JFK Webinar MCH Education Series:

Improving Access to Developmental Evaluations in Colorado

Today’s Speakers*:
Michele Ebendick, Assuring Better Child Health & Development (ABCD) Colorado
Sandra Friedman, MD, MPH, Developmental Pediatrics, Children’s Hospital Colorado
Angie Goodger, MPH, MHA, Colorado Department of Public Health and Environment

*Special thanks to Laura Merrill with Early Intervention Colorado for reviewing content and agreeing to help answer questions as part of our panel!

04/29/2019
10 am - 11:30 am
Anschutz Medical Campus, Ed2 North, RM 2301
Today's Objectives

Following this event, the audience will better understand:

➔ The importance of Developmental Screening & Referrals to
   ◆ Early Intervention (Part C)
   ◆ Schools for screening and assessment of children older than 3 years of age (Part B)

➔ The barriers to receiving a diagnosis of ASD/DD

➔ Examples of strategies for improving access to diagnostic developmental evaluations

➔ Opportunities to improve the referral system (per group discussion)
Improving Access to Pediatric Specialty Care in Colorado: from Services to Systems

Angie Goodger, MPH, MHA
Colorado Department of Public Health & Environment
Children & Youth with Special Health Care Needs Section
Identify and implement policy/systems changes that:

1. support communication and collaboration between programs that provide care coordination for children and youth
2. that enhance statewide access to pediatric specialty care, including behavioral health
3. expand access to information and resources for women of reproductive age, youth, children, including CYSHCN and families
4. improve developmental screening, referral and intervention services
Services to Systems: A Population Health Approach

What is the role of public health?

What has to change if we want to support a shift from services to systems?

What impact do we want to make?
Team-Based from ‘Go!’

From the earliest days of the program, there was injected the concept of treating the whole child rather than a paralyzed arm, a damaged heart, or a “case” of deafness or epilepsy. As a corollary, there developed the concept of care by a team of professional workers, including doctor, nurse, social worker, therapist, psychologist, nutritionist, and educator.

Source: Title V of the Society Security Act: What It Has Meant to Children
Systems-Level Considerations

- Referrals
- Communication
- Follow-up
- Roles & Responsibilities
- Shared Plans of Care
Using Improvement Cycles to Implement Policy Change

Policy enabled practice
Practice informed policy

Project representatives traveled the state and learned that **Communities** want to **Prioritize** access to diagnostic developmental evaluation for their families.

**DATA**

Access to diagnostic developmental evaluation was brought up:

- at all 7 HCP clinic locations
- at all 3 Community Cafés
- by providers, statewide
Developmental Evaluation

→ What is it that communities are asking for? (DIG!)

→ What is currently available?

→ How does our work connect with these systems?

→ What can we try or do differently?
Developmental Evaluation Referrals

- **Medical Referral**
  - Is there a diagnosis?
  - Labs
  - Medical History

- **Specialty Consult**

- **Educational Referral**
  - Is there a delay?
  - Child Age 0-3 Early Intervention
  - Child Age 3-5 Child Find

- Simultaneous Referrals
Opportunities

- Increase simultaneous referrals
- Look for ways to improve communication & collaboration
- Understand systems, services, roles and responsibilities
- Use common language
- Build provider capacity
- Look for policy recommendations
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Developmental Screening & Referral Systems (Part C & B)

Michele Ebendick
Assuring Better Child Health & Development (ABCD) Colorado
Monitoring and Screening: What’s the difference?

- **Developmental Monitoring** is a process of close and continuous observation of a child’s development, in order to identify risk for developmental delay.

- **Screening** is the use of a standardized developmental screening tool (SDST) to identify children with (or at risk for) developmental delay with the purpose of referring to appropriate services.
Recommendations & the Colorado Climate

- American Academy of Pediatrics recommends developmental screening at the 9, 18, and 24/30 month well child visit.
- The most common tool used in Colorado is the Ages and Stages Questionnaire.
- 2017 National Survey of Children’s Health for Colorado reported 49.7% of parents reported they completed a questionnaire about their child’s development.
- Colorado’s rate for recommended developmental screenings for kids birth to age 3 on Medicaid and CHIP was 41.8 percent according to 2016 data.
IDEA: Individuals with Disabilities Act

**Part C: Birth to 3 Years**
- Early Intervention
- Services provided by the CCB
- Eligibility results in the development of an Individual Family Service Plan
- Developmental Services in the home and are family centered

**Part B: 3 to 21 Years**
- Special Education
- Services provided by the school district in which the child lives
- Eligibility results in the development of an Individualized Education Plan
- Educational classroom setting that is student centered
Making a Referral

- Engage the family in referral decision making.
- Completely fill out the referral form.
- Include accurate and complete contact information.
- Attach screening results with referral and include diagnosis if one is known.
- Educate families on the referral process and next steps.
Making a referral

Referral forms: https://www.coloradoabced.org/referral-resources

Making an Early Intervention Referral:

Finding the child’s local Early Intervention Program:


Making a referral to Child Find:

Referrals are made to the school district in which the child resides.
Child Find Directory: https://www.cde.state.co.us/early/childfinddirectoryinfo
Early Intervention Evaluations

- **Family Contacted**
  - Within 3 days

- **Service Coordinator Assigned**
  - Evaluation

- **IFSP Meeting with Family**
  - Determine outcomes and services
  - (Within 28 days)

- **First visit by service provider**

- **Status Update Sent**
Who is Eligible for Early Intervention?

- **Developmental Delay**
  - 25% delay in an area of development

- **Categorical Eligibility**
  - Condition or diagnosis associated with high probability of delay

- **Child who has a parent with a developmental disability**
  - Determined by the CCB

Database of diagnosed conditions:

https://docs.google.com/spreadsheets/d/14ZfUsdLaMiv4ULd9oP-xkUVaPkJQQ7K1_yhrPOiFwqA/edit#gid=0
IDEA Part B: Role of Child Find

Birth through 2 years of age: Assess level of development

3 to 21: Determines eligibility for Special Education services and Supports

3-5 years = Special Education Preschool
Child Find Process (3-5)

1. Referral Received
2. Screening (optional)
3. Evaluation
4. Evaluation Results/IEP

3-5 years = Special Education Preschool
Who is Eligible for Preschool Special Education?

Children 3 to 5 years old, who have an educationally relevant delay, that prevents the child from getting the full benefit of general education.
Problem Statement

Access problems for families to obtain timely diagnostic developmental assessments:

- Medical evaluation
- Diagnostic psychological and other developmental assessments
Reasons for Medical Assessments

- Understanding etiology
- Recurrence risk and genetic counseling
- Prognosis
- Treatment options
- Avoid unneeded tests
- Guide monitoring, other tests and management
- Potential research protocol
- Condition specific support groups
Standard of Care

- Children with GDD and ID require consideration of medical evaluation
- Children with ASD require consideration of minimum of genetic testing
- Should be done step-wise
- Not all children require same evaluation
Potential Etiologic Factors

- Etiologic Factors
  - Genetics
  - Metabolic
  - Infectious
  - Toxic
  - Trauma
  - Environmental
  - Unknown
Developmental Assessment: History

- Parental concerns
- Identify potential pre-, peri-, post-natal factors
  - Developmental – milestones, trajectory
  - Medical
  - Family
  - Social
Physical Examination

- Dysmorphic features
  - 1 feature: 13% all newborns
  - 2 features: <1
  - 3 or > features: 0.05 % (1/2000)
    - ~40 % of those with ID/DD
- Growth parameters
- Positive physical findings
- Positive neurological findings
Formulation of Problem

- Pertinent history/developmental trajectory
- Physical findings
- Developmental testing results
- Working hypothesis regarding etiology
- Information above drives recommendations & plan
Medical Assessment of ID or GDD
(Pediatrics, 2014; 134:e903)
Other Areas of Investigation

- Hearing
- Vision
- EEG
- Infection
- Toxins
- Imaging
- Endocrine
- Immunologic
- Nutritional
- Hematological
Referral to Other Specialists

- High index of suspicion for syndrome or disorder
- Negative results with high index of suspicion
- Abnormal test results requiring further specialized assessments
- Active or potentially complicated neurological process, e.g. seizures, CP
National and Statewide Challenges

- Long waiting lists for assessments
- Increasing rate of disability
- Workforce issues
- Socioeconomic, racial, ethnic disparities
- Underserved regions
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<thead>
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<th>CYSHN (0-17 years)</th>
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<tr>
<td><strong>U.S.</strong></td>
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<td>- 18.2% (13,327,498)</td>
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<td>- Have well-functioning care system</td>
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<tr>
<td>- 14.8% (1,971,876)</td>
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<tr>
<td>- Not well-functioning</td>
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<tr>
<td>- 85.2% (11,355,622)</td>
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<td>- Have medical home</td>
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<tr>
<td>- 43.3%</td>
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<tr>
<td><strong>Colorado</strong></td>
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<tr>
<td>- 18.3% (230,499)</td>
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<tr>
<td>- Have well-functioning care system</td>
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<tr>
<td>- 14.7% (33,867)</td>
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<tr>
<td>- Not well-functioning</td>
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<tr>
<td>- 85.3% (196,581)</td>
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<tr>
<td>- Have medical home</td>
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<td>- 46.7%</td>
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Developmental & Behavioral Problems

74 million children in US

~15% of children with DB problems

~11 million with DB problem

~800 board certified DBP

13,750 children/DBP

Concern for burnout - feeling overwhelmed and undervalued
Consider Different Models of Care

1. Triage methods/Focused Evaluations
2. Improved use of advanced practice providers, RNs, MAs
3. Co-location within Child Health Clinic (CHCO) primary care
4. Building capacity in underserved communities
   a. Training advanced practice providers/ PCPs
   b. Supporting community providers through ECHO and community of practice
5. Telehealth
6. e-Consult (coming in May 2019)
Other Considerations

- Mitigate burden on PCP
- Need for interested partners
- Appropriate billing codes
- Family and PCP satisfaction
- Evaluate effectiveness and quality of services
- Importance of sharing best practices
Questions for the presenters?

Thinking about the three referral systems we presented, what opportunities exist to enhance your referrals?
Resources

Archived JFK Webinars

Successful Early Intervention Transitions Webinar Series presented by JFK Partners and Early Intervention Colorado

Feb 7, 2019 – Webinar 1:
Transition from the NICU to Early Intervention

Apr 25, 2019 – Webinar 2:
Reflections from Parents and Medical Providers on Early Intervention Transitions

Jun 27, 2019 – Webinar 3:
Part C Early Intervention Transition to Part B Preschool Special Education or other settings

Transition from the NICU to Early Intervention (EI) and from Part C EI to Part B School Services can be particularly complex for children with developmental delay or disability.

This 3-part Webinar Series will provide information about Colorado’s current processes for transitions within the Early Intervention system, parent’s experiences when going through transition, and ideas for how Neonatal Intensive Care Unit (NICU) staff, Service Coordinators (SC), EI providers, Primary Care Providers (PCP), Parents or Caregivers, and others involved in the transition process can work together to best support the children going through transition.
Resources Con’t

Developmental Screening, Discussion, & Referral Improving Developmental Screening, Discussion, and Referral in Pediatric Practice


New article by Clinical Pediatrics: This publication summarizes the findings from a quality improvement (QI) project led by the American Academy of Pediatrics (AAP) with support from Learn the Signs. Act Early., a program of the Centers for Disease Control and Prevention.

Autism Case Training (ACT)

A free, web-based continuing education course to help healthcare providers gain knowledge and skills to improve early identification of children with ASD.

Modules contain case studies based on real-life situations.

https://www.cdc.gov/ncbddd/actearly/act.htm
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