

## **Title. Help > 1000 children with autism in Vietnam**

### **Background.**

Autism is a major public health problem. It has been markedly increasing, now with 1/59 children with a formal diagnosis in the USA (1). Many children are diagnosed too late for the most effective early interventions. Eighty percent of adults with autism in the USA are reported to be unemployed (2). The vast majority of children worldwide with autism are not receiving the interventions that would improve their and their family's lives. Families often lack awareness and understanding.

The 67th World Health Assembly adopted a resolution entitled "Comprehensive and coordinated efforts for the management of autism spectrum disorders (ASD)" (3). They reported evidence-based psychosocial interventions positively impact the affected person's wellbeing and quality of life. People with ASD often impose significant emotional and economic burden on their families. Empowerment of families is increasingly being recognized as a critical component of care.

Consortium for Health Action is a nonprofit organization registered in the USA, Vietnam and Cambodia. We work together with experts from around the world to positively impact people's health and wellbeing. Autism is one of our identified tasks the 2018-2023 strategy. This was inspired by a real story. The son of our director was given a diagnosis of autism in 2017 by an American developmental pediatrician. Fortunately, after treatment, he now appears to be almost normal. The director wants to share what his family did in order to positively impact the lives of other children with speech delay and/or autism.

### **What we did we do in combination which we believe led to Alan's remarkable improvement?**

- 1) We realized he was missing developmental milestones and had unusual behaviors. We owe thanks to his grandmother who visited from America when he was 22 months. My mother was a former grade school teacher.
- 2) We sought early medical attention. His diagnosis in Vietnam was developmental delay and by an American developmental pediatrician, autism at 24 months.
- 3) We accepted a diagnosis of speech delay and after time, autism. My wife and I were initially in denial. Fortunately, the interventions for both conditions are the same.
- 4) Our family engaged.
  - a. We stopped all screen time (no TV, cell phone use, etc.). While this intervention is not yet proven, we believed it could not hurt. We are working with American autism investigators who are assembling a case series of children, who like Alan are having a remarkable reduction in autism symptoms following the removal of screens.
  - b. We chose Vietnamese as his primary language; we had been using mostly English for the first two years of his life.
  - c. We had him first learn Vietnamese words to communicate his needs. Those he learned in English on YouTube, like the alphabet, numbers shape and numbers did not help him communicate.
  - d. We used techniques to get him to talk.
  - e. We read to and played with him every day.
  - f. We changed to a nanny who enjoyed talking to and playing with children
  - g. My wife joined an autism support Facebook group having 20,000 members in Vietnam

- h. I became expert on the diagnoses through extensive reading, on-line training and communication with international experts. I closely tracked our son's progress by watching him at school, playing with him every day and use of an on-line autism tracker.
- 5) Lastly and most importantly, we provided him the best available special education we could identify in Hanoi. We were also fortunate to have a volunteer coaching us from the USA.

**Plan.** We will reach large numbers of the general public and especially target families with children at risk, front line doctors and referral specialists. This can be accomplished through Google Adwords (free for non-profit organizations), targeted Facebook messaging, targeting professionals and their organizations and with other messaging methods. Our NGO's website had more than 8500 user sessions in both September and October, largely through to Google Adwords. We believe social media is a powerful tool to reach the people in need.

**Under this proposal we will work in three areas:**

- 1) Help families
  - To recognize developmental delays with milestone tracker apps and links
  - To seek consultation from quality caregivers
  - To accept the diagnoses
  - Seek appropriate interventions as early as possible from the best available programs
  - Learn about what they can do at home
    - Educate about American Academy of Pediatrics screen time recommendations for all children
      - None < 18 months, then no more than 1 hour/day of supervised quality programming 1.5-5 years of age
      - Provide links to quality media
    - Educate about the importance of reading and effective play to learn to speak with parents and other caregivers
  - Identify free family training materials; subtitle in Vietnamese and Khmer
- 2) Educate treatment providers
  - Recognize developmental delays with standard screening tools such as a family questionnaire called the MCHAT.
  - Make correct diagnoses with training and use of standard tools or make appropriate referrals when needed
  - Recommend both special education and family-oriented interventions
- 3) Prepare to conduct research in three main areas:
  - Methods to change the mindset of people which lead to early intervention when it is most impactful
  - To determine the impact of screen removal for children with speech delay of any cause
  - To evaluate the impact of family intervention alone when special education is not possible

**Impact.** We will initially focus on Vietnam; however, the methods will have worldwide impact. We will track the campaign impact with website analytic tools, interviews and forms completed and

feedback from families and medical professionals. Lastly, when our research protocols are approved, we will begin to implement them.

In the USA, fewer than half of children are diagnosed before age 4 (1). This is important because intervention in young children is most effective (1). In the developing world, awareness and access to both diagnosis and treatment are much more challenging. Our targeted approach to reach and help those in need should positively impact far more than 1000 children in the short term in Vietnam and large numbers worldwide in the long-term.

### Initial Deliverables.

#### Help families

- Website updates completed
- Click-throughs to:
  - milestone tracker apps
  - links to quality media
  - family education materials
- Family surveys
- Follow-up form completed with appropriate actions taken
- Families signed up for future research participation
- Our son's story completed
- Background paper published

#### Educate treatment providers

- Website updates completed
- Click-throughs to standard screening tools
- Follow-up forms completed with appropriate actions taken
- Provider surveys
- Providers signed up for future research participation
- Background paper published

#### Prepare to conduct research in three main areas:

- Protocols approved
- Research funding identified and available

### Budget.

| Position/Task        | % Effort   | Time/Units | Cost     | Months | Total     | Note      |
|----------------------|------------|------------|----------|--------|-----------|-----------|
| Project Director     | Colin Ohrt | 33%        | NA       | 6      |           | Volunteer |
| Project Manager      | Tuyen Pham | 50%        | \$ 1,200 | 6      | \$ 3,600  |           |
| Social Media Manager | TBD        | 100%       | \$ 1,200 | 6      | \$ 7,200  |           |
| Website Updates      | TBD        | 3          | \$ 400   |        | \$ 1,200  |           |
| Translation support  | TBD        | 20         | \$ 300   |        | \$ 6,000  |           |
| Indirect costs       |            |            |          |        | \$ 1,800  |           |
| Total                |            |            |          |        | \$ 19,800 |           |

**References.**

<http://consortiumha.org/>

- 1) Data on Autism: Five Facts to Know | Features |
- 2) Hiring autistic workers - CBS News Feb 11, 2018
- 3) Autism spectrum disorders. WHO, 2017.
- 4) Learn the Signs. Act Early. Milestone Tracker M
- 5) Autism Speaks.