

*“Autism and the 2030 Agenda: Inclusion and Neurodiversity”
Dr Natalie Dick, Specialist Developmental Behavioral Pediatrician
Autism Awareness Ceremony – President’s Grounds Trinidad & Tobago
April 14/2016*

Occasion: “Tree Lighting Ceremony” by the Office of President of the Republic of Trinidad & Tobago to Commemorate World Autism Awareness Month, April 2016.

Theme: *Autism and the 2030 Agenda: Inclusion and Neurodiversity*

It is my honour this evening to bring greetings to you, as a health care professional who, by choice, serves persons with Autism Spectrum Disorders and other types of disabilities, within the public health sector; and advocates locally, regionally and internationally for this same population.

Autism Spectrum Disorders or ASD’s, are a complex group of brain-based developmental disorders that begin in childhood, and are lifelong. They have in common: challenges in communication, social interaction and unusual patterns of behavior and perceiving the world, such that they affect the way that these individuals learn and acquire skills that should allow them to live independent and productive lives.

ASD's are found in persons of all classes, creeds and ethnic groups; however, it is 4-5 times more common in males than in females. Most persons with ASD's, appear perfectly "normal", so that persons with very severe challenges related to ASD, are considered to have "hidden disabilities". ASD's remain lifelong, with no current cure but several options for effective management.

ASD's may also be accompanied by medical challenges such as those with eating, nutrition and the digestive system, seizures ("fits"), sleep disturbances, intellectual disabilities, behavioural problems and mental health disorders including anxiety, depression and attention deficit hyperactivity disorder. In many persons with ASD's these medical challenges may present (appear) in unusual ways; and some of those with ASD's may not be able to explain how or what they feel, leading to mis-diagnoses or under-diagnoses or under-treatment without specialized professionals to provide diagnosis and appropriate treatment interventions.

It is important for us to be aware of the challenges of persons with ASD's and collectively strive to help them to preserve all of their rights , and also to improve their level of independence and

*“Autism and the 2030 Agenda: Inclusion and Neurodiversity”
Dr Natalie Dick, Specialist Developmental Behavioral Pediatrician
Autism Awareness Ceremony – President’s Grounds Trinidad & Tobago
April 14/2016*

quality of life. Equally important is the understanding that persons with ASD's, as well as other persons with disabilities (PWD's), are part of the "human experience" and so contribute to human diversity. Indeed there are many who challenge our current way of thinking of autism as a "disorder" to be modified, managed or "cured" - hence the gestation and birth of the **neurodiversity in autism** movement, in which there is a greater emphasis on persons with ASD's speaking up for themselves viewing persons with ASD's and consider ASD's as a variation in a person's genetic makeup, leading to different manner of brain functioning.

According to the World Health Organization, it is estimated that there are as many as one (1) in (160 or less) persons with ASD's. While accurate data on the prevalence of this condition remains unavailable in Trinidad and Tobago, if we assume similar prevalence as the rest of the world this could represent between 10-15 thousand persons with ASD's. Anecdotally, only about 1000 such persons have either assumed that they have an ASD or have been clearly identified with ASD's in Trinidad and Tobago, leaving unexplained differences in our local statistics that need to be explored.

Worldwide, persons with disabilities, such as Autism Spectrum Disorders and other developmental disorders are a vulnerable group, often subject to stigma, discrimination of many forms: including undue gaps in quality health care, educational choices and chances, psychosocial support services; and social isolation and reduced opportunities to engage with and participate in their communities and in the world of work.

In 2014, the 67th World Health Assembly (the governing body of the World Health Organization), adopted a resolution on “Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders”. Member States including Trinidad and Tobago therefore have a **responsibility to increase the capacity of health and social care systems to provide services for individuals and families with autism spectrum disorders and other developmental disorders.**

The United Nations has placed increasing emphasis on "disability" and the importance of counting in persons with disabilities, including those with ASD's in international agenda. By extension, this trend should inform our own individual national policies in the "design, implementation, monitoring and

*“Autism and the 2030 Agenda: Inclusion and Neurodiversity”
Dr Natalie Dick, Specialist Developmental Behavioral Pediatrician
Autism Awareness Ceremony – President’s Grounds Trinidad & Tobago
April 14/2016*

evaluation of policies and programmes in all political, economic and societal spheres, so that inequality is not perpetuated." The United Nations General Assembly, of which the Republic of Trinidad and Tobago is a member, adopted the 2030 Agenda for Sustainable Development, which includes 17 Sustainable Development Goals (SDGs) and 169 targets that promise designed to “**leave no one behind**”. All 17 of these SDG's can be applied universally, however, disability and persons with disabilities (including those with ASD's) are specifically referenced in some of them: # 4) Quality Education; # 8) Decent Work and Economic Growth; #10) Reduced Inequalities; #11) Sustainable Cities and Communities; and #17) Partnerships for the Goals

I now invite you to envision with me, what the application of these four (4) SDG's might look like in our beloved twin island Republic, Trinidad and Tobago.....Let's take a journey from 2016 to 2030 The 2030 “Inclusion” Agenda.

SDG Goal 4: Quality Education

“Obtaining a quality education is the foundation to improving people’s lives and creating sustainable development.”

In 2016 in Trinidad and Tobago - many children with ASD’s are unable to secure a place in any type of school, whether mainstream, special educational, public or private. A few are able to access free education in public schools; fewer can afford a private school. **Many children with autism are kept at home, unable to exercise their right to go to school.** Access to trained and experienced special educators is extremely limited and expensive. Many persons with ASD’s are uneducated or under-educated in Trinidad and Tobago in 2016.

Long before 2030 - we dream of a Trinidad & Tobago where all children with ASD's would have **equal access** to **quality and relevant** early childhood development centres, pre-primary **education** so that they are ready for primary education. At every level, **appropriate educational accommodations** would exist for them, whether they are included in mainstream school, or if by virtue of the (high level) of severity of their ASD, they require a **specialised learning environment**. Technical vocational training and tertiary (university) education would be made more accessible to PWD's including those with ASD's.

*“Autism and the 2030 Agenda: Inclusion and Neurodiversity”
Dr Natalie Dick, Specialist Developmental Behavioral Pediatrician
Autism Awareness Ceremony – President’s Grounds Trinidad & Tobago
April 14/2016*

SDG Goal 10: Reduced Inequities

“A natural consequence of appropriate education and training should be appropriate and dignified employment.”

In our nation in 2016 - A **continued lack of decent work opportunities** is common to persons with ASD's. Even for those who secure relevant education, many are unemployed or under-employed due to the fear of potential employers to hire a person with ASD ; because of inadequate vocational counseling and guidance; inappropriate job placement or simply being passed over in the selection queue in preference for an employee who is perceived as “normal”.

As we journey to 2030, we dream of more equitable job placements for persons with ASD's - **quality, respectable jobs that take into account their strengths** (e.g. diligence and focus) and their skills and that provide support for their areas of challenges.

SDG Goal 11: Sustainable Cities and Communities

Common urban challenges, especially in Trinidad and Tobago in 2016, include (traffic) congestion, declining infrastructure, inaccessibility in the built environment, lack of funds to provide basic services, a shortage of adequate housing.

Long before 2030, we should provide for persons with ASD's spaces and places that are sensory-safe and sensory-friendly to allow them to fully participate and be socially included in everyday activities e.g. movies or recreational facilities.

SDG Goal 17: Partnerships for the Goals

“A successful sustainable development agenda requires partnerships between governments, the private sector and civil society. These inclusive partnerships must be built upon **principles and values, a shared vision, and shared goals** that place people at the **centre**. These partnerships must occur at the “global, regional, national and local levels”.

*“Autism and the 2030 Agenda: Inclusion and Neurodiversity”
Dr Natalie Dick, Specialist Developmental Behavioral Pediatrician
Autism Awareness Ceremony – President’s Grounds Trinidad & Tobago
April 14/2016*

Trinidad and Tobago ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in June 2015. Where are we now in 2016? As we continue our mental journey from 2016 to 2030, let's ponder on a Trinidad and Tobago in which there is greater adherence to the tenets of the UNCRPD, in which **meaningful, implemented and enforced legislation are combined with robust and cohesive policies.**

Let's also reflect on ways that each of us, individually and collectively can all advocate for persons with Autism Spectrum Disorders as well as other types of Disabilities. They may include:

(1) ***Lobbying for the establishment of a coordinated, nationwide developmental surveillance programme*** to identify children at risk for disabilities, including those at risk for autism;

(2) ***Requesting for and providing for early intervention for those presenting with developmental challenges***; (This must be part of the public health service, so that all of the relevant services are readily available for those who need them, regardless of their socio-economic status);

(3) ***Strengthening the multi-disciplinary professional capacity and community based resources*** to treat with ASD's. This means that the educational, social and other challenges that arise from autism spectrum disorder. (Imagine with me, a public health service in which there are adequate ***qualified and passionate professionals***; able to provide ***comprehensive services***; ***without*** current and emerging administrative and bureaucratic restrictions, obstacles and barriers; with ***adequate and relevant tools and resources*** to be able to diagnose and treat persons with ASD's (among other disabilities)! Let's hope that this will happen long before 2030 !

(4) ***Data collection and research*** that are done in such a way to reflect this important national issue - the management of our nation's most vulnerable and marginalized citizens. Can you imagine, when we meet again next year, that we could actually quote authoritatively, on locally and regionally derived data about persons with ASD's and other disabilities in T&T!

*“Autism and the 2030 Agenda: Inclusion and Neurodiversity”
Dr Natalie Dick, Specialist Developmental Behavioral Pediatrician
Autism Awareness Ceremony – President’s Grounds Trinidad & Tobago
April 14/2016*

5) Establishment of **evidence-based, innovative solutions to train and empower persons with autism throughout the lifespan**. In countries, such as ours, where professional resources are limited, we need to consider the benefits of including caregivers of persons with ASD's and other developmental disabilities. With training, professional support and guidance, we can ensure great improvement in the level of care for persons with ASD's so that they can be better included in mainstream society.

Today we have the privilege of participating with the Office of the President of the Republic of Trinidad and Tobago, an advocacy initiative for persons with disabilities, specifically ASD's.

Since 2008, the United Nations General Assembly resolved to designate April 2nd every year, as World Autism Awareness Day. We are participating in one of the largest, unified annual worldwide Autism Awareness events. It was started by the world's largest autism-specific NGO's, the USA-based “Autism Speaks®”. As we “Light It Up Blue” in today's 3rd Tree Lighting Ceremony hosted by the Office of the President of the Republic of Trinidad and Tobago, we join with over 100 other countries, as well as 1000's of corporate organizations, NGO's and other organizations which will be highlighting the issue of Autism Spectrum Disorders.

I publicly thank and commend the Office of the President of the Republic of Trinidad and Tobago for their continual support for the community of persons with disabilities.

As you prepare to enjoy the rest of this evening's festivities, it is my hope that at the end of it all you will leave with much more just than a sentimental feeling of satisfaction at having participated in a “good and charitable thing”. Instead it is my earnest wish that these remarks would have left you pensive and even “slightly **uncomfortable and dissatisfied**” you will then be in a perfect place for change: thoughtfully considering what you can do, individually – within your sphere of influence can do to advocate for, and advance the cause of the community of persons with disabilities; and secondly to be a catalyst for change to take us from awareness activities to ongoing ACTION !, meaningful ACTION !, sustained ACTION ! and effective ACTION !, ACTION !, ACTION !!! on behalf of all Persons with Disabilities, including those with Autism Spectrum Disorders.

*“Autism and the 2030 Agenda: Inclusion and Neurodiversity”
Dr Natalie Dick, Specialist Developmental Behavioral Pediatrician
Autism Awareness Ceremony – President’s Grounds Trinidad & Tobago
April 14/2016*

I close with a quote from the 2016 message of the United Nations Secretary-General Ban Ki-moon.

“On this World Autism Awareness Day, I call for advancing the rights of individuals with autism and ensuring their full participation and inclusion as valued members of our diverse human family who can contribute to a future of dignity and opportunity for all.”

Remarks were delivered by Dr. Natalie Dick, Specialist Developmental Behavioral Paediatrician (North Central Regional Health Authority); She is the founder of Kairos Developmental Behavioral Pediatrics, Caribbean Ltd. Dr Dick serves on the Board of Directors of the National Centre for Persons with Disabilities; as well as the Board of Directors of Caribbean Kids and Families Therapies Organization; is an active member the Epilepsy Society of the Caribbean; the English/Dutch Caribbean Community Based Rehabilitation Network; the American Academy for Cerebral Palsy and Developmental Medicine, among others.