Prevention and Treatment of Autism – A Call to Action

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Health-Action
Help Children Develop Worldwide

ASTMH Abstract LB-5170

SSAS-C the Society for the Study of ASD and Social-Communication

Key messages

- Autism is now a common disorder, having serious consequences
- Resources to help in the developing world are nearly non-existent
- The majority of autism cases can be ameliorated (or even prevented)
- Treatment solutions may exist to improve outcomes at scale
- Critical research has not yet been done
- **We seek partners and volunteers** to:
  - Document that autism can be ameliorated or prevented with worldwide outreach possible
    - Large international web-based case series
    - Followed by randomized controlled trials (RCTs)
  - Autism can be more effectively treated in all settings
    - Large international web-based case series
    - Followed by randomized controlled trials (RCTs)
  - Translation of the US CDC Act Early app into other languages
    - For teaching and tracking developmental milestones
    - Vietnamese version under development
    - Additional languages very feasilbe
  - **Support or in lead areas of our mission to help children (see below)**
  - We call on ASTMH, the media, non-profits, researchers, donors, autism professionals, parents and global partners to join us in this agenda

Abstract (updated)

Autism is a massive, growing and unmet global health challenge. Autism is becoming common, now affecting about 1 in 34 boys in the USA (1 in 20 in New Jersey) (1). Globally, it has increased 20-30 fold in the last 50 years (2). Worldwide, about 40 million people live with the condition, including at least 3 million preschool children currently (unpublished data). These preschool children are in need of early intervention; most will never receive it as it is not available, unaffordable or children are diagnosed too late (unpublished observations). Lifetime costs in the USA are $1.4 - $2.4 million per person (3). Early intervention decreases lifetime costs (4, 5) and improves lives (6-8). In the developing world, the burden is carried by the family. It will be decades before early intervention is feasible worldwide. An urgently needed solution is prevention. Several readily correctable environmental risk factors are known or suspected, yet no prevention trials have been conducted. Several risks relate to a decrease in eye contact, two-way communication and play in the first year of life, such as screen usage by children and their caregivers (9-12), city environment (13-15), shorter duration of breast feeding (16, 17) and post-partum depression/stress (17). Several additional correctable factors have been identified (16, 17). For young children with autism, screen time reduction/removal, parent education and teacher training are achievable in the short term. The Consortium for Health Action with Society for the Study of ASD and Social Communication are planning a research and outreach agenda to document that autism can be ameliorated (or even prevented) and more effectively treated at scale worldwide. **We call on ASTMH, researchers, donors, autism professionals, parents and global partners to join us in this agenda.**

Introduction

Consortium for Health Action is a 501(c)3 non-profit based in the USA and Vietnam. We recently realized that autism and excessive screen exposure are massive unmet public health needs worldwide.

Health-Action's New Initiative: "Help Children Develop Worldwide"

- **Strategies for autism that effectively**
  - Prevent the disorder
  - Improve outcomes
  - Are scalable and effective everywhere
- **Methods to limit screen time**
  - Demonstrate the benefits of limits
  - Achieve widespread awareness

What is Autism?

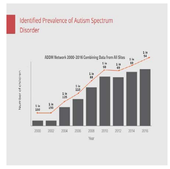
- Characterized by challenges with (18):
  - Eye contact
  - Speech and nonverbal communication
  - Social skills
  - Restricted interests and repetitive behaviors
- Many commonly co-occurring challenges (18):
- Develops in the first year of life (19)
- **Most have lifelong challenges** (18)

Massive Unmet Public Health Need

- ~ 40 million people world-wide currently have autism
- At least **3 million preschool children with the disorder**
  - All in need of early intervention
  - Majority will never receive it (especially in developing countries)
    - Not available
    - Unaffordable
    - Diagnosed too late
- What can be done to help these children?

Growing Challenge

- 20-30 fold increase in last 50 years (2)
- Now 1/34 boys in USA (1/20 in New Jersey) (1)
- **In northern Vietnam** (14)
  - Dramatic increase since 2000
  - 3-fold higher in urban areas
  - **In cities, now about the same rates as USA**
  - Only special education in the biggest cities
- Similar unmet public health need worldwide

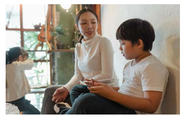


Impact in the USA

- Majority of children are diagnosed "late" (> 4 years) (20) missing the best opportunity for intervention (6-8)
- Lifetime cost $1.4 - $2.4 million per person (3)
- **National expenditures projected to total $1 trillion** in 2025 (22)
- Poor employment and education outcomes after high school (23)
- Social isolation and suicide are a big challenge (24)

Impact in the Developing World

- **Families and children often suffer** (25)
  - Stigma
  - Discrimination
  - Human rights violations
- Children often unable to go school (26)
- Those who can go to school often have difficulties (26)
  - Crowded classes
  - Teachers lack needed skills for support
  - Challenged by bullying



Treatment (Early Intervention)

- Increased effectiveness when started at young age (e.g. 2 years) (6-8)
- With early intervention
  - 3–25% lose their autism diagnosis (27)
  - Majority improve
  - Substantially decrease lifetime costs (4, 5)
  - Standard of care in USA
- What can be done at scale where early intervention is not available?
  - **Milestone teaching and tracking from birth (US CDC App)**
  - **Follow AAP/WHO screen time limits (25, 34)**
  - Parent/caregiver training
  - Teacher training

Screen Time Risks

- Excess screen time associated with adverse childhood outcomes
  - Social-emotional development, aggression, obesity and more… (18)
  - Poor language development (30)
  - **Autism (9-12)**
- For young children at risk for or having autism, screens:
  - Interfere with parent child interactions (31)
  - Offer little opportunity for learning compared with real-life interactions (32, 33)
  - **Are a powerful source of competition for the child's attention** (28)

Screen Time Limits/Removal

- **Can lead to reversal of autism symptoms** (12, 29)
- A three-month trial has no risk and potentially large benefits (12)
- Is the most readily available intervention anywhere in the world
- Is recommended by leading authorities (34, 36)
  - None to 18 months; <1 hour/day with parent co-viewing age 1-5 (34)
  - Insufficient awareness worldwide
- We believe outreach and definitive research must be a priority
- We invite participation in our case series of screen removal from around the globe

Prevention is the Best Solution

- Susceptibility genes and/or other risk factors lead to (35):
  - Altered early social interactions
  - Resulting in abnormal neurologic development and autism
- Early intervention can lead to (35):
  - More typical development
  - A proportion of children with no evidence of autism
- **Several suspected correctable risk factors**
  - Related to decrease in eye contact, two-way communication and play
    - Screen time by young children and their caregivers (9-12)
    - City environment/shorter duration of breastfeeding/maternal depression/stress (14-17)
  - Air pollution/ pesticide/chemical/progestin exposure (15-17)
  - Vitamin D/folate/iron deficiency (16, 17)

Prevention is the Best Solution (continued)

- **Interventions for infants**
  - **Screen time avoidance** per AAP/WHO recommendations (34, 36)
  - Elicit lots of eye contact, two-way communication, and play (28)
  - Teach steps to develop "joint attention" (28)
  - Address other correctable risk factors (16, 17)
- All have potential to more broadly improve outcomes (17)
- Outreach and definitive research must be a priority

About the Authors

Colin Ohrt a research scientist, clinical trialist and public health physician living in Vietnam. He spent a career developing prevention and treatment solutions for malaria. He is now using his skill set to tackle a new global health challenge – autism.

Linda Copeland is a developmental pediatrician and board certified behavior analyst. She spent a career helping children with developmental challenges. She now will utilize her skill set to help us have global impact.

Leonard Oestreicher is a physician and author of a book (37) and peer reviewed article (11) about screen time and autism. He and his non-profit will be using their skill set and resources to design and execute clinical case series and trials.

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