Understanding Autism and

The Works of Nia Foundation

Nia Foundation
Joy Center for Autism

Nifas silk lafto sub ciy, Woreda
04, House no. 887, Egypt Street,
Sarhet, Next to Abadir Mosque

Phone: 011-3-2061059
Mobile: 0911 21 05 35
E-mail: info@nia-foundation.org
Website: www.nia-foundation.org
P.O.Box: 1695 code 1110
Addis Ababa
Ethiopia

Commercial Bank of Ethiopia
Acc. #: 00209534904
SWIFT: DASHETAA

Dashen Bank
Acc. #: 10000628588
SWIFT: CBETETAA

Donate @

2017
BOOKLET

AUTISM
MESSAGE FROM THE EXECUTIVE DIRECTOR, MRS. ZEMI YENIUS

From our very existence in the charities and societies sector back in 2002, the extreme positive intention of doing well to the community and giving turn in service is deep rooted in our organizational values and reflected in every path we have taken so far. We have reached, worked with and influenced the lives of thousands of children, youth and parents vulnerable due to their conditions, socio-economic status, different abilities and disabilities; along with the mass awareness raising undertakings we have been to reaching millions in the country and abroad on the issue of AUTISM.

The important causes of the Nia Foundation, I believe are really attached to the needs of the community and focuses on alleviating the deep rooted challenges that is holding them from moving forward. Such an effort definitely requires a multi-sectoral interventions and collaboration. To this end, I call up on all stakeholders relevant to our work; the government & its sector offices, donor agencies, related CSOs, the media, educational and research facilities, and the private sector to get involved and make a difference in the community groups we serve.

MESSAGE FROM H.E. LATE PRIME MINISTER OF FDRE, MELES ZENAWI

To minister to the needs of individuals with autism and to ensure that they enjoy equal opportunities for education and other goods that would enable them to lead meaningful lives poses formidable challenges in a poor society such as ours.

In Ethiopia those with autism and their families rely on everyone’s help. The valuable work accomplished by the Joy Center for Autism in order to draw public attention to the plight of autistic children, to counsel family members and other caretakers and, above all, to provide care and skills to autistic children deserves high praise and generous support.

Let us all extend our help so that the Joy Center’s work can reach many more desperately seeking assistance. To support research and professional training on autism as well as the provision of education answering to the special needs of children with autism is also a responsibility of government.

Since a good society is perhaps best measured by how well it treats its most disadvantaged citizens, I call on Ethiopians, in and out of government, to show special care and concern to our children with autism.
Organizational Profile

Initiated in May 2002, Nia Foundation is an indigenous, nonprofit and non-governmental humanitarian organization established from the outset to alleviating the all-rounded challenges faced by persons with autism and other related developmental disorders, and young men and women living in challenging socio-economic circumstances. Having made the necessary multispectral preparations and forging partnerships with the government, national and international NGOs, Nia Foundation was legally registered and licensed by the FDRE Ministry of Justice in 12th January 2006. While recently, the foundation is re-registered in November 2009 by the FDRE Charities and Societies Agency Proclamation No. 621/2009, as Ethiopian Residents Charity Organization with registration No0854 and permitted to operate in all regional states of the country. Its head office is located in Addis Ababa Nifas Silk Lafto Sub City, Woreda 04, House # 887.

Thus, over the years, Nia has grown to serve the overlooked, most vulnerable and marginalized segments of the society through designing and employing participatory community-based development programs. Participation and community-based development are among NIA’s major concepts and strategies that Nia implicitly see these as an active process to increase community control. This is evident in most of its programmes such as the ‘Yagebagnal/I care’ movement in which it envisages a prosperous Ethiopia with comprehensive growth and development effectuated by the concerted effort of its citizens.

Joy Center for Autism is the primary and largest program of Nia Foundation. The center focuses on full integration of children with autism into society by working closely with the children, their parents and extended family networks, as well as the Ethiopian community.

The Joy Centre is a center with the core purpose to train, rehabilitate, protect and ensure the well-being of Children with Autism and Related Developmental Disorders. The center, in its organizational sense, is the first in East Africa specifically commenced to provide holistic rehabilitation services to children, adolescents and youth with Autism.

Nia Foundation aspires to seeing a concerned society whereby less privileged community groups enjoy quality of life to the best of their potentials in spite of their different abilities, disabilities and gender.

Nia strives to inspire, empower and improve the holistic wellbeing of less privileged children, youth, and women mainly through education, rehabilitation, training and awareness raising, dialogue and discussion forums, entrepreneurship and leadership development programmes.

- Mutual Trust
- Love and Empathy
- Hope and Optimism
- Responsibility and Integrity
- Commitment
- Partnership and Collaboration
- Innovation and Excellence
Understanding Autism

The mysterious disorder

AUTISM is a lifelong neuro developmental disorder that affects the brain’s function. The first signs usually appear before a child is three years old. People with autism often find social interaction difficult, have problems with verbal and non-verbal communication, demonstrate restrictive and repetitive behavior, have a limited set of interests and activities, and experience over or under sensitivity to sound, touch, taste, smell, light or colors.

Autism is one of the five recognized disorders in the autism spectrum (ASDs), the other four being Asperger syndrome, Rett syndrome, Childhood disintegrative disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (commonly abbreviated as PDD-NOS).
The three main areas of difficulty; which all people with autism share are sometimes known as the 'triad of impairments'. They are:

- Difficulty with social communication: People with autism have difficulties with both verbal and non-verbal language.
- Difficulty with social interaction: People with autism often have difficulty recognizing or understanding other people's emotions and feelings, and expressing their own, which can make it more difficult for them to fit in socially.
- Difficulty with social imagination: Difficulties with social imagination mean that people with autism find it hard to understand and interpret other people's thoughts, feelings and actions, predict what will happen next or what could happen next, understand the concept of danger, engage in imaginative play and activities, prepare for change and plan for the future, and cope in new or unfamiliar situations.

**Symptoms of Autism**
- Repetitive Behavior / Love of routines
- Sensory sensitivity
- Inability to communicate & socially interact
- Learning disabilities

**Cause of Autism**
A cause for autism has not yet been identified. Many theories about autism from that past have now been proven to be false. The truth is:

- Autism is not a mental illness.
- Children with autism do not choose to sometimes misbehave and act distracted.
- Bad parenting does not cause autism.
- Children do not have autism because they are possessed by bad spirit or evil's eye.
- Children do not have autism as a result of sins parents committed.
- There are no known problems that can occur in childhood that will cause autism.

**Who is affected by Autism?**

Autism tends to occur more in boys than in girls. It can appear in children of all races, religions, and ethnic groups. Family economic status, lifestyle, and educational levels do not have an effect on whether or not a child is born with autism.

**Autism Diagnosis**
A diagnosis is the formal identification of autism. The person who makes the diagnosis must be very familiar with autism because there are so many different ways that autism can appear in a child. The best approach to diagnosis is to have a team of professionals which include a neurologist, psychologist, developmental pediatrician, learning consultant, and/or any other professional who knows about autism.

**Management of Autism**
At present, there is no 'cure' for autism. However, there is a range of interventions - methods. There are many therapies that help people manage autism, such as Applied Behavior Analysis (ABA), speech/language therapy, occupational therapy, sensory integration, vision therapy, music therapy, and auditory training. Certain medications, supplements and/or food restrictions may also help.

The main goals when treating children with autism are to lessen associated deficits and family distress, and to increase quality of life and functional independence. No single treatment is best and treatment is typically tailored to the child's needs. Families and the educational system are the main resources for treatment.

At an early age, children with autism should learn job skills and activity of daily living skills (ADLs) that will help them live in the community. Job skills may for example include sorting by color or size so they may get a job as a mail person in an office. ADLs include brushing one's teeth, looking both ways when one crosses the street, speaking to another person while maintaining eye contact, and buying something at the supermarket. The more skills the child has, the more independent he/she may be in the future.
Our Therapeutic and Training Services

The Joy center strongly believes in incorporating several forms of therapy that will enable autistic children to unleash their potential and enhance their quality of life within and outside of the academic setting. It is also Joy center’s strengths that our class sizes are small so that each child gets the attention and time that they need from the caregivers. It is our constant effort that the student to caregiver ratio doesn’t exceed 2:1. Joy center’s children attend nine types of different programs in each seven-hour academic day. The children have six hours of therapy and skills training programs and an hour of break.

1. Attending Skills Training

When children are initially admitted to Joy center they are enrolled into the attending program. This program’s goal is to smoothly and calmly transit the child from isolation to a group setting. In this program the child learns to remain calm in group settings, to self-soothe and to transition successfully. Independency in personal care skills such as toileting and self-hygiene are also important goals of this program. Once a child can independently remain seated for thirty minutes and has started to grasp personal care and direction following skills, the child is then transitioned into the other program.

2. Speech Therapy

The speech therapy program is designated so that the children will learn the basics of languages and speech. Each speech program is paced according to the verbal and non-verbal/expression communication abilities of the group of children that the teacher has enrolled within the class. The children learn the basics of writing and reading alphabets, numbers, words, and phonetics and simple sentence constructions. Regarding the training the center uses a homemade/indigenized methodology called ABUGIDA FONETIKS which is a language curriculum and tool based on Geez alphabet, (the root of northern languages such as Tigraic and Amharic or Fidel) mixed with phonetics using visual aids.

3. Sensory Integration Therapy

This program integrates the multiple research advances in Occupational and Sensory therapy. The children are provided with several forms of sensory stimulation via different methods. The children process sensory data through tactile, visual input, touch auditory stimulation as well as physical and massage therapy. The sensory program is integral part of Joy center’s curriculum because it enables the children to learn self-soothing skills as well as provide them with enough sensory data input to ensure the success of the remainder of the programs.

4. Outgoing/Shopping and Social Interaction

The shopping program was designated to build skills that the children could utilize outside of the Joy center gates. The children are provided with a list of items to purchase and prepare a meal. The program enables the children to work on money goals, develop mathematical skills, and practice their social thinking and skills. Most importantly, the children are able to go outside in the community and interact with the society while purchasing their items. They also improve their direction following skills by utilizing recipes to prepare the meals.
5. Physical Exercise / Sports
Joy center recognizes that physical health is as important as mental health. Therefore, sport activities and treatments are also part of our curriculum. The program’s goal is to help the children develop their gross and fine motor skills, strengthen their inner and outer balance, and building muscular and skeletal strength. Different forms of physical exercises are an integral part of this therapy program.

6. Pre-Academic Training
The main purpose of this program is to prepare the students for the academic program. The academic is more rigorous and requires focus and work. Therefore, the children learn to work in a group setting, sit for extended periods of time, listen to verbal prompts and complete certain tasks on demand. This program is focused on transitioning the children smoothly into their academic divisions.

7. Academic Training
Once students transition from the pre-academic program, the rigorous curriculum begins. The children learn mathematics operations, reading, writing and comprehension, shapes and colors and logic. The children receive adequate breaks and the types of subject matters being taught are also rotated so that they remain engaged. The children also have access to the playroom throughout the day, where the media center and sand box is provided for play and entertainment.

8. Occupational Therapy
This program integrates many forms of occupational therapy, personal and self-care skills, fine and gross motor skills. The children learn cloth care skills (dressing and undressing), how to make a bed, maintain a clean space, shoe tying, making and receiving a phone call, and different activities that build their motor skills. Some examples of this are bead work, arts and crafts, tracing, cutting, and origami.

9. Play and Music Therapy
The main focus of this program to teach the children how to play with a variety of toys and music, to work on social skills that will prepare the child for play dates with her/his peers, and to increase the capacity for participation in social situations. Play and music are wonderful tools for helping children (and sometimes even adults) to move beyond autism’s self-absorption into real, shared interaction. Properly used, they can also allow youngsters to explore their feelings, their environment, and their relationships with parents, siblings and peers.
Major Achievements

Nia Foundation has shown a significant organizational development since its inception in 2002. It has registered remarkable growth and strength in various areas including organizational governance and management, external relations, and program expansions that include type of services, scope and geographical coverage and logistics. The organization is gradually building its human resource in terms of size, diversity and capacity. Its financial resources are managed through computerized double entry accounting system and externally audited every year.

Nia was also able to organize higher level events that engaged the late Prime Minister intended to raise awareness about the issues of our overlooked target groups thereby pull the attention of the decision makers to in-place relevant and appropriate policy and strategic measures. In due course, the late PM had sent us a personal message about the issue of children with autism and the efforts that Nia is exerting in which he appreciated and encouraged us to work more in our interventions.

To mention few of our achievements at a glance, here below are summarized;
- Being an eye-opener on the issue of Autism in the country, created awareness in the wider community and bring children with autism out of the closet including their parents and siblings
- More than 150 autistic children - boys and girls provided with access to education and rehabilitation services in the all-day long serving autistic school and rehabilitation center
- Contributed a lot in-view of bringing the issue of autism and other developmental disorders to be on the table of the government, policymakers, international donors and pertinent professionals
- Diagnosing and conducting professional assessment of Autism which initially had been conducted abroad
- The professional diagnosis at Nia has saved quite a number of people from wrong believes on the causes of Autism such as demonic, curse, etc., while parents relieved from guilt, anger, frustration, grief, among others
- We have a record of more than 1,000 children from all parts of the country diagnosed for autism and other developmental disorders, while we provided counseling for more than 3500 family members – this is the direct result of our efforts on awareness creation and education on the issues
- Economically empowered 1,500 vulnerable women and girls (These include low income parents and guardians of autistic children) out of which most of them are running their own small scale businesses
- Nia has inspired Researchers, Writers and Filmmakers to engage in the areas of Autism
- The Foundation has secured 5,000 m² land from the government to establish the Joy Autism Center Excellence
- An average estimation of 3 million people reached and aspired through the ‘Yagebagnal/It Concerns Me’ Movement – it includes community dialogues, mass-media information, and education, live Radio discussions, organizing relevant trainings and wide events such as art exhibitions, mass walk, and related events

Our stories and achievements have been covered and communicated by a wide range of media outlets; both international and local. To mention few;
- CNN - BBC - PRESS TV - Aljazeera - CCTV
- EBC - EBS - AATV
- National and All FM Stations
- All the Major Newsletters and Magazines
Critical Issues in Focus

- Lack of Schools and rehabilitation centers for persons/children with autism against the high unmet needs
- Existence of inclusion policies, albeit lack of inclusive practices
- Socio-Economic Wellbeing of Poor Mothers and Children
- Lack of awareness and knowledge on the “How of treating children with autism in different service areas”
- The “So then?” of our growing kids, youth and Adults with Autism
- Lack of relevant infrastructures to provide Therapy; Lack of Manuals, Audio-Visual Equipment for CWA and related development disorder
- Lack of ICT Infrastructure; office space, training and mentoring centers
- Human Resources
- Standardized M&E System and Documentation
- Resource Mobilization and Marketing

The Future

- Promote holistic rehabilitation of children and youth with autism and related development disorders’
- Promote inclusive education for children and youth with autism and related development disorders’ at all levels, and through establishing model centers in Nia’s operational areas
- Raised awareness on Autism and related development disorders’ among parents and community members through radio and TV programs, IEC/BCC materials and facilitate discussion sessions
- Train and educate community leaders, decision makers, CSOs, research institutes, media, and sectors pertaining to public service provision to create awareness on the issue of autism and related development disorders’ for their respective actions
- Promote children’s roles at the family level and within society and enable them to be active partners on issues affecting their life.
- Improve the protection of children under difficult circumstances
- Promote and establish “Autism Parks” in each of Nia Foundation’s implementation areas
- Work closely with the Transport sector to promote the protection of rights of CWA
Stakeholders’ Say

“During the past decade and half, Nia Foundation has partnered with the David and Lucile Packard Foundation to address the reproductive health needs of disadvantaged youth and people with special needs. Nia Foundation pioneers in identifying and addressing emerging issues in the community and challenges everyone to think differently. Nia Foundation is a good role model for social entrepreneurs and activists.”

Yemesrach Belayneh, (Mrs)
Country Advisor, The David and Lucile Packard Foundation

“The embassy acknowledges the organization’s concerted effort in sensitizing the public and lobbying the policy makers to understand the problem and protect the victim children from abuse.”

Jukka Pajarinen, (Mr)
Counsellor, Finland Embassy Deputy Head of Mission

“We call upon all relevant stakeholders and the community members engage in the process and support the noble causes of the Nia Foundation.”

Board of Directors, Nia Foundation

“Because of this school I have been able to go to school myself. I have even had time to meet with other people. And even acquired a diploma in accounting.”

Alemtsehay, (Mrs)
Parent of a Child with Autism, Beneficiary

“After I found this school for my child, I went back to school. I started working. I was able to live a normal life.”

Aster, (Mrs)
Parent of a Child with Autism, Beneficiary

Partners