

Autism Prevention and Treatment Research and Outreach Program Outline

Background: The Consortium for Health Action (Health-Action.org) with the Society for the Study of ASD and Social Communication (SSAS-C.org) are planning a research and outreach agenda to promote more effective treatment and, importantly, to research the effectiveness of prevention strategies with regard to autism, in all settings. We encourage researchers, donors and partners worldwide to help build the evidence base to stop the current autism upward trajectory and help the millions of children who have the disorder now.

Autism is a massive growing and unmet global health challenge. It is becoming common, now affecting about 1 in 34 boys in the USA (1 in 20 in New Jersey) (1). In Vietnam, the number of children identified with autism has rapidly increased in the last two decades, with rates in urban areas similar to the US (2). Globally, it has increased 20-30 fold in the last 50 years (3). Worldwide, about 40 million people live with the condition, including at least 3 million preschool children currently (unpublished data).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early intervention; most will never receive it as it is not available, unaffordable or children are diagnosed too late (unpublished observations).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 very high (\$1.4 - \$2.4 million per person) (4). Early intervention decreases lifetime costs (5, 6) and improves lives (7-9). In the developing world, the burden is carried by the family. The disorder is associated with stigma, discrimination and human rights violations (10). Most affected people have lifelong challenges (11).

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 (12-15), city environment (2, 16, 17), shorter duration of breast feeding (18, 19) and post-partum depression/stress (19). Several additional correctable factors have been identified (18, 19).

What can be done to improve the effectiveness of early intervention for those with autism if such intervention is not currently available in an area or is limited in scope or availability? Screen time reduction or removal is a likely answer. For young children with or at risk for autism, screen time is a powerful distraction in children already less inclined to desire social interactions (20). Screen viewing, which is noninteractive, isolates infants and replaces social interactions and real world experiences. Furthermore, excessive screen time exposure is associated with symptoms of autism (12-15), and its removal can lead to reversal of these symptoms (15, 21). Based on many developmental and health risks, the American Academy of Pediatrics (AAP) and World Health Organization (WHO) recommend limits on screen-based media (22, 23), including no screen time to 18 months and then less than 1 hour of parent co-viewing from ages 2-5 years. A key challenge is lack of awareness or disbelief about these recommendations (unpublished observations). For children with symptoms of autism, we believe a trial of screen time removal should be implemented as soon as feasible and definitive research on this topic must be a priority.

Plan outline:

A. Autism severity reduction/prevention with interventions from birth

1. Translation of the US Centers for Disease Control "Act Early" app into other languages



2. Case series/cohort study with intervention package (no screen exposure for first 18 months of life, teaching of milestones, correcting risk factors to the best of the family's ability).
 - i. Face-to-face in Hanoi and other locations per partners
 - ii. Internet-based worldwide (primary purpose is outreach)
3. Randomized-controlled trial with the control being management as usual
 - iii. Face-to-face in Hanoi or others per partners
 - iv. Internet-based worldwide
4. Epidemiology studies
 - v. Follow-up of prior epidemiology studies to address risk factors not yet sufficiently studied (e.g. screen time, progesterin-contaminated seafood) (Vietnam, China, others per partners)
 - vi. Regional or nationwide autism prevention campaign with accompanying epidemiological research to investigate whether or not a marked decrease in autism (and improvement of other childhood conditions) following nationally recommended interventions occurs

B. Autism treatment in young children

1. Early interventionist expert opinion on the importance of screen time removal/reduction based on their experience with young children with autism
2. Case series of screen removal in young children with autism
 - i. Face-to-face in Hanoi and at other locations per partners
 - ii. Internet-based worldwide (primary purpose is for outreach)
3. Randomized-controlled trial of screen time reduction/removal in young children with autism
 - iii. Face-to-face in Hanoi and other sites per partners
 - iv. Internet-based worldwide
4. Regional or nationwide autism intervention campaign with accompanying epidemiological research to investigate whether or not a marked decrease in autism symptoms (and improvement of other childhood conditions) following nationally recommended interventions occurs.

C. Other questions we would like to address

1. How screen time reduction/removal improves other childhood conditions (e.g. behavior challenges, attention problems, cognitive development, school performance, obesity). This work can be readily developed and executed based on the above autism research approach.
2. How to achieve high uptake of use of screen time limits worldwide?
3. How to achieve widespread use of developmental monitoring and autism screening worldwide?
4. How to educate parents, other caregivers and teachers worldwide?
5. How to get potentially hazardous materials (e.g. videos targeted at very young children) removed from the market or at least having warning labels in the relevant language.
6. How to help parents move from the denial to acceptance stage and take action?
7. What is the broader public health impact (improved pregnancy and childhood development) outcomes of the autism prevention package (for example prevention of low birth weight, cerebral palsy, cognitive performance in school, etc.)?
8. How to motivate researchers, donors and organizations focusing on the areas with the greatest potential for impact?

D. References

1. Maenner MJ, Shaw KA, Baio J, EdS, Washington A, Patrick M, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. *MMWR Surveill Summ.* 2020;69(4):1-12.
2. Hoang VM, Le TV, Chu TTQ, Le BN, Duong MD, Thanh NM, et al. Prevalence of autism spectrum disorders and their relation to selected socio-demographic factors among children aged 18-30 months in northern Vietnam, 2017. *Int J Ment Health Syst.* 2019;13:29.
3. CDC. Developmental Disabilities Monitoring Network Surveillance Year Principal, Investigators Centers for Disease Control and Prevention. Prevalence of autism spectrum disorder among children aged 8 years - autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *MMWR Surveill Summ.* 2014;63(2):1-21.
4. Buescher AV, Cidav Z, Knapp M, Mandell DS. Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatr.* 2014;168(8):721-8.
5. Peters-Scheffer N, Didden R, Korzilius H, Matson J. Cost comparison of early intensive behavioral intervention and treatment as usual for children with autism spectrum disorder in The Netherlands. *Res Dev Disabil.* 2012;33(6):1763-72.
6. Jacobson J, Mulik, J., Green, G. Cost-Benefit Analysis for Early Intervention Services for Young Children with Autism- General Model and Single State Case. *Behavioral Interventions.* 1998;13:201-26.
7. Lovaas OI, Koegel R, Simmons JQ, Long JS. Some generalization and follow-up measures on autistic children in behavior therapy. *J Appl Behav Anal.* 1973;6(1):131-65.
8. Hyman SL, Levy SE, Myers SM, Council On Children With Disabilities SOD, Behavioral P. Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. *Pediatrics.* 2020;145(1).
9. Dawson G, Rogers S, Munson J, Smith M, Winter J, Greenson J, et al. Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. *Pediatrics.* 2010;125(1):e17-23.
10. WHO. World Health Organization. Autism spectrum disorders 2020 [Available from: <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>].
11. AAP. American Academy of Pediatrics. *Developmental and Behavioral Pediatrics.* American Academy of Pediatrics. Kindle Edition. Robert G. Voigt M, FAAP editor 2018.
12. Waldman M, Nicholson S, N A. Does Television Cause Autism? NBER Working Paper No 12632, October 2006, JEL No I1. 2006.
13. Chonchaiya W, Nuntnarumit P, Pruksananonda C. Comparison of television viewing between children with autism spectrum disorder and controls. *Acta Paediatr.* 2011;100(7):1033-7.
14. Heffler KF, Oestreich LM. Causation model of autism: Audiovisual brain specialization in infancy competes with social brain networks. *Med Hypotheses.* 2016;91:114-22.
15. Harle B. Intensive early screen exposure as a causal factor for symptoms of autistic spectrum disorder: The case for <<Virtual autism>>. *Trends Neurosci Educ.* 2019;17:100119.
16. Luo Y, Pang L, Guo C, Zhang L, Wang Y, Zheng X. Urbanicity and autism of children in China. *Psychiatry Res.* 2020;286:112867.
17. Li L, Li M, Lu J, Ge X, Xie W, Wang Z, et al. Prenatal Progesterone Exposure Is Associated With Autism Spectrum Disorders. *Front Psychiatry.* 2018;9:611.



Health-Action

Help Children Develop Worldwide

18. Emberti Gialloreti L, Mazzone L, Benvenuto A, Fasano A, Alcon AG, Kraneveld A, et al. Risk and Protective Environmental Factors Associated with Autism Spectrum Disorder: Evidence-Based Principles and Recommendations. *J Clin Med*. 2019;8(2).
19. Cheng J, Eskenazi B, Widjaja F, Cordero JF, Hendren RL. Improving autism perinatal risk factors: A systematic review. *Med Hypotheses*. 2019;127:26-33.
20. Rogers S, Dawson G, Vismara L. Rogers, Sally J.. *An Early Start for Your Child with Autism* . Guilford Publications. Kindle Edition.: THE GUILFORD PRESS New York; 2012.
21. Sadeghi S, Pouretemad H, Khosrowabadi R, Fathabadi J, Nikbakht S. Behavioral and electrophysiological evidence for parent training in young children with autism symptoms and excessive screen-time. *Asian J Psychiatr*. 2019;45:7-12.
22. AAP. American Academy of Pediatrics, council of communication and media. Media and young minds. *Pediatrics*. 2016;138:e20162591.
23. WHO. World Health Organization. Guidelines on physical activity, sedentary behaviour and sleep for children under 5 years of age. <https://apps.who.int/iris/bitstream/handle/10665/325147/WHO-NMH-PND-2019.4-eng.pdf>. 2019.