

Training of Medical Professionals about IDD: What are the Barriers and How do we *Overcome Them*?

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Almost Home Kids

Disclosures

- No conflicts
- No off-label medications discussed
- Willing to compromise our ethics, for a price

Objectives

1. Name the multiple oversight organizations involved in medical education
 - Briefly describe each
 - Outline how each can present barriers for teaching IDD
2. Describe strategies to overcome barriers
3. Describe one example (ours!) for teaching IDD
 - Barriers encountered (#1 = \$)
 - “results”
 - Lessons learned

“alphabet soup”

- AAMC
 - Association of Medical Colleges
 - Medical Schools (“NOT yet doctors”)
- ACGME
 - Accreditation Council for Graduate Medical Education
 - Resident and Fellow Programs (“doctors in training”)
- “JUST” pediatrics:
 - ABP: American Board of Pediatrics (INDIVIDUAL doctors)
 - APPD: Association of Pediatric Program Directors
 - AAP: American Academy of Pediatrics
- Others (not discussed): ACP, AAFP, ACOG, etc.

Barriers

Medical Students (4 years)

- Learners do NOT have clear goals/perspectives/context
- Dominated by Surgery & Internal Medicine & Subspecialties
- Curriculum HARD to enter
 - “Basic Sciences” (e.g., Cell Biology, Pathology, etc.) for 2 years
 - “Clinical rotations” (e.g., OB/GYN, Pediatrics, Surgery, etc.) for 2 years
 - Increasing mandates from AAMC

Residents (3 years in Pediatrics)

- Dominated by ICU’s (NICU, PICU) and inpatient “floors”
- Curriculum HARD to enter
 - Mandatory rotations throughout (100% in 1st year) and few “electives”
 - “General” clinic curriculum has no IDD component
 - Increasing mandates from ACGME

Barriers (continued)

In ALL settings:

- NO Department (or even faculty) to “Champion”
 - Pediatrics is ONLY place with formal Developmental Faculty
- NO formal mandates specific to IDD
 - Other groups/diseases have been better advocates
 - NIH funding “drives the bus”
- “Teaching” can be
 - Outright WRONG (least common, e.g., Down syndrome)
 - Biased (very often)
 - Absent (most often)

How to Overcome

1. Administrative Support: “From Above”
 - Medical Center leadership (“champions”)
 - Mandates
 - Advocacy organizations/media
2. Administrative Support: “Here and Now”
 - Coordinators
 - Program/Rotation Directors
 - [Faculty]
3. Administrative Support: “From below”
 - Clinic staff
 - Trainees

One Example – Medical Education



AHK Education Program

History:

- Not in hospital/medical school/residency
- WAS no administrative support (here and now)

Turning Point:

- Philanthropic grant named after MD who served AHK's 1st child
- IS administrative support (here and now)

Unexpected Twist:

- Affiliation with Lurie Children's Hospital/Northwestern
 - Diplomacy crucial
 - Complicated to explain/understand

Almost Home Kids

Mission = provide transitional care in a home-like setting for children with complicated health needs, as well as **training** for their families and respite care.

- Transitional Care:
 - Bridge from Hospital to Home
 - Parent/Caregiver training
 - Up to 120 day stay
 - Community Supports – Home Nursing, DMEs, Foster Care
 - Subspecialty & PCP Community Coordination
 - Newborn – age 22
 - *NOT a long-term care facility*
- Respite Care:
 - Planned or Emergency Short Term stay (up to 2 weeks)
 - 24/7 Nursing care and recreational volunteers
 - Opportunity to review Home Medical Plan and DME
 - Newborn – age 22

Snapshot of Diagnosis

- Neuromuscular Disease
- Spinal Muscular Atrophy (Type 0, I & II)
- Premature Birth
- Central Hypoventilation Syndrome
- Metabolic Disorders
- Cerebral Palsy
- Spina Bifida
- Oncology (cancer)
- Chromosomal Disorders
- Cardiac Anomalies
- Traumatic Brain & Spinal Cord Injury
- Gastric Anomalies - Short Gut Syndrome
- Palliative Care
- Hospice
- Neonatal Withdrawal Syndrome

Accomplishments

1. Meet and “get to know” the “players”
 - GMEC/Legal @ LCH/Northwestern
 - Pediatric Program @ LCH
 - AHK staff (communication, development, volunteer, clinical)
2. Formalize the curriculum (didactic and experiential)
 - “observer-ships” as “way out”
 - FAQ, pre-reading, logistics
 - Paperwork/documentation
3. Processes and procedures
 - Pre- & Post-tests (software = Redcap)
 - Schedules

1 July 2015 – 31 May 2016

- 73 learners
 - 23 medical students
 - 50 residents & fellows
- 11 different medical centers
 - Chicago: Lurie Children's Hospital (LCH), Northwestern, University of Chicago, Loyola, UIC, Rush, Advocate, Schwab (rehabilitation), Rosland-Franklin, Midwestern
 - Distance: Vanderbilt
- 292 total training hours

Comment from Post Test

“... it was an amazing experience, everyone I worked with was fantastic, and I will highly highly recommend this rotation. . .”

Questions?

