



PROGRAM PROFILE

Holistic Development of Children and Youth with Autism and Related
Developmental Disorders



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NIA FOUNDATION

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The problem and importance of the intervention

Autism is a developmental disorder that was first described by Leo Kanner in 1943, in a classic article that included case studies of 11 children. Within recent decades the chances of a child being diagnosed with autism spectrum disorder has increased dramatically throughout the world including Ethiopia. Some believe this is due to the increased recognition of an autism spectrum disorder in doctors as well as parents/caregivers, teachers and other individuals that may work with children. At the present time, autistic disorder is defined in terms of qualitative impairments in social interaction and communication, and restricted, repetitive, and stereotyped patterns of behaviors, interests, and activities, with impairments in one of these areas prior to the age of 3 years. It is best described autism as a neurological dysfunction. Thus sight, sounds, and tastes and feelings may be experienced very differently. The word Autism refers to the tendency to withdraw in to self, ignoring much of what goes on in the environment.

Autism spectrum disorder (ASD) is a group of developmental disabilities that can cause significant social, communication and behavioral challenges. Individuals with Autism have extreme difficulties in social skills, communication skill, self-expression and behavior. In addition, they have difficulty in making sense of the world in the way most people do.

Due to the recent knowledge, it is critical to not only identify the disorder early, but also begin to receive various early intervention services in a timely manner. Early intervention is a combination of services such as but not limited to occupational therapy, speech and language therapy, physical therapy, developmental therapy, psychological services, and social work services. Although all of these services are available, depending on the specific child, services will be chosen accordingly. Each child who receives early intervention services is assessed under three categories.

- child has a developmental delay,
- Child has a diagnosed medical or physical condition with a high probability of leading to developmental delay, and
- Child is at risk of developmental delay (the final category is up to the state's discretion).

Although the typical age of diagnosis for an autism spectrum disorder is older than three years of age, due to the advancement in assessments children are being diagnosed as young as two years of age and younger, allowing for early intervention services.

Autism is found throughout the world among all races, nationalities and social classes. Three to four out of every five people with autism are male. Although autism was originally thought to be a rare disorder, more recent studies have described that one in every 150 children is now diagnosed with Autism Spectrum Disorders and is being regarded as a global pandemic.

In the Ethiopian context, there is no reliable estimate due to the absence of surveys and researches on the area of intellectual disabilities in general and Autism Spectrum Disorders in particular. Nevertheless, according to a crude estimation by the Nia Foundation, there are an estimated 540,000 persons in the autism spectrum disorders in Ethiopia. Generally, due to the severity as well as ever growing rate of the problem effective intervention could increase quality of life for people with autism spectrum disorders and their families.

These thousands of children with autism in Ethiopia are still the most forgotten and vulnerable ones. Several of them are underprivileged of their very basic rights to enjoy the day light, the sunshine and their freedom to mix with the society due to wrong beliefs. People often mistake them for unruly or poorly behaved ones, blaming them and their parents instead of the disorder for the children's behavior.

Most of them are often abused, chained or locked viciously when they cannot be managed. In some cases, they are considered useless and unworthy to invest on.

There is lack of adequate awareness amongst the public. Majority including many professionals in the medical, educational and vocational training fields are still unaware of how autism affects people and how to effectively work with individuals with autism. As a result, persons with autism and related disorders have been deprived and denied of all the opportunities and the rights to get their academic, social, communicational skills training and, involvement in the overall socioeconomic activities in the community.

From all these problems and our prior experience in the sector, we can come in to the conclusion of saying that the prevailing attitude and perception of our community and the associated practices with in the family, working government systems, and the society at large determine the types of services and support systems provided to persons with autism spectrum disorders. It has negatively influenced their life.

The purpose of this intervention is to enable the Nia Foundation to execute an effective center based holistic rehabilitation and education services for children with Autism, strengthen the psychosocial & economic support for the parents, engage more in large scale awareness raising initiatives and reach out to places where service access is missing to holistically address the needs of persons with autism and related developmental disorders.

Strategic objective

Improve children and youth with autism and related development disorders' protection mechanisms by enhancing the awareness of communities thereby reducing different forms of abuses and neglect and continue to empower them to have an appropriate socio-economic status.

Immediate objectives

- 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
- Increase awareness on the problems of children and youth with 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

Intervention areas

- Promotion of holistic rehabilitation
- Promotion of inclusive education – schooling, Education support and Health support (including physiotherapy)
- Awareness creation and Training programs - Enhancing the awareness of the larger community
- Action research and development study
- Promotion of children protection and participation
- Strengthening support for child protection structures
- Engaging children with autism and related development disorders in environmental protection activities
- Establishing Autism Parks that has its own full-fledged services such as library, information center, cafes and recreational services

Direct Beneficiaries

- Children and youth with autism and related developmental disorders
- Parents of children and youth with autism and related developmental disorders

Intervention Strategies

- Holistic Rehabilitation
- Training of Caregivers/Therapists
- Parents Empowerment
- Awareness and Media Engagement

Achievements

For the last fourteen (14) years we have been intensively working towards providing quality holistic rehabilitation service for children and adolescents with autism at the Joy Center for Autism, aware the community, work with the government in a way to influence national policies and strategies and of course forge partnerships that matter. Among the long list of the achievements we had and proud of, some are the following;

- 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, policy-makers, 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
- 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

Major Future Plans

For the last fifteen (15) years we have been intensively working towards providing quality holistic rehabilitation services. Now we aspire to do more;

- Establish state of the art autism center of excellence with huge capacity in Ethiopia.
- Expansion to and reaching out for children with autism in all areas of the country
- Establish research center and conduct surveillance and operational researches.