Improving Services for Iowa Children with Autism Using A Framework for Action

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Introduction

- Iowa children with Autism Spectrum Disorders (ASD) continue to face significant gaps in the coordination of their care including provider non-compliance with universal screening, delayed diagnosis, and inadequate access to applied behavioral analysis (ABA) therapy.
- ASD affects 1-68 children in the U.S.1
- The yearly cost of children with ASD is estimated to be $115,560.9 billion.2
- The American Academy of Pediatrics recommends universal ASD specific screening at 18-24 months.1
- By age 2 an autism diagnosis by an experienced professional is considered very reliable.1
- Many children with ASD who complete ABA programs can be mainstreamed into schools and “normalized” in terms of IQ and adaptive functioning.3,4
- Cost analysis research supports that ABA therapy can lead to a lifetime cost savings of up to $2.8 million per child.5

Purpose

Purpose: To build a case for the management of autism spectrum disorders (ASD) through awareness, evidence based practice, and policy change.

Objectives:
1. Improve access to ABA therapy for children in Iowa with ASD through policy change.
2. Improve early identification of ASD in Iowa through educational outreach to providers.
3. Collaborate with Child Health Specialty Clinics (CHSC) and Regional Autism Assistance Program (RAP) to identify gaps in coordination of care for children with ASD.

Methods

- Model: “Framework for Action” model utilized, which outlines four spheres of influence where nurses can shape policy and impact change in the health system.8
- How spheres of influence were utilized to impact change for Iowa children with ASD:
  1. Community: ASD Family Study with CHSC (IRB approval received, surveys sent to 438 children age 0-21 who received RAP services in 2016)
  2. Workplace: Presentations to providers on identification and treatment of ASD.
  3. Organizations: Collaboration with the Iowa Autism Council (IAC), RAP Coalition, and Iowans for Autism Insurance Reform.

Evaluation

- Objective 1: ABA Therapy Policy Change
  - Autism insurance reform bill passed Iowa House 96-0 and passed Iowa Senate 48-0. It is awaiting approval from Governor Branstad.
  - ASD educational outreach seminars were completed with 216 providers including DNP students, BSN students, primary care providers, educators and paraprofessionals.
- Objective 3: Identify Gaps in ASD Care
  - Only 40% received ASD specific screening
  - 79% noticed symptoms, but only 39% diagnosed by age 3
  - 40% reported waiting longer than 6 months for diagnosis
  - Only 7-8% of children with ASD receiving ABA therapy.
  - 25% of children 6 years or younger receiving ABA
- Change in Data from 2015-2016
  - Children waiting >6 months for diagnosis increased 15%
  - Children receiving an ASD diagnosis by age 3 decreased 17%
- Limitations:
  - Only 2 years of data collection
  - Unable to see impact of policy change

Conclusions

- Improved coordinated care for Iowa children with ASD through identification of current gaps in care, provider education, and, advocacy efforts for policy change.
- Next Steps:
  - Community: RAP and CHSC will address gaps in coordination of care for children with ASD identified through survey.
  - Workforce: Project being disseminated at the Iowa Association of Nurse Practitioners (IANP) conference on April 28, 2017.
  - Organizations: Future collaboration with IAC and RAP.
  - Government: Continued advocacy for Iowa children with ASD.

References


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