Early Access to Care: A Collaborative Effort to Improve Early Autism Diagnosis and Intervention

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The Challenge

• Evidence based methods for autism screening, diagnosis, and treatment exist

• Reliable diagnosis of ASD possible by 24 months, yet average age of autism diagnosis in US is 4-5 years (CDC, 2009)

• Many individuals have poor access to intervention:
  • Treatment gap in developed countries (35-50%)*
  • Treatment gap in developing countries (>85%)*

• Great disparities exist in diagnosis and access to services based on awareness/sigma, geography, ethnic/racial background, and other factors
The Need

Coordinated, strategic effort focused on addressing key barriers to diagnosis and treatment

- focus on underserved
- use of novel technologies
- innovative access to care
- train providers
- coordinate with state and federal partners
What do we want?

- Lower the age of detection of ASD
- Improve access to early intervention services
Areas of focus:

• Awareness of ASD focusing on those that traditionally are underserved
• Improving screening and increasing screening
• Reducing time from first concern to diagnosis
• Increasing the availability and access to evidence based early interventions
Isn’t someone doing this?

Need for coordinated effort

Learn the Signs. Act Early.
Across government, academic, non-government organizations and professional societies
We need more partners!

- Educators
- Advocates
- Parents
- Organizational leaders
What works?
A review of the evidence-base for early detection and access to care

First concern  Screening  Diagnosis  Treatment
Evidence-base for early detection

Surveillance (n=1)

• State-wide surveillance program of all child in intensive care for >48 hours
• Active screening by risk level
• Larger % of higher risk children screened positive, and referred for EI services

Awareness (n=1)

• Evaluation of CDC “Learn the Signs. Act Early”
• Multimedia campaign targeted at parents, health care professionals and early educators on early detection of autism
• Increase in parental awareness and knowledge, and physician confidence to address developmental concerns
Evidence-base for early detection

Screening (n=13)

- Majority in primary care/pediatric offices and during well-child visits
- Three took place in urban settings, one focused on foster care population
- Non-health care settings included: preschool, WIC site, 211
- Screening fidelity most common outcome assessed, and ranged from 54-98%
- Fewer studies examined changes pre-post in screening and referral rates or more distal outcomes
Evidence-base for early detection

Practice improvement (n=5)

- National and state implementation of screening guidelines
- Academic detailing
- Project First step - comprised of community outreach, pediatrician and parent training, screening, and family support
- Use of service coordinators to enhance referrals and diagnosis

Provider training (n=4)

- Educating medical students on developmental screening
- Web-based training in early autism screening
- In-office training for PHCs on surveillance and referral
- Training general pediatricians on how to diagnose autism
Evidence-base for access to early intervention services

Brief, intensive parent-training (n=2)

- Weeklong, intensive center-based training program for parents of newly diagnosed children
- Parent and child outcomes persisted post-intervention

Clinic to parent-directed (n=1)

- randomly assigned children to a clinic-directed group or a parent-directed group to receive intensive behavioral treatment
- Cognition, language, social and academics were similar in both groups at four years follow-up.
Evidence-base for access to early intervention services

Distance/eLearning (n=8)

- To train parents and/or professionals on principles of evidence-based early intervention from a distance (i.e. web)
- 2 targeted parents & professionals; 4 parent-only; 2 professional only
- Half of included studies measured pre- and post-test scores only, and no parent/professional or child behavior

Implementation (n=1)

- Parent-training program for early intervention and early childhood special education programs
Research gaps and next steps

Early detection

• Design and measurement
• Awareness and detection in non-traditional settings with underserved populations
• Strengthening link between positive screen and evaluation/treatment

Access to care

• Design and measurement
• Development of waitlist solutions
• Characterization of active components of distance learning
What Autism Speaks can offer
Family Services

Resources Outreach Grants

School-Age Children

Transitioning Adolescents and Young Adult

Adults

Aging Adults

Young Children

The Community at Large
AUTISM SPEAKS™

100 Day Kit

A tool kit to assist families in getting the critical information they need in the first 100 days after an autism diagnosis.

Autism Speaks does not provide medical or legal advice or services. Rather, Autism Speaks provides general information about autism as a service to the community. The information contained in this kit is not a representation, referral or endorsement of specific books, programs, therapies, methods, or service providers and does not replace the advice of medical, legal or educational professionals. This kit serves informational and referral purposes and is not intended to be used as a substitute for professional medical, legal, or educational advice. Autism Speaks is not responsible for any information or services provided by these sources. You are advised to use independent judgment and appropriate references when considering any resource associated with this provider of services related to autism.
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Autism Response Team (ART)

• ART is trained to empower individuals with autism, their families and caregivers with resources and information to make informed decisions.

From Jan – Dec 2012, ART has had 24,436 contacts!

• Toll Free: 1-888-AUTISM 2
• Dedicated line for Bilingual ART Coordinator
  • En Español 1-888-772-9050
• Email: familyservices@autismspeaks.org
• Office hours – live chat
Responding to Community Needs

**Top Five Types of ART Requests**
*January-December 2012*

- **Family Services Resources and Tool Kits**: 44%
- **Resource Guide - local service providers**: 24%
- **Financial Aid Resources**: 18%
- **Educational/Legal Advocacy**: 8%
- **Concerned about Developmental Disability "Learn the Signs"**: 6%

68% of ART contacts concern the need for resources and how to access them in the community.

6% of contacts have concerns about signs of autism.
Age of ART Contacts

- ART provides information and resources that meet unique needs

- 21% of ART contacts are families of children 0-3 yrs old and are eligible for **Early Intervention** services.
Awareness – Ad Council Campaign

Odds of a child becoming a pop singer: 1 in 58,000

Odds of a child being diagnosed with autism: Every 20 minutes a child is diagnosed with autism.

Learn the signs. autismspeaks.org
Awareness – Ad Council Campaign

Change in concept and style

• Targeting African American, Hispanic and underserved
• Eye contact/repetitive behavior
• New methods to reach parents
• New materials for parents and professionals
Advocacy

OUR PRIORITIES:

• maximizing support and funding for autism research, surveillance, awareness and services.

• Advocating autism insurance reform that maximizes coverage for evidence-based treatments including behavioral health treatments.

AUTISM VOTES
AN AUTISM SPEAKS’ INITIATIVE
A coordinated strategic approach