# Autism -C.O.P.E.

a project of the rotary club of pos west

# Autism spectrum disorder (ASD)

- group of complex disorders of brain development characterized by difficulties in
- social interaction
- verbal and nonverbal communication
- repetitive behaviors

# Autism spectrum disorder (ASD)

- a broad spectrum
- 40 percent have average to above average intellectual ability
- 25 percent non verbal (ability to use other means of communication)
- 1 in 68 births
- 1 in 42 boys
- 1 in 189 girls
- 287 children estimated born in trinidad and tobago each year

### ideal world

- signs recognized 2-3 years
- early diagnosis
- early intervention and supportive care by public health providers
- child achieves best possible outcome / maximum potential

### trinidad

- signs recognized 2-3 years
- diagnosis difficult in private/ very difficult in public sector
- limited private provider/NGO interventions available.
- very limited public sector services provided

# ngo/private providers

- mix of
- private providers
- no charge NGOs
- for charge NGOs

### evidence based therapies

- aba
- pivotal response training
- early start denver model

# develop capacity

- capacity for early screening
- capacity for multi disciplinary assessment
- education for the parents/providers to understand treatment options.

## public/private partnership

- rotary club of pos west
- Dr P. Bahadursingh SWRHA training department, UWI Child Health department and Community Paediatrics SWRHA
- University of the West Indies, Child Health Unit, Faculty of Clinical Medical Sciences
- Zachary Warren, Ph.D TRIAD Vanderbilt Kennedy Center
- all regional health authorities in Trinidad and Tobago represented

# develop capacity

- STAT-MD Training April 18 2015(early diagnostic tool)
- ADOS April 19-20 2015 (diagnostic tool up to 12 years)





# first stage results

- 42 persons trained in STAT-MD in the public health sector
- 30 persons trained in ADOS in the public health sector
- public and local medical providers exposed to the latest data on evidence based therapies
- fellowship among medical providers with links to autism support
- link between Vanderbilt Kennedy Center and UWI and the RHAs
- ADOS and STAT-MD performed weekly in the various RHA's
- two ADOS tool kits delivered to public health providers

- Caregivers Outreach Program of Education
- Provides functional training for caregivers and parents of children with Autism
- Based on successful program (Families First) run by Vanderbilt University which has provided training for over 2500 participants

- partnership between Rotary POS West,
  Vanderbilt University, UWI and public health providers in Trinidad
- program consists of 12 modules
- 30 public health providers trained in providing modules to parents

- Communication
- Challenging Behavior
- Toilet Training
- Improving Communication in Children who are Talking
- Structuring Routines and Community Outings
- Teaching Safety Skills
- Including Children with ASD and other Developmental Disabilities in Religious Activities
- Developing Successful Sleep and Feeding Habits or Developing Successful Sleep Habits
- Successfully Completing Medically-Related Activities: Appointments, Procedures, and Daily Practices
- Supporting Siblings of Children with ASD
- Promoting Inclusion in Community Arts and Education: Zoos, Museums, Libraries, etc.
- Developing Successful Social and Play Skills

- three days of training one module per day
  - Communication
  - Challenging Behavior
  - Toilet Training
- public health providers trained by Vanderbilt University providers
- performed over weekend of 11-13th March 2016
- public lecture given by Vanderbilt
- three more weekend sessions planned over the next two years





Guardian www.guardian.co.tt Tuesday, March 15, 2016 **A24** 

Dr Zachary E Warren, director, Vanderbilt Kennedy Center Treatment and Research Institute for Autism Spectrum Disorders (Triad), left, and paediatrician Dr Raj Bahadursingh. PHOTOS: ANDRE ALEXANDER



#### Parents learn to manage autistic children's needs

The Rotary Club of Port-of-Spain West, reached a new milestone on March 11 with the opening of a threeday training programme at the Student Study and Recreational Centre, Eric Williams Medical Complex, Mt Hope. The programme is aimed at empowering parents to effectively manage the needs of children with autism.

were also trained to deliver these modules and it is envisaged that this training course will be made available to parents through the regional health authorities.

This project was held in collaboration with the University of the West Indies, Child Health Unit, Faculty of Clinical Medical Sciences and the Vanderbilt University School of Medicine, and sponsored by Republic Bank Ltd. The

The Caregivers Outreach Pro- training team is lead by Dr Zachary Wargramme of Education, a project of the ren, director, Vanderbilt Kennedy Center Treatment and Research Institute for Autism Spectrum Disorders (Triad) and includes Dr Alacia Stainbrook, educational consultant at Vanderbilt University and Dr Whitney Loring, assistant professor of Paediatrics, Department of Paediatrics at Vanderbilt University School of Medicine.

As director of Vanderbilt Kennedy Professionals in the public service Centre Treatment and Research Institute for Autism Spectrum Disorders, Dr Warren leads the autism evaluation and diagnostic clinics within the Department of Paediatrics, Division of Developmental Medicine, and he provides oversight of Triad Outreach and Training.

He looks forward to future collaboration to improve public services for children with autism in Trinidad.

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Dr Natalie Dick, specialist developmental behavioral paediatrician, North Central Regional Health Authority, left, and Stephanie Minty, speech language



Clinical psychologists Catriona Persad, left, and Giselle Dumas.



Nigel Aqui, past president, Rotary Club of Port-of-Spain West, Dr Alacia Stainbrook, educational consultant at Vanderbilt University and Dr Whitney Loring, assistant professor of Paediatrics, Department of Paediatrics at Vanderbilt University School of Medicine.



Rehanna Ramroop, assistant social intervention officer, Republic Bank Ltd, left, and Eichelle Mohammed of the Rotary Club of Port-of-Spain West.



Charles A Mouttet, general manager—treasury, Foreign Exchange Centre (Forex), Republic Bank Ltd, left, Dr Victor Terapalli, primary care physician 2, Paediatrics, North Central Regional Health Authority, and Allison







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Vindra Amar, immediate past president, Rotary Club of Port-of-Spain West, left, and Richard Teelucksingh, president elect, Rotary Club of Port-of-Spain West.



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# second stage results

- 30 persons in the public health sector trained in providing functional training to parents
- public health education via public lecture
- publicity for the good work of Rotary via appearances on two tv stations and two page coverage in daily newspaper
- link between Vanderbilt Kennedy Center and UWI and the RHA's - postgraduate UWI involvement in outcome tracking

# Summary

- reach of project is national
- total cost of entire C.O.P.E. program is US \$60,000
- project is sustainable
- only 2-4 persons were ADOS certified and now 30 persons available locally in the public health system
- no STAT-MD trained persons available locally and now 42 available in the public health system