Caring for and About Children with Disabilities and Special Health Care Needs: 
Professional Paths Taken 
February 25, 2019, 7-8 pm Central Time 

Presented by the American Academy of Pediatrics 
Council on Children with Disabilities 
www.aap.org/cocwd
MODERATOR

Eva Catenaccio, MD
Pediatric Neurology Fellow
Johns Hopkins University
Section on Pediatric Trainees Liaison
Council on Children with Disabilities
WEBINAR OBJECTIVES

• Define and describe the population and prevalence of children with disabilities.

• Discuss possible training needs for physicians who care for children with disabilities.

• Discuss different career pathways for pediatric trainees interested in caring for children with disabilities.

• Identify at least three resources that pediatric trainees can utilize to learn more about career options in caring for children with disabilities.
AGENDA

• Overview of the population of children with disabilities
• Family perspectives
• Career pathways presentations
  – General pediatrics
  – Developmental and behavioral pediatrics
  – Neurodevelopmental disabilities
  – Physical Medicine & Rehabilitation/Pediatric Rehabilitation Medicine
• Questions from the audience
• Resources
FACULTY

Dennis Z Kuo, MD, MHS, FAAP
UBMD Pediatrics, University of Buffalo
Chairperson, Council on Children with Disabilities
Who are these children?

- Children with disabilities
- Children with special health care needs
- Children with medical complexity
They’re Your Patients, too!

- Approximately 15% of children have a developmental disability
- Nearly 20% of children have a special health care need
- 1 in 5 families have a child with a special health care needs
- 1/3 of all pediatric health care spending is spent on children with medical complexity
- Every pediatrician will see children and youth with disabilities and special health care needs in their practice
WHAT’S NEEDED TO CARE FOR CHILDREN WITH DISABILITIES?

• Experience and training
  – Technical skills
  – Chronic care management
  – Other

• Supportive system of care – what do you need to ask for?

• Above all else, the strong desire to care for children with disabilities
HOW DO YOU GET THERE?

- Training
- Networking
- Experience
HOW CAN THE COUNCIL ON CHILDREN WITH DISABILITIES (COCWD) HELP?

• Mentoring
• Education
• Networking

• ...webinars like this!
AAP COUNCIL ON CHILDREN WITH DISABILITIES (COCWD)

• Mission
  – Develop clinical guidance
  – Educate pediatricians
  – Provide expertise and advocacy on local and national issues
  – Create collaborations with partner organizations
  – Provide opportunities for members to actively engage in all the above
FACULTY

Cara Coleman, JD, MPH
Family Voices Liaison
Council on Children with Disabilities
Supplies
-12 + different suppliers

Schools
15 member IEP team

Family
Home Health Care
-2+ agency administrators
-2-3 nurses

Doctors
-PCP + 15+
Specialists
-2 health systems

Appointments, hospitalizations, procedures, treatments, surgeries etc.

Support
Support Staff
-20+ places

10+ local and state agencies

RN, PA, CNP & Team
-20+

Doctors
-PCP + 15+
Specialists
-2 health systems

Support Staff
-20+ places

10+ local and state agencies

RN, PA, CNP & Team
-20+

PARENTING

“Coleman Chaos” Care Map
Why this path is the one you want to take!!

• Chance to partner with “Rasta Justy” & her family
• Training needs from family perspective
  – Real life, PFCC, PFCMH, Partnership/ Team
• Story: Mighty PCP & “Ortho for Life”
RESOURCES FOR FAMILY/PROFESSIONAL PARTNERSHIP AND PATIENT-FAMILY CENTERED CARE

• Family Voices and the National Center for Family/Professional Partnership
• The Institute for Patient-and-Family Centered Care
• American Academy of Pediatrics Resources:
  – Partnering with Youth and Families
  – Family Partnerships Network
CAREER PATHWAYS:
PRESENTATIONS FROM EXPERTS IN THE FIELD

Christopher J Stille, MD, MPH, FAAP
University of Colorado
Field: General Pediatrics/Primary Care

Susan L Hyman, MD, FAAP
University of Rochester
Field: Developmental and Behavioral Pediatrics

Mary O’Connor Leppert, MD, FAAP
Kennedy Krieger Institute
Field: Neurodevelopmental Disabilities

Susan Apkon, MD, FAAP
University of Colorado
Field: Pediatric Rehabilitation Medicine
GENERAL PEDIATRICS/PRIMARY CARE FOR CHILDREN WITH AND WITHOUT DISABILITIES
FIELD: PRIMARY CARE FOR CHILDREN WITH AND WITHOUT DISABILITIES

• Training Needs
  – Residency, practice experience (community or academic)
  – +/- fellowship (depending on academic goals)

• Practice site/population
  – Typically underserved, diverse
  – Often associated with academic center (more resources)

• Training and research opportunities
  – Lots of teaching!
  – Caring for these kids is what pediatricians do!
  – Many research opportunities if you have training, time, and resources.
FIELD: PRIMARY CARE FOR CHILDREN WITH AND WITHOUT DISABILITIES

• Personal Path
  – Residency at academic center: Interest in primary care provider-specialty interface
  – Community practice x 2 years: “Referral” practice for family medicine
  – General Academic Pediatrics fellowship (for training in research and education primarily)
  – Academic primary care: Children with disabilities gravitate there. You get good at what you have to
  – Complex care clinic: Multiple resources really help
DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS
FIELD: DEVELOPMENTAL-BEHAVIORAL PEDIATRICS

• (How?) Training Needs
  – Pediatric Residency ➔ 3 Year ACGME Developmental and Behavioral Pediatrics Fellowship
  – American Board of Pediatrics certification information

• (What?) Training and research opportunities/What does a developmental/behavioral pediatrician do?
  – Multidisciplinary assessment and care of children and youth with a wide range of medical and behavioral disorders
  – Research on biological, social and behavioral causes and treatments of developmental disorders
  – Education to promote the optimal developmental and behavioral care of children and youth
**FIELD: DEVELOPMENTAL-BEHAVIORAL PEDIATRICS**

- **(Where?/ Who?) Practice site/population**
  - Great demand in academic settings, community practice, public health, policy and advocacy
  - Children and youth with or at risk for a wide range of developmental and behavioral disorders and disabilities and their families

- **Personal Story/Personal Path**

  ![Mentorship](Image)

  ![Research](Image)

  ![Training/Advocacy](Image)

  ![Clinical Practice](Image)
NEURODEVELOPMENTAL DISABILITIES
FIELD: NEURODEVELOPMENTAL DISABILITIES

• Training Needs
  – 2 years of pediatrics, 4 years of neurology and development

• Practice site/population
  – Birth to 21+
  – Disorders of cognition, learning, language, movement, social skills, and related behavior
  – Consequences of genetic, perinatal, traumatic, infectious, immunologic, metabolic, toxic etiologies
**Field: Neurodevelopmental Disabilities**

- **Training and research opportunities**
  - 1 year adult neurology
    - 6 months inpatient, 6 months outpatient
  - 18 months clinical neurodevelopmental disabilities/child neurology
    - Inpatient, outpatient, community, consultative
  - 18 months of clinical sciences
    - 1 month minimum of neurosurgery, rehab, psychiatry
    - Neuropathology neuroradiology, genetics
    - Research: classroom instruction on research methodology and design
      ~ Mentored, clinical or bench and one quality improvement project

- **Personal Story/Personal Path**
PEDIATRIC REHABILITATION MEDICINE/
PHYSICAL MEDICINE & REHABILITATION
**FIELD: PEDIATRIC REHABILITATION MEDICINE**

**Training Needs:** 2 tracks
- Combined residency in Pediatrics and Physical Medicine & Rehabilitation (5 years)
- Residency in Physical Medicine & Rehabilitation (4 years) followed by 2 year Pediatric Rehabilitation Medicine fellowship

**Population:** Children with acquired and congenital disabilities
- Common diagnoses: cerebral palsy, spina bifida, spinal cord injury, brain injury, neuromuscular conditions
- Focus on functional impact of illness or injury
- Multi-disciplinary approach to care
FIELD: PEDIATRIC REHABILITATION MEDICINE

• Practice site
  – Inpatient and outpatient settings
  – Majority of pediatric rehabilitation medicine physicians practice in academic settings

• Training and Research opportunities
  – Clinical research > basic science research
  – Dedicated research time during fellowship is limited
  – Focus on outcomes-based research
AMERICAN ACADEMY OF PEDIATRICS RESOURCES

• Council on Children with Disabilities
• Section on Developmental and Behavioral Pediatrics
• Section on Pediatric Trainees
• Section on Early Career Physicians
• AAP Mentorship Program
BOARD CERTIFICATION INFORMATION

- General Pediatrics Certifying Examination Requirements, American Board of Pediatrics
- Developmental-Behavioral Pediatrics Certification Requirements, American Board of Pediatrics
- Neurodevelopmental Disabilities Certification Requirements, American Board of Psychiatry and Neurology
- Pediatric Rehabilitation Medicine Certification Requirements, American Board of Physical Medicine & Rehabilitation
ADDITIONAL RESOURCES

- Council on Pediatric Subspecialties
- Society for Developmental and Behavioral Pediatrics
- Association of University Centers on Disabilities
  - Leadership Education in Neurodevelopmental and Related Disabilities
  - University Centers for Excellence in Developmental Disabilities
Council on Children with Disabilities

Optimal health, function, and development of children and youth with disabilities—in partnership with their families, providers, and communities—in all settings.

Autism Initiatives

www.aap.org/cocwd  www.aap.org/autism

AAP Staff: Alex Kuznetsov, akuznetsov@aap.org