

## **Peter J. Smith, M.D., M.A.**

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Section of Developmental and Behavioral Pediatrics  
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### **ACADEMIC APPOINTMENTS**

2001-2002 Instructor, Department of Pediatrics, Harvard University,  
2002-2012 Assistant Professor, Department of Pediatrics, The University of Chicago,  
2002-2003 Section of General Pediatrics  
2003-2012 Section of Developmental and Behavioral Pediatrics  
2012-present Associate Professor, Department of Pediatrics, The University of Chicago  
Section of Developmental and Behavioral Pediatrics

### **Ph.D.-Granting Committee, Program, Institute, and Center Appointments**

2002-present MacLean Center for Clinical Medical Ethics, The University of Chicago,

### **ACADEMIC TRAINING**

1986-1990 B.A. with honors (Theology and Pre-Medicine),  
University of Notre Dame, Notre Dame, IN  
1990-1991 Postgraduate Studies  
University of Edinburgh, Scotland: (Rotary Scholarship)  
1991-1995 M.D., Duke University, Durham, NC  
1995-1998 Residency, General Pediatrics, Washington University, St. Louis, MO:  
1998-2000 Fellowship in Neurodevelopmental Disabilities  
Harvard Medical School & Children's Hospital, Boston, MA:  
2000-2002 Fellowship in Developmental-Behavioral Pediatrics  
Harvard Medical School & Children's Hospital, Boston, MA:  
2000-2002 M.A. (Theology), Boston College, Boston, MA

### **BOARD CERTIFICATION AND LICENSURE**

1998-2015 General Pediatrics, #65829  
2001-present Neurodevelopmental Disabilities, #127  
2002-present Developmental-Behavioral Pediatrics, #263

### **SCHOLARSHIP**

(a) Peer-reviewed publications in the primary literature, exclusive of abstracts:

1. Smith PJ, Morris A, Reller B. 2003. Predicting Urine Culture Results by Dipstick Testing and Phase Contrast Microscopy. *Pathology* 35:161-165.  
<http://www.swetswise.com.proxy.uchicago.edu/eAccess/viewFulltext.do?articleID=155854556>
2. Smith PJ, Mahowald MM. 2007. Review of Choosing Children: The Ethical Dilemmas of Genetic Intervention. *Perspectives in Biology and Medicine* 50(3):471-474.  
[http://muse.jhu.edu/journals/perspectives\\_in\\_biology\\_and\\_medicine/v050/50.3smith.html](http://muse.jhu.edu/journals/perspectives_in_biology_and_medicine/v050/50.3smith.html)
3. Bauer SC, Smith PJ, Chien AT, Berry AD, Msall ME. 2009. Educating Pediatric Residents About Developmental and Social-Emotional Health. *Infants & Young Children* 22(4):309-320.  
[http://journals.lww.com/iycjournal/Fulltext/2009/10000/Educating\\_Pediatric\\_Residents\\_About\\_Developmental.7.aspx](http://journals.lww.com/iycjournal/Fulltext/2009/10000/Educating_Pediatric_Residents_About_Developmental.7.aspx)
4. Walsh-Lang C, Smith PJ, Friedman Ross L. 2009. Ethics and Professionalism in the Pediatrics Curriculum: A Survey of Pediatric Program Directors. *Pediatrics* 124(4): 1143-51. <http://pediatrics.aappublications.org/content/124/4/1143.full>
5. Leewenburgh-Pronk, WG, Smith, PJ, vanVught AJ, Lantos, JD, Tibboel, D, deHoog, M, Buysse, C. 2012. Ethics Rounds: A Baby with Meningococemia and Septic Shock. *Pediatrics* 130(1): 134-38.  
<http://pediatrics.aappublications.org/content/130/1/134.full.pdf+html>
6. Tian, W, Smith, PJ, Msall, M. 2015. An Emerging Problem Due to Prior Successes: A Case Report of a Medically Complex Child in Need of a Comprehensive Medical Home. *Pediatric Annals* 44(1): 36-39.  
<http://www.healio.com/pediatrics/journals/pedann/2015-1-44-1/%7B00788dc1-ec5f-4909-849d-3a4e5768dc60%7D/medically-complex-children-and-early-intervention-for-comprehensive-medical-care-at-home>
7. Kuo DZ, Houtrow AJ, AAP Council on Children with Disabilities. Recognition and Management of Medical Complexity. *Pediatrics*. 2016; 138(6): e20163021  
<http://pediatrics.aappublications.org/content/early/2016/11/17/peds.2016-3021>
8. Friedman SL, Norwood KW, AAP Council on Children with Disabilities. Out-of-home Placement for Children and Adolescents with Disabilities – Addendum: Care Options for Children and Adolescents With Disabilities and Medical Complexity. *Pediatrics*. 2016; 138(6): e20163216.  
<http://pediatrics.aappublications.org/content/early/2016/11/24/peds.2016-3216>
9. Cohen GJ, Weitzman CC. AAP Committee on Psychosocial Aspects of Child and Family Health, AAP Section on Developmental and Behavioral Pediatrics. Helping Children and Families Deal with Divorce and Separation. *Pediatrics*. 2016; 138(6): e20163020.  
<http://pediatrics.aappublications.org/content/138/6/e20163020>
10. Gleason MM, Goldson M, Yogman MW. AAP Council on Early Childhood, AAP Committee on Psychosocial Aspects of Child and Family Health, AAP Section on Developmental and Behavioral Pediatrics. Addressing Early Childhood Emotional and Behavioral Problems. *Pediatrics*. 2016; 138(6); e20163023.  
<http://pediatrics.aappublications.org/content/138/6/e20163023>
11. Glasgow AE, Martin MA, Caskey R, Gerges M, Johnson M, Marko M, Perry-Bell K, Risser HJ, Smith PJ, & Van Voorhees B. An Innovative Health Care Delivery Model for Children with Medical Complexity. *Journal of Child Health Care*; Vol 21, Issue 3, pp. 263 – 272 First published date: June-05-2017; 10.1177/1367493517712063
12. Adams RC, Levy SE. AAP Council On Children With Disabilities. Shared Decision-Making and Children with Disabilities: Pathways to Consensus. *Pediatrics*. 2017. 139(6): e20170956.

13. Hauer J, Houtrow AJ, AAP Section on Hospice and Palliative Medicine, Council On Children With Disabilities. Pain Assessment and Treatment in Children With Significant Impairment of the Central Nervous System. *Pediatrics*. 2017; 139(6): e20171002
14. Renee M. Turchi, Vincent C. Smith, Committee on Substance Use and Prevention and the Council on Children with Disabilities, The Role of Integrated Care in a Medical Home for Patients With a Fetal Alcohol Spectrum Disorder. *Pediatrics* 2018;142; 10.1542/peds.2018-2333
15. Mattson G, Kuo DZ, AAP Committee on Psychosocial Aspects of Child and Family Health, AAP Council on Children with Disabilities. Psychosocial Factors in Children and Youth With Special Health Care Needs and Their Families. *Pediatrics*. 2019;143(1):e20183171
16. Houtrow A, Murphy N, AAP Council on Children With Disabilities. Prescribing Physical, Occupational, and Speech Therapy Services for Children With Disabilities. *Pediatrics*. 2019; 143(4):e20190285

(b) Peer-reviewed works in 'non-traditional' outlets and editorials or reviews in traditional outlets:

1. Smith PJ, Crocker AC. 2000. Training Health Care Providers: Two Doctors Reflect on Values and Priorities. *Impact* 13:6-7.
2. Smith PJ, Mathews KS, Hehir T, Palfrey JS. 2002. Educating Children With Disabilities: How Pediatricians Can Help. *Contemporary Pediatrics* 9:102-27.  
<http://www.modernmedicine.com/modernmedicine/article/articleDetail.jsp?id=126665>
3. Smith PJ, Alexander CG, Siegler M. 2006. Should Editorials in Peer Reviewed Journals be Signed? *CHEST* 129(6):1395-6. (Invited editorial)  
<http://chestjournal.chestpubs.org/content/129/6/1395.2.full.pdf+html>
4. Smith PJ. 2006. The Desperate Parent and the Lure of Experimental Treatment. *Virtual Mentor*. October 2006, Volume 8(10)649-53. <http://virtualmentor.ama-assn.org/2006/10/pdf/ccas2-0610.pdf>
5. Smith, PJ. 2016 Commentary: Old Perceptions Were Too Limited. *Intellectual and Developmental Disabilities*: 54 (2): 81-82.  
<http://dx.doi.org/10.1352/1934-9556-54.2.81>

(c) Peer-reviewed works accepted or in press (n/a)

(d) Non-peer-reviewed original articles

5. Smith PJ. 2010. Children with Disabilities and the Sacraments. *America*, Volume 202(17/4895): 13-15.  
[http://www.americamagazine.org/content/article.cfm?article\\_id=12310](http://www.americamagazine.org/content/article.cfm?article_id=12310)

(e) Book chapters:

1. Smith PJ. 2006. Health issues in school. In: Rubin IL and Crocker AC. *Developmental Disabilities: Delivery of Medical Care for Children and Adults*, 2<sup>nd</sup> Edition, Baltimore, MD: Paul H. Brooks Publishing Company. pp 72-7.
2. Smith PJ, Coulter DL. 2006. Ethical Care. In: Rubin IL and Crocker AC. *Developmental Disabilities: Delivery of Medical Care for Children and Adults*, 2<sup>nd</sup> Edition, Baltimore, MD: Paul H. Brooks Publishing Company. pp. 657-61
3. Smith PJ. 2008. Ethical Issues in Disabilities. In: Accardo PJ. Capute & Accardo's *Neurodevelopmental Disabilities in Infancy and Childhood*, Baltimore, MD: Paul H. Brooks Publishing Company. pp. 743-51.

4. Smith PJ, Hardt J. 2009. Ethics. In: Carey WB, Crocker AC, Coleman WL, Elias ER and Feldman HM. *Developmental Behavioral Pediatrics*, 4<sup>th</sup> Edition, St. Louis, MO. Elsevier Publishing. pp. 985-8.
5. Smith PJ, Hardt J. 2010. Ethical Issues in the Withdrawal of Support for Individuals With IDD: Charting a Course Between Scylla and Charybdis In: Friedman SL and Helm DT. *End-of-Life Care for Children and Adults with Intellectual and Developmental Disabilities*. Washington, DC. American Association on Intellectual and Developmental Disabilities (AAIDD) publications. pp. 161-70.
6. Acharya, K, Lewis M and Smith PJ. 2012. Ethical Dilemmas. In: Batshaw ML, Roizen NJ and Lotrecchiano GR. *Children with Disabilities*, 7th Edition. Baltimore, MD: Paul H. Brooks Publishing Company Chapter 39, pp. 681-90.
7. Smith, PJ. 2016. Principles of Care. In: Rubin IL, Merrick J, Greydanus DE, and Patel DR. *Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan*, Dordrecht: Springer, Chapter 8, pp. 303-310.
8. Smith, PJ, Acharya K, and Contompasis, S. 2018. Transition to Adult Medical Care, In: Voigt RG, Macias, MM, Scott, M, Myers, SM, and Tapia, CD. *AAP Developmental and Behavioral Pediatrics, 2nd Edition*, AAP: Chapter 26, ISBN electronic: 978-1-61002-135-7

(f) Other works that are publically available (websites, interviews, publications in the popular press, testimony, computer programs, protocols, reagents, inventions, patents not listed above, etc.)

Testimony to the Illinois Senate Executive Committee on March 25, 2015 regarding Senate Bill 987, the “Down Syndrome Information and Awareness Act,” which eventually was successfully combined with Illinois House Bill 3158 and passed both bodies unanimously, and signed into law as Illinois Public Act 099-0142, effective January 1, 2016.

For the testimony, see:

<http://www.chicagotribune.com/suburbs/burr-ridge/community/chi-ugc-article-radogno-introduces-measures-to-address-immuni-2015-03-26-story.html>

For the law, see:

<http://www.ilga.gov/legislation/publicacts/fulltext.asp?Name=099-0142>

(g) Clinical trials that are ongoing and unpublished

Ongoing protocol examining current state of services for children with special needs in a “typical” Midwestern school district. See University of Chicago IRB151338: “Pilot Study to Describe Attitudes-Beliefs Regarding Special Education in a Representative Midwestern School District”

## FUNDING

(a) Past:

1. CDC P30 CD000147. PI: D Meltzer. My Role: PI of pilot project funded through this primary grant for the Chicago Center of Excellence in Health Promotion Economics (CCEHPE) at the University of Chicago. *Developing an Instrumental Variables Approach for Generating Causal Inferences of Breast Feeding’s Impact*

- on Infant Development*, Total Direct Costs \$23,687, 3% Effort. Project Period: 01/01/08 – 06/30/09.
2. HRSA/AAP H02 MC02609. PI: P. Smith. *Illinois Medical Home Project*. Direct Costs: \$20,000, 5% Effort. Project Period 09/01/07-06/30/11
  3. FACCTS (France and Chicago Collaborating in the Sciences) (Smith & Stutz) *Efficacy Assessment of Folinic Acid and Thyroid Hormone Systemic Treatment on the Psychomotor Development of Young Children with Down syndrome*. \$10,000, 0% effort. Project Period 01/31/13-06/30/13.
  4. IJL (Institut Jérôme Lejeune). *Efficacy Assessment of Folinic Acid and Thyroid Hormone Systemic Treatment on the Psychomotor Development of Young Children with Down syndrome*. \$85,939, 3% Effort. Project Period 07/01/13 - 08/31/14.
- HRSA. T73 MC11047 Overall PI: K. Acharya (UIC). My role: Pediatrics Coordinator. *Illinois Leadership for Children with Neurodevelopmental and Related Disabilities (IL LEND)*, Sub-award to University of Chicago Annual Total Direct Costs \$50,000. Project Period 09/01/08 – 08/31/16. 2% Effort.

(b) Current:

1. HRSA. T73 MC11047 Overall PI: K. Acharya (UIC). My role: Ethics Consultant. *Illinois Leadership for Children with Neurodevelopmental and Related Disabilities (IL LEND)*, Sub-award to University of Chicago Annual Total Direct Costs \$50,000. Project Period 09/01/16 – 08/31/212. 1% Effort.
2. Coleman Foundation. My role: Co-PI. *Coleman Foundation Training Program in Developmental & Behavioral Pediatrics (DBP) for Advance Practice Registered Nurses (APRN's) at Almost Home Kids*. Total grant \$425,000. Project period 09/01/18-08/31/21.
3. The Oberweiler Foundation. My role: Co-PI. *Keith Veselik, M.D. Medical Education Program at Almost Home Kids*. Total grant \$75,000. Project period 11/01/18-10/31/21

(c) Pending: None

**HONORS, PRIZES, AND AWARDS**

- 1990 Cavanaugh Award (Outstanding Undergraduate in the Department of Theology), University of Notre Dame
- 1990 Rotary Foundation Ambassadorial Scholar
- 1999 Von Meyer Fellowship Award, Harvard Medical School
- 2000 NIMH Award Program in MH/DD, Institute for Community Inclusion, Harvard Medical School & Children's Hospital, Boston, MA
- 2000 Dyson Advocacy Fellowship, Harvard Medical School & Children's Hospital, Boston, MA
- 2001 Chief Fellow, Division of General Pediatrics, Children's Hospital, Boston, MA
- 2002 Mel Levine Award for the Outstanding Fellow, Division of General Pediatrics, Harvard Medical School & Children's Hospital, Boston, MA
- 2002 Distinguished Service Award "for commitment to individuals with developmental disabilities" The ARC of Eastern Middlesex, Reading, MA
- 2012 Elected Fellow, American Association on Intellectual and Developmental Disabilities
- 2016 Outstanding Teacher Award, Feinberg School of Medicine, Northwestern University

**INVITED SPEAKING**

- 2000 *Dealing with Ethical Issues in the Medically Fragile Child*, National Conference on Care of the Medically Fragile Child in the New Millennium, New England Consortium of

- Pediatric Nursing Homes and Massachusetts Extended Care Federation, Platform presentation, Seekonk, MA, 4<sup>th</sup> May 2000 *{invited}*
- 2003 *What is 'Nondirective' and do we really want it?* Graduate Program in Genetic Counseling, Seminar Lecture, Northwestern University School of Medicine, Chicago, IL, 13 February, 2003 *{invited}*
- 2003 *Exceptional Ethics: Building on Relationships*, Ken-Crest National Conference on Medically Fragile Children, Keynote presentation, Philadelphia, PA, 1<sup>st</sup> April 2003 *{invited}*
- 2004 *Doctors and Genetics: How do we help families choose the future?* Department of Pediatrics Grand Rounds, University of Calgary, Calgary, Canada, 3 March, 2004 *{invited}*
- 2004 *How Should Doctors Help Families Choose the Future?* Department of Pediatrics Distinguished Lecture, Children's Hospital of Omaha, 12 November 2004 *{invited}*
- 2006 *Looking Forward and Looking Up*, National Association for Down Syndrome Annual Meeting, over 600 parents and professionals attended. 4 November 2006, *{invited}*
- 2007 *The Ethics of Body Alteration in Children with Disabilities: the Controversy Surrounding the "Ashley Treatment"* Schwab Rehabilitation Hospital, Panel Member, 16 May 2007, *{invited}*
- 2007 *How to Conduct a Quality Improvement Program in Primary Care Practice*, Annual Meeting of the Illinois Chapter American Academy of Pediatrics, Lincolnshire, IL, Platform, 19 May 19 2007 *{invited}*
- 2007 *The Ethics of Body Alteration in Children with Disabilities: the Controversy Surrounding the "Ashley Treatment*, Schwab Rehabilitation Hospital Grand Rounds, Panel Member, 16 May, 2007 *{invited}*
- 2009 *Autism Spectrum*, Riverside Medical Center, CME seminar, 29 September 2009, *{invited}*
- 2010 *Subcontracting a Social Construction: ADHD and the Primary Care Provider*, Community Hospital, Munster, IN, CME seminar, 30 June 2010, *{invited}* 2010 Illinois State Team Leader for the *Act Early Region V Summit*, sponsored by the Association of University Centers on Disabilities, the National Center on Birth Defects and Developmental Disabilities at the CDC, and MCHB/HRSA, with emphasis on autism. Indianapolis, IN. 27-28 Sept. 2010.
- 2011 *IDEA and Intellectual Disabilities for Child Psychiatry*. Combined University of Illinois at Chicago and Rush University Medical Center Summer Didactics for Child Fellow I and II Program, Chicago, IL, 1 September 2011.
- 2012 *Ethical Conundrum: The Patient that you Never Forget*. Ada Canyon Medical Education Consortium, Boise, ID, 5 October 2012.
- 2012 *Management of Behavioral Problems in the Primary Care Office: Enuresis and Encopresis*. ABC Conference of the Illinois Chapter of the American Academy of Pediatrics, Park Ridge, IL, 16 November 2012.
- 2013 *The Brain and Behavior*. Glenview Education Foundation Parent Education Night. Glenview, IL 24 April 2013.
- 2013 *Management of Behavioral Problems in the Primary Care Office: Enuresis and Encopresis*. Annual Educational Conference of the Illinois Chapter of the American Academy of Pediatrics, Downers Grove, IL, 18 May 2013
- 2013 *Ethics and Intellectual Disabilities: A Conversation*. Platform Presentation. American Association of Intellectual Disabilities Annual Meeting, Pittsburgh, PA, 4 June 2013
- 2013 *Ethics and Intellectual Disabilities*. Departement de Pediaatraie Reunion du Departement, Universite Limoges, Limoges, France, 13 June 2013.
- 2013 *The Relationship Between Prenatal Diagnosis and Termination Rates: What is Known?* 20<sup>th</sup> Annual Summer Conference for The Center for Bioethics & Human Dignity, Trinity International University, Deerfield, IL, 18 July 2013.

- 2014 *ADHD: Addressing Questions about Diagnosis and Management* AAP's Healthy Children Conference, Donald E. Stephens Convention Center, Rosemont, IL, 9 March 2014
- 2014 *Dealing with Behavioral Issues for the Child with Down syndrome*, Gigi's Playhouse Down syndrome Achievement Center Speaker Series, Hoffman Estates, IL, 14 April 2014
- 2014 *The Good, Bad, and Not-So-Pretty with Children with Disabilities in 2014: A Conversation*, Panel Presentation, American Academy of Pediatrics National Conference and Exhibition, San Diego, CA, 11 October 2014
- 2015 *Current State of Research, Practice, & Policy of Community Health for Individuals with IDD* Post Conference Workshop: American Association of Intellectual Disabilities Annual Meeting, Louisville, KY, 4 June 2015
- 2016 *Relationships Between DBP and Child & Adolescent Psychiatry*, Panel presentation and discussion; Illinois Council of Child and Adolescent Psychiatry Meeting; Chicago, IL 27 January 2016
- 2016 *Autism 101*; Workshop presentation and discussion; Southwest Cook County Cooperative Association for Special Education; Orland Park, IL, 24 February 2016
- 2016 *Ready, Set, Smile: Oral Health Care for Children with Special Health Care Needs*, Panel Presentation, Chicago Dental Society Annual Midwinter Meeting, Chicago, IL, 25 February 2016
- 2016 *The Bioethics of Health Disparities: Intellectual Disabilities*, Platform Presentation, National Med-Peds Residents' Association Midwest Regional Conference, Chicago, IL, 30 April 2016
- 2016 *The Almost Home Kids Model*, Grand Rounds, Ann and Robert H. Lurie Children's Hospital, and Department of Pediatrics, Feinberg School of Medicine, Northwestern University, Chicago, IL, 15 July 2016
- 2016 *Down Syndrome Enters a New Era*, Combined Grand Rounds, Rush College of Medicine, Department of Pediatrics, and John H. Stroger, Jr. Hospital of Cook County, Department of Pediatrics, Chicago, IL 16 August 2016
- 2016 *The Down Syndrome Information Act*, Workshop presentation, National Association for Down Syndrome Annual Meeting, Chicago, IL 1 October 2016
- 2017 *Attitudes Towards Diverse Learners in a Representative School District*, Platform Presentation, Council for Exceptional Children, Annual Convention, Boston, MA, 19 April 2017
- 2017 *Exploring Crucial Issues in Health Care and IDD with the CDC*, Pre-conference workshop, American Association of Intellectual Disabilities Annual Meeting, Hartford, CT, 26 June 2017
- 2017 *Managing More Severe And Less Common Delays in Childhood In the Medical Home*, Platform Presentation, H Program, Council on School Health, American Academy of Pediatrics National Conference and Exhibition, Chicago, IL, 18 September 2017
- 2018 *Teaching About IDD at Almost Home Kids*, Grand Rounds, Department of Pediatrics, University of Illinois at Chicago, Chicago, IL, 12 January 2018
- 2018 *The Almost Home Kids Model*, Grand Rounds, Department of Pediatrics, University of Illinois at Peoria, Peoria, IL, 12 April 2018
- 2019 *Ethics, Public Policy, and Care of Individuals with Intellectual Disability*, Ethics Champions National Webinar, Trinity Health System, [on-line] 6 March 2019

#### **INTRAMURAL PRESENTATIONS**

- 2002 *Exceptional Bioethics: An Argument Against Selective Termination for Trisomy 21*, Department of Pediatrics Grand Rounds, University of Chicago, 15 August 2002

- 2002 *Exceptional Bioethics: An Argument Against Selective Termination for Trisomy 21*, LaRabida Children's Hospital Grand Rounds, 13 September 2002
- 2003 *Children Who Are Medically Fragile or Technology Dependent: Building Relationships, Respecting Diversity* 7<sup>th</sup> Annual Perspectives in Care Symposium of LaRabida Children's Hospital, Seminar Presentation, Chicago, IL 4 April 2003
- 2004 *Point Counterpoint in Medical Ethics*, 8<sup>th</sup> Annual Perspectives in Care Symposium of LaRabida Children's Hospital, Seminar Presentation Chicago IL. 2 April 2004,
- 2004 *How Should Doctors Help Families Choose the Future?* Department of Obstetrics and Gynecology Grand Rounds, University of Chicago. 19 November 2004
- 2008 *Who Are Those 'Autism Doctors' and What Do They Actually Do?* Invited conference presentation, Autism: through the Lens of the Social Sciences, Presented by the Master of Arts Program in the Social Sciences at the University of Chicago, Chicago, IL 4 April 2008
- 2008 *Who Cares for and about Resource-intensive Low-incidence Special Needs Children?* 12th Annual Perspectives in Care Symposium for LaRabida Children's Hospital Seminar Presentation, Chicago, IL, April 4, 2008.
- 2008 *Ethical Issues in the Withdrawal of Support for Individuals with Cognitive Impairments* Department of Pediatric Grand Rounds, The University of Chicago, Chicago, IL 24 July 2008.
- 2009 *Supporting and Sustaining Families in an Era of Technology: A Model for Transition and Respite* Department of Pediatrics Grand Rounds, The University of Chicago, Chicago, IL 12 March 2009.
- 2012 *Transitional Care and Respite in Illinois in 2012: A New Era.* Department of Pediatrics Grand Rounds, The University of Chicago, Chicago, IL 13 December 2012.

#### **INVITED, ELECTED, OR APPOINTED EXTRAMURAL SERVICE**

- 1998-2002 Ethics Advisory Committee, Children's Hospital, Boston, MA
- 2000-2002 Committee on Disabilities, Massachusetts Chapter, American Academy of Pediatrics
- 2002-present Committee on Children with Disabilities, Illinois Chapter, American Academy of Pediatrics. Chair of Committee 2008-2011
- 2003 NHLBI ad hoc committee for RFA "Specialized Centers of Clinically Oriented Research in Pediatric Heart Development and Disease" (RFA HL-02-027)
- 2004-present Bioethics Committee, Illinois Chapter, American Academy of Pediatrics. Chair of committee 2010-current (see below)
- 2006-present Committee on Child Development, Illinois Chapter, American Academy of Pediatrics
- 2007-2013 Board of Directors, Almost Home Kids Care Center, Naperville, IL
- 2007-present Charter Member, Quality Improvement Innovation Network, American Academy of Pediatrics
- 2007-2012 PediaLink Fellowship Workgroup Member, American Academy of Pediatrics
- 2008-2011 Chair, Committee on Children with Disabilities, Illinois Chapter, American Academy of Pediatrics (committee member since 2002).
- 2009-2013 Advisory Council, Center for Children & Families, the Erikson Institute, Chicago, IL
- 2009-present Medical Director, Epic Home Care, [home care agency for pediatric home health care, Illinois Region
- 2010 State of Illinois Team Leader for the *Act Early Regional Summit Project* organized by the Association of University Centers on Disabilities (see



- <http://aucd.org>) and sponsored by the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, and by the Maternal and Child Health Bureau (MCHB) at Health Resources and Services Administration (HRSA).
- 2010-present Chair, Bioethics Committee, Illinois Chapter, American Academy of Pediatrics (committee member since 2004).
- 2010-2012 Fellowship Director Chair, Association of Pediatric Program Directors (APPD), Midwest Region
- 2010-2014 At-Large Member, Board of Directors, American Association on Intellectual and Developmental Disabilities (AAIDD)
- 2011-2012 State of Illinois Department of Healthcare and Family Services Children with Complex Medical Needs (CCMN) Working Group
- 2014-present Member, Section on Developmental and Behavioral Pediatrics (SODBP) Executive Committee, American Academy of Pediatrics (AAP)
- 2014 Key Informant, Agency for Healthcare Research and Quality's (AHRQ) Effective Health Care (EHC) Program, EPC Project Title: Genetic Testing for Developmental and Intellectual Disabilities
- 2014-2015 Member, Illinois State Project Team for *Action Learning Collaborative (ALC): Using the National Standards for Systems of Care for CYSHCN to Strengthen State Health Systems*; Team lead by DSCC and funded by a grant from The Association of Maternal and Child Health Programs (AMCHP), with support from the Lucile Packard Foundation for Children's Health (LPFCH)
- 2015-present Committee on Governmental Affairs, Illinois Chapter, American Academy of Pediatrics.
- 2015-present Member (Liaison from SODBP Executive Committee), Council on Children with Disabilities (COCWD) Executive Committee, American Academy of Pediatrics (AAP)
- 2015-2016 Associate Editor, *Intellectual and Developmental Disabilities*
- 2015-2016 Member, Working Group on Policy Statement for the Policy & Positions Subcommittee, The Arc of The United States
- 2015-2017 Member, Annual Conference Planning Committee, American Association on Intellectual and Developmental Disabilities (AAIDD)
- 2017-present Member, Advisory Committee for the 12<sup>th</sup> Edition of the AAIDD Definition Terminology & Classification Manual, American Association on Intellectual and Developmental Disabilities (AAIDD)

## PROFESSIONAL SOCIETIES

### Elected or invited membership:

- 2003 Fellow, American Academy of Pediatrics
- 2012 Fellow, American Association on Intellectual and Developmental Disabilities

### Other:

- 1993-1995 North Carolina Pediatric Society
- 1995-present American Academy of Pediatrics
- 2014-present Executive Committee, Section of DBP
- 1999-present American Association on Intellectual and Developmental Disabilities
- 2010-2014 National Board of Directors
- 2001-2002 Massachusetts Medical Society
- 2002-2010 American Society for Bioethics and Humanities
- 2005-2011 Association of Pediatric Program Directors

**EDUCATION**The College (B.A., B.S.):

2005-2018 *Anthropology of Dis/ability* [Anthropology/Human Development 30405, or Social Services Administration/Master of Arts Program in Social Sciences 36900]. This is a course for undergraduates in the College and is cross-listed in several graduate programs. Along with the course director, M. Fred, Ph.D., J.D., Senior Lecturer in MAPSS, I help construct the curriculum, present two seminars each year, serve as a resource for several other sessions, and supervise any students who choose to pursue their required ethnography in one of the medical areas that I oversee.

Graduate programs (Ph.D.):

None

Pritzker School of Medicine (M.D.):

(a) Didactic

2002-2010 Led weekly discussion groups (one quarter/year) for "The Doctor-Patient Relationship," a required course for MS1 students. Along with the MacLean Center for Clinical Medical Ethics faculty, I led discussion groups weekly and served as a resource for background on medical care and ethics.

(b) Clinical

2002-present Host Pritzker students as "shadows" for 1-6 months in various clinical sites

Graduate medical education (residency and clinical fellowships):

(a) Didactic

2002- 2012 &

2018-present Create and run DBP rotation didactic curriculum (8 hourly sessions/month)

2005- 2012 Create and run DBP Fellowship Seminar Series (4 two-hour sessions/month)

2017-present Create and present monthly DBP seminars for Gen Peds residents

(b) Clinical

2002- 2012 &

2018-present Create and run DBP rotation clinical curriculum (12 hours/month)

2002-present Supervise Pediatric Residents in DBP clinic 1-2 half-day clinics/week

2005-present Supervise Fellows in DBP clinic 1-2 half-day clinics/week

Continuing medical education:

2003 *Individuals with Disabilities are not a Problem to be Solved.* Joint Meeting: Bioethics Across Borders, American Society of Bioethics and Humanities and the Canadian Bioethics Society. Paper presentation, Montreal, Canada, October 24, 2003.

2004 *An Ethics Meta-Analysis of the Differences in Perception Between Doctors and Families Regarding Disabilities.* Pediatric Academic Societies Annual Meeting, Platform Presentation, San Francisco, CA, May 3, 2004.

2004 *Changing Attitudes of Professionals in Training.* American Association of Mental Retardation Annual Meeting, Poster Presentation, Philadelphia, PA, June 2, 2004

- 2005 *Teaching Clinical Ethics to Pediatric Residents Using a Case-Based Method.* Pediatric Academic Societies Annual Meeting, Educational Workshop Leader, Washington DC, May 15, 2005.
- 2006 *Prenatal Diagnosis of Down syndrome: A Medical Opportunity or Moral Dilemma.* Pediatric Academic Societies Annual Meeting, Platform Presentation, San Francisco, CA, May 2, 2006.
- 2007 *Teaching Clinical Ethics to Pediatric Residents.* Pediatric Academic Societies Annual Meeting, Educational Workshop Leader, Toronto, Canada, May 6, 2007.
- 2007 *Educating Pediatric Residents in Developmental and Social-Emotional Health.* Pediatric Academic Societies Annual Meeting, Poster Presentation, Toronto, Canada, May 6, 2007.
- 2009 *Autism Spectrum,* Riverside Medical Center, CME seminar, 29 September 2009, {invited}
- 2010 *Subcontracting a Social Construction: ADHD and the Primary Care Provider,* Community Hospital, Munster, IN, CME seminar, 30 June 2010, {invited}
- 2010 *Web-based Teaching Platform for DBP with a Secure/Private Social Networking Capability* Workshop. Society for Developmental and Behavioral Pediatrics Annual Meeting, Boston, MA September 13-14, 2010.
- 2010 *The ABC Conference.* Planned, organized and hosted the first annual University of Chicago, Developmental and Behavioral Pediatrics CME conference for general pediatricians. *The ABC Conference* covered **A**utism, **B**ehavior and **C**omplex Medical Needs. There were didactic sessions and interactive workshops presenting the latest information on diagnostics and therapeutics for developmental disorders. Chicago, IL 19 Nov 2010. The conference continues annually.
- 2011 *Housing Salon* Program moderator with Royal Walker JD, University of Southern Mississippi, Jay Klein, MSW, Arizona State University and Tim Weins, Jubilee of Maryland. American Association of Intellectual Disabilities Annual Meeting, St. Paul, MN, June 7, 2011.
- 2013 *Preconference Workshop:* American Association of Intellectual Disabilities Annual Meeting, Pittsburgh, PA, 4 June 2013
- 2014 *Medical Issues of Concern to Dentists Who Treat Children With Special Needs,* for "Ready, Set, Smile," An Oral Health Initiative by DuPage County Health Department, DuPage County, IL, 7 May 2014 & 26 September 2014
- 2015 *Genetic Syndromes: A Brief Overview,* for "Ready, Set, Smile," An Oral Health Initiative by DuPage County Health Department, DuPage County, IL, 8 April 2015

Other:

2018 *Celiac and the Brain: Developmental and Behavioral Disorders, within Celiac Disease in the 21st Century: Understanding the Latest Management and Treatment Options for CD* [online CME Webinar]

<https://cme.uchicago.edu/content/celiac-and-brain-developmental-and-behavioral-disorders>

Research trainees:

(a) High school students and teachers      None

(b) Undergraduate (B.A., B.S.)

2012 Ms. Allison Rzepczynski, "Respite Care for Children with Special Health Care Needs" May, 2012; she completed her BS at University of Notre Dame in May of 2013 and matriculated into Stritch School of Medicine, Loyola University, Chicago, IL in 2013.

2013-2015 Wendy Tian, Graduate of the College, University of Chicago, *Medically Complex Children*; She completed a post-graduate research associate year in the MacLean Center for Clinical Medical Ethics from 2015-2016 and matriculated into Rush Medical College, Chicago, IL in 2016; **co-author on peer-reviewed publication (see above).**

(c) Medical (M.D.)

2007-2009 Sarah Sobotka, Pritzker Medical Student, MD and MSCP (Master of Science for Clinical Professionals), The University of Chicago Department of Health Studies, *Attitudes Towards Individuals with Disabilities*, Completed a residency in General Pediatrics at Lurie Children's Hospital and recruited back as a Fellow in DBP here at the University of Chicago. Currently, Dr. Sobotka is Instructor, Department of Pediatrics, Section of Developmental and Behavioral Pediatrics, and Advanced Research Fellow, the University of Chicago.

(d) Graduate (PhD and MA/MS)

2006-2007 Katherine E. Caldwell, Graduate Student in the Master of Arts Program in the Social Sciences (MAPSS) at the University of Chicago, September 2006 through August 2007, **MA** in MAPSS, *family experiences of inpatient care*; she has completed her **Ph.D.** in Disability Studies at the University of Illinois at Chicago in May, 2014, and is now a Postdoctoral Research Associate at the Institute of Disability and Human Development at the University of Illinois at Chicago.

2013 Rachel Lewin, University of Chicago, **MA** in the Master of Arts Program in the Social Sciences (MAPSS), "*When Doctors Get Sick: Managing the Personal Illness Narrative*," June 2013; matriculated in 2014 and is currently a Doctoral Student at University of California, Los Angeles, California.

2013-2016 Heather Stone, Department of Disability & Human Development, Interdisciplinary **Ph.D.** Program in Disability Studies, University of Illinois at Chicago, *Girls with Autism Becoming Women: A Text-based Qualitative Approach*, she defended her dissertation in 2016 and I was on the dissertation committee.

(e) Postdoctoral Research Trainees

2006-2009 Laura Hans, MD, Fellow in DBP from 1 July 2006 through 30 June 2009. *Breast feeding impacts on development*. She completed her fellowship training in DBP and was hired as faculty and attending at University of Illinois, Chicago. Dr. Hans is now Developmental and Behavioral Pediatrician and Medical Director of CAAD Clinic at Contra Costa Regional Health Services in California.

2004-2006 Sarah Bauer, MD General Pediatrics Resident, 1 July 2004 through 30 June 2008 (including year as Chief Resident in Pediatrics), *Educating Pediatric Residents About Developmental and Social-Emotional Health*. She completed her fellowship training in DBP and was hired as a faculty member at Northwestern, and an attending physician at The Lurie Children's Hospital. She is now Medical Director at the Pediatric Developmental Center at Advocate IL Masonic Medical Center.

**CLINICAL**

- 1998-2002 Pediatrics inpatient attending South Shore Hospital, South Weymouth, MA (two weekends & consultant/month)
- 2002-2010 Developmental and Behavioral Pediatrician, LaRabida Children's Hospital, Chicago, IL  
(two outpatient clinic sessions/week, initially eight, eventually four, then no weeks inpatient attending/year)
- 2002-2010 Developmental and Behavioral Pediatrician, Friend Family Health Center  
(two outpatient clinic sessions/week)
- 2002-present Clinical Medical Ethics Consultation Service, The University of Chicago  
(one month as primary or secondary attending consultant/year)
- 2004-present Medical Director and pediatrician, Illinois Center for Rehabilitation and Education (ICRE), State of Illinois Office of Rehabilitation Services  
(one session/week, plus full-time on-call)
- 2005-present Medical Director and pediatrician, Sonia Shankman Orthogenic School  
(one session/week plus full-time on-call)
- 2010-2013 Developmental-Behavioral Pediatrician, NorthShore University Outpatient Clinic (2 clinics/week)
- 2012-present Medical Director and Pediatrician, Almost Home Kids [respite and transitional care program for children with complex medical needs]  
(1 session/week & full-time call)
- 2013-present Developmental-Behavioral Pediatrician, University of Chicago Medicine (Comer Children's Hospital) Clinic (1 clinic/week)
- 2015-present Medical Director, Easter Seals of DuPage & Fox Valley Medical Diagnostic Clinic (2 Interdisciplinary, Birth-to-three assessments every other Friday)
- 2017-present Medical Director and Developmental-Behavioral Pediatrician, Center for Children and Families at the Erikson Institute (1.25 clinics/week)

**SERVICE****University of Chicago**Committee membership:

- 2007-2011 Admissions Committee, The Pritzker School of Medicine
- 2010 Pediatrics Informatics Committee
- 2010 Committee for the Advancement of Pediatric Educators
- 2012-present Chicago Careers in Health Professions (UCIHP) Health & Medicine Committee

Leadership:

- 2002-present Medical Ethics Clinical Case Conference, Attending Faculty Member
- 2005-2012 Program Director, Fellowship in Developmental and Behavioral Pediatrics
- 2006-2009 Chief of Medical Staff, LaRabida Children's Hospital
- 2008-2014 Associate Director, Illinois' Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program, the University of Illinois at Chicago and the University of Chicago