



Effective Health Care

Childhood Developmental Disabilities Nomination Summary Document

Results of Topic Selection Process

The topic, *Childhood Developmental Disabilities*, is an important topic. While developmental disabilities are an important issue, because of the breadth of conditions and interventions, we were not able to assess this nomination. While further activity will not be undertaken on this topic, we have identified related AHRQ evidence reviews that may be relevant to this topic.

- Sun F, Oristaglio J, Levy SE, Hakonarson H, Sullivan N, Fontanarosa J, Schoelles KM. Genetic Testing for Developmental Disabilities, Intellectual Disability, and Autism Spectrum Disorder. Technical Brief No. 23. (Prepared by the ECRI Institute–Penn Medicine Evidence-based Practice Center under Contract No. 290-2012-00011-I.) AHRQ Publication No.15-EHC024-EF. Rockville, MD: Agency for Healthcare Research and Quality; June 2015.
- Weitlauf AS, McPheeters ML, Peters B, Sathe N, Travis R, Aiello R, Williamson E, Veenstra-VanderWeele J, Krishnaswami S, Jerome R, Warren Z. Therapies for Children With Autism Spectrum Disorder: Behavioral Interventions Update. Comparative Effectiveness Review No. 137. (Prepared by the Vanderbilt Evidence-based Practice Center under Contract No. 290-2012-00009-I.) AHRQ Publication No. 14-EHC036-EF. Rockville, MD: Agency for Healthcare Research and Quality; August 2014.
- McPheeters M, Davis AM, Taylor JL, Brown RF, Potter SA, Epstein RA. Transition Care for Children With Special Health Needs. Technical Brief No. 15 (Prepared by the Vanderbilt University Evidence-based Practice Center under Contract No. 290-2012-00009- I). AHRQ Publication No.14-EHC027-EF. Rockville, MD: Agency for Healthcare Research and Quality. June 2014.
- Berkman ND, Wallace I, Watson L, Coyne-Beasley T, Cullen K, Wood C, Lohr KN. Screening for Speech and Language Delays and Disorders in Children Age 5 Years or Younger: A Systematic Review for the U.S. Preventive Services Task Force. Evidence Synthesis No. 120. AHRQ Publication No. 13-05197-EF-1. Rockville, MD: Agency for Healthcare Research and Quality; 2015.
- Chou R, Dana T, Bougatsos C. Screening for Visual Impairment in Children Ages 1–5 Years: Systematic Review to Update the 2004 U.S. Preventive Services Task Force Recommendation. Evidence Synthesis No. 81. AHRQ Publication No. 11-05151-EF-1. Rockville, MD: Agency for Healthcare Research and Quality; February 2011.

Nomination

Topic Number: 0296

Received On: 08/11/2010

Topic Name: Childhood Developmental Disabilities

Nominator: Physician with Kaiser Permanente

Nomination Summary: The nominator is interested in research related to a broad range of developmental disabilities. The nominator poses questions related to the burden of these

conditions, screening practices, rehabilitation services, utilization of therapies, emerging technologies and interventions, and future research needs. The population in which the nominator is interested in includes underserved and underrepresented minorities.

Key Questions from Nomination:

Key Question 1: What is the burden and incidence of childhood developmental disabilities (hearing loss, kernicterus/jaundice, intellectual disability and visual impairment) in the US?

Key Question 2: When is screening for childhood developmental disabilities indicated and in what care setting?

Key Question 3: What is the comparative effectiveness of current screening tools and methods for the diagnosis of developmental disabilities?

Key Question 4: What is the effectiveness of screening tools on assessment, access to care and interventions for developmental disabilities?

Key Question 5: What is the comparative effectiveness of different models of child development and rehabilitation services on improving functional, social, and health outcomes of children with developmental disabilities?

Key Question 6: What are the current rates of utilization of current therapies and interventions for developmental disabilities?

Key Question 7: What are the harms and benefits of current therapies and interventions for developmental disabilities?

Key Question 8: What are emerging technologies, interventions, and models of care to screen, diagnose, and treat developmental disabilities?

Key Question 9: What are the future effectiveness and comparative effectiveness research needs of developmental disabilities?

Policy and/or Clinical Context from the Nomination: In the US, 17 % of children have developmental disabilities. Less than 50% of these children are diagnosed with a developmental disability prior to beginning school and may miss opportunities for early intervention and treatment. In addition, developmental disabilities are a diverse group of severe chronic conditions that are due to mental and/or physical impairments which further complicates the assessment of children early in the course of development in addition to sociocultural barriers and limited provider, care-giver and family education. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities begin anytime during development up to 22 years of age and usually last throughout a person's lifetime.

AHRQ's Effective Healthcare Program has developed several systematic reviews related to children with developmental disorders. This nomination postulates that a 'series' of comprehensive reviews of childhood developmental disabilities (kernicterus/jaundice, intellectual disabilities, visual impairment) will complement these reviews and provide an examination of both clinical and policy controversies and issues which can help direct further comparative effectiveness research and effectiveness research efforts within the breadth of this AHRQ priority condition area.

Original Nomination

Topic Suggestion Description

Date submitted: August 11, 2010

Briefly describe a specific question, or set of related questions, about a health care test or treatment that this program should consider.

KQ 1 - What is the burden and incidence of childhood developmental disabilities (Hearing Loss, Kernicterus/Jaundice, intellectual disability and visual impairment) in the US? KQ 2 - When is screening for childhood developmental disabilities indicated and in what care settings? KQ 3 -What is the comparative effectiveness of current screening tools and methods for the diagnosis of developmental disabilities? KQ 4 - What is the effectiveness of screening tools on assessment, access to care and interventions for developmental disabilities. KQ 5- What is the comparative effectiveness of different models of child development and rehabilitation services on improving functional, social and health outcomes of children with developmental disabilities? KQ 6 – What are the current rates of utilization of current therapies and interventions for for developmental disabilities? KQ 7 - What are the harms and benefits of current therapies and interventions for developmental disabilities? KQ 8- What are emerging technologies, interventions and models of care to screen, diagnose and treat developmental disabilities? KQ 9 -What are the future effectiveness and comparative effectiveness research needs of developmental disabilities?

Importance

Describe why this topic is important.

In the US, 17 % of children have developmental disabilities. Less the 50% of these children are diagnosed with a developmental disability prior to beginning school and may miss opportunities for early intervention and treatment. In addition, developmental disabilities are a diverse group of severe chronic conditions that are due to mental and/or physical impairments which further complicates the assessment of children early in the course of development in addition to sociocultural barriers and limited provider, care-giver and family education. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities begin anytime during development up to 22 years of age and usually last throughout a person's lifetime. Currently, the AHRQ-Effective Healthcare Program are sponsoring three comparative effectiveness reports on Autism Spectrum Disorders and Cerebral Palsy. This proposed nomination postulates that a 'series' of comprehensive reviews of childhood developmental disabilities (kernicterus/jaundice, intellectual disabilities, visual impairment) will complement these concurrent reviews and provide an examination of both clinical and policy controversies and issues which can help direct further comparative effectiveness research and effectiveness research efforts within the breadth of this AHRQ priority condition area.

Potential Impact

How will an answer to your research question be used or help inform decisions for you or your group?

This process will help the AHRQ-EHC program comprehensively survey the literature of developmental disabilities in order to further inform areas of comparative effectiveness research topics that could be conducted as AHRQ systematic reviews.

Technical Experts and Stakeholders

Are there health care-focused, disease-focused, or patient-focused organizations or technical experts that you see as being relevant to this issue? Who do you think we should contact as we consider your nomination? This information will not influence the progress of your suggestion through the selection process, but it may be helpful to those considering your suggestion for further development.

National Center of Birth Defects and Development, American Academy of Pediatrics, American Academy of Ophthalmology, American Ophthalmological Society, American College of Gastroenterology, President's committee for intellectual disabilities, American Association for Intellectual and Developmental Disabilities, NINDS, Administration on Developmental Disabilities (ADD), Administration for Children and Families, Center for Medicaid and Medicare Services (CMS), DisabilityInfo.gov, Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, National Library of Medicine, National Council on Disability (NCD), National Institutes of Health (NIH), National Eye Institute (NEI), National Institute of Child Health and Human Development (NICHD)

Nominator Information

Other Information About You: (optional)

Please choose a description that best describes your role or perspective: (you may select more than one category if appropriate)

Patient/Consumer and Physician

Please tell us how you heard about the Effective Health Care Program

Medical Officer

May we contact you if we have questions about your nomination?

Yes