sit in the waiting room? How can you support a family who is in denial that their loved one with I/DD is coming to the end of their life? For many years, parents thought they would outlive their sons and daughters with IDD and, thus, did little planning for their loved ones' older years. With advances in healthcare and changes in life expectancy, aging and health matters are now a growing concern for families of older adults with I/DD. Families often turn to health care providers with expectations that they will get guidance and answers to their questions. Too often, they find it extremely difficult to get the information they need to address their specific issues. Families report that their encounters with medical providers range from impatient and indifferent, to supportive and collaborative. Unfortunately, those of the latter kinds are primarily in areas of the country where adult specialty clinics for individuals with I/DD are located, while families all throughout the United States would also like a team approach with their medical providers. These and additional concerns families have about aging and health care can help inform on adopting strategies for use in health care settings that can be implemented to compassionately support patients with IDD, and their families.

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Neurodiversity and how I came to be a founder of DifferentBrains.com

Abstract: The neurodiversity community site DifferentBrains.com and Hackie Reitman M.D. (author of *Aspertools*, neurodiversity advocate, filmmaker, former professional heavyweight boxer and orthopedic surgeon) are working to establish a new normal—one where variations in brain function are understood to be as normal as variations in race or sex, and where society understands that one size does not fit all. Most practitioners have some knowledge of how to treat patients that could be considered “neurodiverse.” The conditions that fall under that vast umbrella are becoming increasingly prevalent – 1 out of 68 births are on the autism spectrum, 20% have dyslexia or another language-based learning disability, 20% of adults exhibit signs of mental illness, 7% of adults have clinical depression, 9% of adults have ADHD, 15 million adults have Alzheimer’s disease. Add up these diagnoses along with the plethora of others – Asperger’s syndrome, bipolar, OCD, Down syndrome, Parkinson’s, and many more – and soon you find that many us have what could be termed a “different brain.” And, virtually none of the entities occur as solitary entities, but rather as co-morbidities. However, medical and dental professionals’ training in the recognition and accommodation of these conditions remains woefully insufficient, as does such training in every other profession and throughout most of our institutions. That lack of knowledge reduces diagnostic accuracy, has negative ramifications on outcomes, bedside manner, as well as on the morale of staff, and the efficiency and financial bottom line of medical practices. Dr. Reitman used his personal journey of discovering his daughter’s numerous neurodiversity issues, including the much later discovery of his daughter’s undiagnosed Asperger’s syndrome in addition to her other issues, even as he made a full-length feature film that retrospectively showed his own ignorance at the time. There are important tools for identifying and accommodating neurodiverse individuals along with the role that DifferentBrains.com plays that can bridge the gap between health care providers, researchers, parents,

educators, society in general, and the people whose brains may be a little different. There can be a new way of looking at the world through a new lens of awareness, because understanding “different brains” doesn’t just apply to treating patients, it applies to how we interact with every person in our sphere. Society needs to understand and embrace neurodiversity for the benefit of all of us. (PLENARY)

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Workshop in Oral ID – a pathology tool for physicians and dentists

Abstract: Oral mucosa disease is omnipresent; the incidence of oral cancer has stayed constant over the past 20 years. Screening for oral cancer is a pillar of comprehensive and periodic oral evaluations. Fortunately, new technology is now available. Understanding tissue autofluorescence is advantageous because it may enhance the dentist’s and physician’s ability to visualize oral lesions. This can lead to earlier detection and improved prognosis. This conference workshop addressed the following: familiarized attendees with an introduction to fluorescence technology, explained different fluorescence technology modalities, showed how to utilize these diagnostic instruments to identify fluorescence differences in various areas of the mouth, explained how to use the OralID to examine other attendees to distinguish and identify mucosal variations such as amalgam tattoo, varicosities, physiologic pigmentation and bacteria, and helped attendees develop a plan to utilize this new technology in all oral examinations with protocol. [WORKSHOP]

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Living while dying: End-of-life considerations for people with intellectual disability

Abstract: Much like other persons, adults with intellectual disability (ID) are now surviving into old age and are susceptible to age-related cognitive health conditions that include the diseases that result in dementia. Adults with Down syndrome particularly are at a high risk for Alzheimer’s disease, which is viewed as early onset as it emerges during the fourth and fifth decades of ages. This shifting paradigm has challenged the system and all its parts. Many of the palliative care and end-of-life needs of adults with ID and dementia are quite similar to those of the general population. These include the need for pain detection and management, other symptom assessment and interventions, psychosocial support, awareness of the condition as terminal, identifying dementia as a cause of death, and goal setting with options for care and treatment along with more effective end-of-life care planning. Yet, for people with ID, there are unique considerations that warrant discussion. At the International Summit on Intellectual Disability and Dementia, which took place in Glasgow, Scotland, in October 2016, a workgroup reviewed these end-of-life concerns. Some of the distinctive concerns discussed included ascertainment or determination of end of life, consent and legal constrictors, family involvement and conflicts in decision making, communication with non-verbal adults with ID, the

applications of active treatment in advanced dementia, and the different systems and knowledge banks among the experts in the relevant specialties, including intellectual disability, dementia, and hospice/palliative care.

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End-of-life decision making and developmental disabilities: Issues, challenges, and approaches

Abstract: Everyone eventually faces a need for end of life decision-making. However, the special considerations associated with intellectual and developmental disabilities (IDD) result in practical and ethical issues, along with additional procedures that vary widely state to state and hospital to hospital. We have been engaged by our hospital and community to provide capacity and other inputs to end-of-life decision making for children and adults with IDD. A key first step is to establish the individual's baseline abilities, regarding functional status, capacity for medical decision making, and expressed wishes. It is essential to consider medical factors as separately as possible from developmental disability factors in determining the burdens associated with intervention. Inputs from the individual's circle of support are critical. Some advocates view survival as the only goal of care, distrusting the health care world's ability to consider factors that might vary by individual. A stepwise process to establishing baseline function, capacity, and specific medical factors allows an individualized approach that can help to provide appropriate care in line with individual wishes.

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Building Bridges Reactor Panel

Abstract: In a discussion, facilitated by Sara Weirs, the moderator, a reactor panel provided their insights on 'Building Bridges' from various perspectives. The panel, composed of several top national healthcare providers and support leaders in the field of intellectual and developmental disabilities reviewed how their organizations could create an atmosphere and framework of care that could provide a high level of specialized healthcare for persons with intellectual disability. They explored the challenges and lessons learned. A 'Q and A' followed the panel discussion. (PLENARY)

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Interdisciplinary professional education in developmental disabilities clinics: Directors symposium

Abstract: The session involved an open forum format and included faculty members from various dental and medical schools. The content of the session involved a discussion of program and curriculum trends that focus on the treatment and management of patients with disabilities of various types. There was a specific focus on patients with IDD, as well as the role of Inter-professional education. The goal of the session was to review trends, share conceptual ideas and potentially collaborate to

establish guidelines for updating current and developing future curriculum throughout the pre-doctoral programs. Course directors and others interested in developing curriculum within their program were welcomed to add to the discourse and develop recommendations.

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Interprofessional virtual grand rounds: A case study forum of the American Academy of Developmental Medicine and Dentistry

Abstract: Healthcare providers serving individuals with intellectual and developmental disabilities (IDD) recognize the importance of an interdisciplinary team approach to meeting the complex needs of these individuals. Few accessible venues exist for these passionate and busy practitioners to connect with seasoned colleagues to discuss best practices and collaborative referral strategies. Even fewer initiatives of this nature offer mentorship to entry-level practitioners that may have an interest in developing the skills for providing care to persons with IDD. An American Academy of Developmental Medicine and Dentistry (AADMD) membership survey in Spring 2015 identified a desire for more opportunities in which skill sets and knowledge base from case study reviews could be expanded. In addition, the survey called for clinical and didactic webinars as well as other educational opportunities that would be easily accessible and readily available. The Education and Student/Resident Curriculum Committees have launched the AADMD Interprofessional Virtual Grand Rounds (vigor), an online case-based discussion series. Introduced at the AADMD 2015 Annual Conference during a Roundtable Session, 3 professional members from the fields of dentistry, psychiatry, and optometry individually introduced cases from their discipline's perspective as a preview of what they would deliver via GoToMeeting webinar with additional peer learning and discussion. These sessions form the CE-eligible AADMD Virtual Grand Rounds Library. Convening in an interprofessional context offers opportunity to eliminate discipline-specific terminology and adopt a diverse outlook on a case to improve communication. Scheduling across time zones is a challenge for achieving the benefit of a live discussion, but these sessions facilitate connections to experts beyond the webinar presentation to foster collaborative learning and referral practices. In addition, the vigor recordings library contains the recordings from all iVGR presentations and is available for viewing at any time via YouTube. The AADMD aims to serve as a leader in connecting professionals, residents and students with like-minded practitioners while equipping them to provide exceptional comprehensive care to persons with IDD. Facilitating further case-based discussion forums is a goal as the AADMD iVGR both support current practitioners and wish to build a future workforce of practitioners capable of providing high quality care to persons with IDD. (POSTER)

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E-Consults: An effective intervention to improve the primary care of adults with Down syndrome

Abstract: While an increasing number of syndrome-specific clinical guidelines have been developed, their

adoption into clinical practice is often deficient. This has been well-documented in health services research pertaining to adults with Down syndrome. The purpose of this health system-level intervention was to improve the primary care of adults with Down syndrome. About 1100 adults receiving primary care through the Cleveland Clinic Health System were identified by an electronic health record (EHR)-based algorithm. In advance of pre-scheduled appointments with their primary care physician, an e-Consult was placed in the EHR and forwarded to the physician. The e-Consult, a written abstract containing screening, diagnosis, and treatment recommendations and suggested referrals to community resources, was generated through an EHR-based review by a multidisciplinary team comprised of a developmental medicine physician expert, a clinical pharmacist, and a disabilities advocate. Uptake of clinical recommendations was measured by reviewing the EHR before and after 100 e-Consults, provided over the course of nine months. Compared to baseline, there were improvements in receipt of screening blood tests for thyroid disease and celiac disease, screening echocardiography studies for heart disease, immunization against pneumococcal disease, and referrals to vision and hearing specialists.

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Training for support staff in clinical settings providing healthcare services to patients with intellectual and developmental disabilities

Abstract: Individuals with intellectual and developmental disabilities (IDD) are receiving more healthcare services from community primary care physicians. It is imperative that providers, and their ancillary and support staff, be prepared to care for these patients. Ancillary and support staff are often the first to encounter patients as they enter the healthcare system. Patients with IDD experience a variety of barriers when attempting to access healthcare, and often encounter staff with negative attitudes and behaviors toward them. In addition to providing physicians, and other healthcare providers, with the knowledge and skills necessary for effective patient-provider communication and quality care, it is equally important to provide staff members with similar tools and resources. By creating tools (fact sheets and video promotions) for staff members, barriers and misconceptions about caring for patients with IDD can be dispelled. These materials seek to establish the basics of effective communication (i.e., respect, people first language), addressing logistical issues (i.e., transportation), environment (i.e., avoiding sensory overload in crowded waiting rooms) and avoiding common pitfalls (i.e., not establishing communication preferences, using caregivers and family members as surrogates for communication). It is estimated of the 4.6 million Americans who have an intellectual or developmental disability, many will seek healthcare services in the community primary care setting. IDD has been found to be a risk factor for dissatisfaction and disappointment with healthcare encounters. Providing resources to ancillary and support staff is equally as important as training providers on how to effectively communicate with patients with IDD and provide them with quality care. By providing resources like these for staff members – the initial interface of the healthcare system for many patients – we can further help reduce dissatisfaction and disparities for patients with IDD. (POSTER)

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A new model for care management: An innovative program to enhance care and community transitions at Texas's State Supported Living Centers

Abstract: In 2015, AxisPoint Health, a national care management company, launched a new program in the Texas State Supported Living Centers (SSLCs). Through a contract with the Texas Department of Aging and Disability Services (DADS), the program is designed to provide in-depth nursing assessments on all residents in the SSLCs. Through the assessment process, health nurses identify opportunities for increased care coordination and compliance with national guidelines. Risk factors and chronic condition barriers are shared with the SSLCs' Interdisciplinary Teams to provide the needed supports and resources to improve each resident's health and quality of life. In addition, board-certified behavioral health analysts (BCBAs) conduct assessments on select residents and collaborate with the nurses and SSLC staff to enhance behavioral support. The organization also has developed a community outreach program which focuses on increasing access to community-based medical providers in order to improve the transition process for residents moving from the SSLCs to a community setting. Through this unique partnership with the DADS State Office, AxisPoint Health has begun to have a positive impact at the SSLCs by helping to disseminate clinical tools and information, improving consistency in meeting standards, and identifying and sharing best practices across facilities.

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"Providing a window of insight": Physician feedback to e-consultations of adults with Down syndrome

Abstract: This project's aim was to address poor adherence rates to syndrome-specific health care guidelines for adults with Down syndrome (DS) via an e-consultation intervention introduced to primary care physicians in the Cleveland Clinic Health System. We examined the attitudes and opinions of primary care physician recipients of these e-consultations regarding this intervention. Post-e-consultation, we conducted 20 voluntary semi-structured telephone interviews with primary care physician recipients of e-consults. In advance of scheduled appointments with the primary care physician, a physician expert in developmental disabilities medicine, a clinical pharmacist, and a representative of the disabilities advocacy community reviewed electronic health records of adults with DS, then generated an email consultation report to the primary care physician, outlining recommendations for health care services and potential community resources tailored to the individual patient's needs. Upon completion of the appointment, a research assistant conducted a semi-structured telephone interview with the primary care physician, soliciting feedback and critique of the e-consultation. The surveys included the Information Assessment Method Cognitive Checklist, as well as open-ended questions. We found that many primary care physicians reported that the consultation to be beneficial, educational, and a helpful

clinical support tool that they hope will remain as an ongoing clinical decision support. Features of the e-consults that physicians found particularly useful were resources and navigation for overweight and obese patients, recommendations for diagnostic testing for celiac disease, and inclusion in the electronic health record as an immortalized document available for future reference in subsequent clinical encounters. Recommendations for improvement of the e-consultation intervention included: (1) prioritization of the recommendations from highest to lowest importance, (2) inclusion of a biosketch for each e-consultation team member, detailing relevant credentials and expertise, and (3) a balance of succinct, concise, parsimonious verbiage with justification and rationale for each clinical recommendation and referral. (POSTER)

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Improving quality of lives in persons with intellectual and developmental disabilities by alleviating malnutrition

Abstract: Impaired nutrition occurs frequently in persons with intellectual and developmental disabilities (IDD). Malnutrition adds to the severity of diseases commonly affecting this group. Macronutrient deficiencies leading to conditions such as marasmus and kwashiorkor are uncommon in this population, but micronutrient, vitamin, mineral, and anti-oxidant deficiencies are common. These deficiencies can dramatically affect well-being and quality of life of anyone. Correlations can be demonstrated among micronutrient/vitamin deficiencies (e.g., selenium, zinc, vitamins C and D, etc.) and health conditions. The negative outcomes can be dramatic in children, but adults with disabilities are not immune from conditions related to malnutrition. For example, inadequate vitamin D status exacerbates an array of disorders, from high blood pressure and fractures to cardiovascular diseases, immune disorders, and increased incidence of cancer. Most adequately powered, epidemiological, and biological studies have reported favorable outcomes with sufficient supplements of nutrients in deficient populations. Supplementing with vitamin D to raise and maintain throughout the year serum 25(OH)D levels beyond 30 ng/mL is one such example. However, most of the randomized controlled clinical trials (RCTs) of nutritional supplementations are poorly designed, and few or none exist in persons with IDD. Meanwhile, many observational studies are underpowered and designed for non-nutritional outcomes; thus, difficult to interpret correctly. The value of such studies is undermined when study participants are allowed to take additional medications or supplements. Nevertheless, reported data indicate that optimizing nutritional status improves the functionality of bodily systems, reduces comorbidities, improves quality of life, and increases survival. Although accumulating evidence supports biological associations of nutritional sufficiency with improved physical and mental functions, no definitive evidence exists from well-designed, statistically powered RCTs in persons with IDD.

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The use of caries risk assessment, minimally invasive dentistry, and hospital dentistry in a

multidisciplinary approach to the oral care of special populations

Abstract: According to the Surgeon General's Report on Oral Health In America, and validated by numerous studies since (including by the Institute of Medicine), dental caries continues to be a significant health crises in special populations. In fact, dental caries continues to be one of the most unmet needs in patients with intellectual and developmental disabilities (IDD) in the United States. Because patients with IDD in many cases face tremendous barriers to accessing basic oral health services, they often present for dental care with significant dental disease, pain, and infection. For the IDD population with other comorbidities, this may mean that a small dental infection can spread and become life threatening. In addition, special patients may present with varying abilities to receive treatment in a typical dental setting. This may delay treatment significantly, and result in patients presenting for care in hospital emergency departments. These venues are typically ill equipped for the management of chronic oral diseases, putting the patient at risk for further dental destruction and continued poor oral and overall health. One alternative to the care of large amounts of dental disease is in an operating room environment, by advanced trained dentists knowledgeable in the unique needs of the special patient. Because patients with IDD are living longer, more productive lives, the need for appropriate, ongoing oral health care has never been greater. Current philosophy and best practices incorporating minimally invasive dentistry into a hospital dentistry environment and strategies to minimize caries risk and oral disease can decrease the need for hospital dentistry as the patient ages. New techniques can serve to assess caries risk, and the assessment process for hospital dentistry performed under general anesthesia, the use of desensitization for patient transition into typical dental venues, the conservative restoration of teeth using glass ionomer materials, and the maintenance of dental health with fluoride varnish and silver diamine fluoride.

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To drill or not to drill: Caries management with silver diamine fluoride in adults with intellectual disability

Abstract: Does the sound of the dental drill scare you? Dental visits are often overwhelming for adults with complex medical and behavioral differences, such as adults with intellectual and developmental disabilities. While dentists are known to 'drill-and-fill', it is no longer the only way to control the progression of dental caries. Various fluoride products have been used for dental caries prevention and treatment of dentin sensitivity for more than a century. Silver diamine fluoride (SDF), an agent derived from silver nitrate, was cleared by the FDA in 2016 for use in the management of dentin sensitivity. Studies have found that SDF can also control the progression of dental caries. In some situation, it is not possible to place a restoration on a tooth due to the location of the decay or a patient's lack of compliance in the dental setting. Since SDF has been shown to have caries preventing and arresting properties, it offers dental professionals an alternative option in situations where dental restoration is not an immediate option. It is useful to know about the contributing factors of dental caries, understand the principles of SDF in caries management and prevention, and relate these to practical applications

of SDF in geriatric patients, patients with complex medical histories, and persons with intellectual and developmental disabilities.

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Polypharmacy and its consequences

Abstract: Individuals with intellectual disabilities (ID), like the general population, will likely experience a variety of illnesses or conditions during their lives. Those with multiple conditions often take several medications, and as the number of medications increases, as they often do when aging and seeing multiple practitioners, they introduce an increased risk for drug interactions, side effects, and adverse drug reactions. Older adults with ID have a higher incidence of comorbidities, such as psychiatric conditions, epilepsy, dental disease, dementia, and osteoporosis, potentially increasing the amount of various medications they may take. Detection and diagnosis of illness are more complex for this population and may contribute to the overuse and underuse of medicines. Studies indicate differences in the severity and combinations of comorbid conditions in people with ID as they age, including a high incidence of multiple diagnoses. Psychiatric and neurological concerns also increase the likelihood of polypharmacy. Both long-term usage and taking multiple drugs may lead to harm. This risk of harm and complexity of prescribing is compounded by age-related adverse risk and the presence of organic dysfunctions may lead to idiosyncratic responses, and increased sensitivity to drugs. Increasing emphasis on autonomy and community integration may also mean greater utilization of primary care services where there may not be specialist knowledge of the unique medical issues of some people with ID as they age. Limitation of polypharmacy and of psychotropic use has been encouraged as one of the core elements of good physical health in persons with ID, especially among those who are aging. Monitoring of polypharmacy has been identified as a key indicator of quality of healthcare for people with ID as polypharmacy may cause harm and confound healthy aging. Key to addressing and controlling medication usage is having the healthcare team advocate medically and ensure that medications are monitored for basis and outcome.

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Associated caries risk in children with orofacial clefts compared with age- and sex-matched controls

Abstract: Assessments of the oral health of cleft lip and/or palate (CLP) patients have produced opposing results. Inconsistency in findings among researchers could be attributed to the multifactorial nature of dental caries, differences in methodologies used, patient's dental health literacy, and differences in cultural practices within populations. Differences among results noted in publications indicates that further research is required to obtain a firm conclusion on actual caries risk within the entire CLP patient population as well as within specific cleft types. The purpose of this study was to determine if having CLP is a risk factor for developing dental caries. DMFT/dmft scores were summarized for the CLP (n=115) and non-CLP patients (n=115). Non-CLP patients were

matched to the following variables: age, sex, race, other comorbidities, and behavior. Comparisons between the CLP patients and the matched healthy non-CLP patients were made using paired t-tests. To identify differences between cleft types, One-way ANOVA was used. It was found that patients with CLP have a higher overall average DMFT/dmft score than patients without CLP in the primary and permanent dentition, however, there was no statistically significant difference ($p=0.0626$). There were also no significant differences among cleft type ($p=0.3606$) or other variables such as possessing a syndrome as a CLP patient ($p=0.9767$). Prevention and early detection of dental caries is an important aspect of the management of patients with orofacial clefts. Plans for prevention should be personalized to everyone's needs. Even when early caries prevention and detection is a priority, maintenance of oral health may prove difficult. However, sustainment of efforts may moderate caries risk. (POSTER)

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