



Your Child's Journey Plan

A guide through their neurodevelopmental assessment







+ Introduction

This document has been written and designed by professionals who provide assessment, diagnosis and support for children and young persons who have neurodevelopmental conditions.

It is designed to help guide parents / carers who have concerns about their child's neurodevelopment but it should also be of interest to people who suspect that they may have a Neurodevelopmental condition and those who take an interest in or work with individuals with neurodevelopmental conditions.

Our aim is to provide a multi-agency approach with professionals from Care Agency, Education and Health to support children and young people with neurodevelopmental conditions.

We will work with you and your child to collect all the necessary information. This will facilitate our support in helping you access the most suitable service for your child's needs.

+ Getting a Diagnosis

The decision to undertake an assessment for neurodevelopmental condition is an important and highly individual one.

Here are some things that you may wish to consider before engaging with the process. If you have any queries, a member of the Multi-Agency Team (MAT) will be happy to answer any questions.

People often say that having had a diagnosis helps them to better understand themselves, or the young person that they care for.

It can help you and the people around you to understand the types of support that might be helpful.

There are several groups locally for parents and carers offering support. You can find information about these on the Supported Needs and Disability Office's website:

www.disability.gov.gi

Sometimes a diagnosis may be used as a reason for exclusion – for example, the UK military do not currently accept people with a diagnosis of Autism Spectrum, though they are considering changing this as there is increasing understanding that people with Autism can have exactly the skill set and personal characteristics that are useful in some areas of the military.



+ What Are Neurodevelopmental Conditions?

The term “neurodevelopmental conditions” refers to a group of disorders in which the growth and development of the brain and the nervous system is affected. This can impact on an individual’s thinking, feeling, communication, behaviour, learning and physical abilities like movement and coordination.

Examples of Neurodevelopmental conditions are:

Autism Spectrum

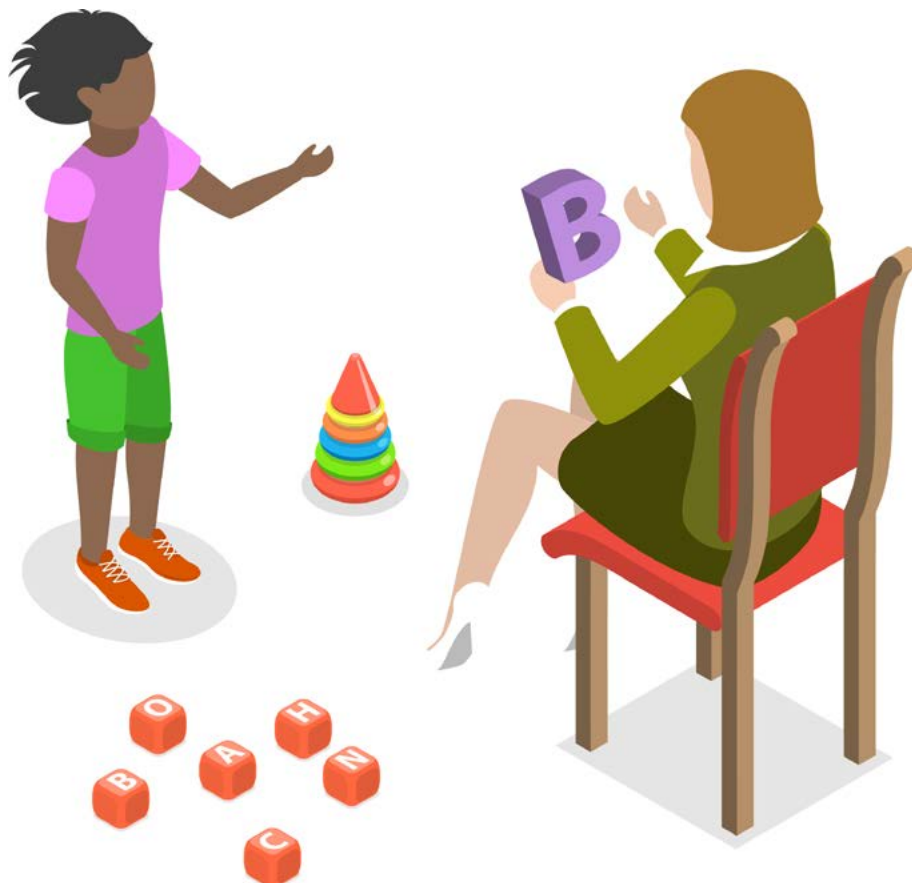
Down Syndrome

Attention Deficit Hyperactivity Disorder (ADHD)

Ticks and Tourette’s Syndrome

Cerebral Palsy

Developmental Coordination Disorder



+ Symptoms of Neurodevelopmental Conditions

Each neurodevelopmental condition presents with different symptoms and these symptoms will differ between individuals

Differences in this area may be apparent in:

- Delayed or impaired speech development
- Difficulties socialising or interacting with peers
- Impaired motor skills
- Inability to focus or concentrate
- Behavioural issues



Severity ranges between persons and some individuals may be affected mildly whilst others may be more severe.

+ What Causes Neurodevelopmental Conditions?

The causes of neurodevelopmental disorders are still largely unknown. Researchers believe that the following factors may contribute to the development of these conditions:

- Genetic factors; a neurodevelopmental disorder may run in certain families
- Environmental factors
- Issues in pregnancy and / or birth



+ Treatment for Neurodevelopmental Conditions

Neurodevelopmental conditions are present in childhood and are expected to remain present throughout life.

There are no cures for Neurodevelopmental conditions but there are treatments available to help manage the symptoms.

These typically include:

- Speech and language therapy
- Occupational therapy
- Physiotherapy
- Dietitian
- Behaviour support
- Counselling
- Medication

Other therapies such as Art Therapy, Music Therapy and Drama Therapy are available privately within the community.

Educating the individual about their condition is also an important part of treatment as it can help them understand how to live with and manage their disorder.

It is important to note that treatment often involves a combination of home and school based programs. The reason for this is that therapy provided in a child's natural environment is ideal. This is a "safe space" to engage in new activities and it can make the child feel more confident, which positively influences their ability to successfully participate in therapy. Therapy also revolves around functionality and home and school are the perfect places for this.

This means that parents / carers play a vital role in therapy. Going to visit the therapist is not enough. Strategies devised by the therapists need to be practised continuously by those close to the child on a daily basis so that the objective is achieved. The child's therapist will teach school and parents how to do this. They will then provide the necessary support and review the child's plan as and when necessary.



+ When Are Neurodevelopmental Disorders Diagnosed?

Neurodevelopmental conditions can be diagnosed at any age; however, early diagnosis is often key to getting the most effective treatment.



+ The Assessment Process

A group of professionals within GHA known as the Multidisciplinary Team (MDT) meet regularly to discuss the needs of children and young people who display traits of neurodevelopmental conditions.

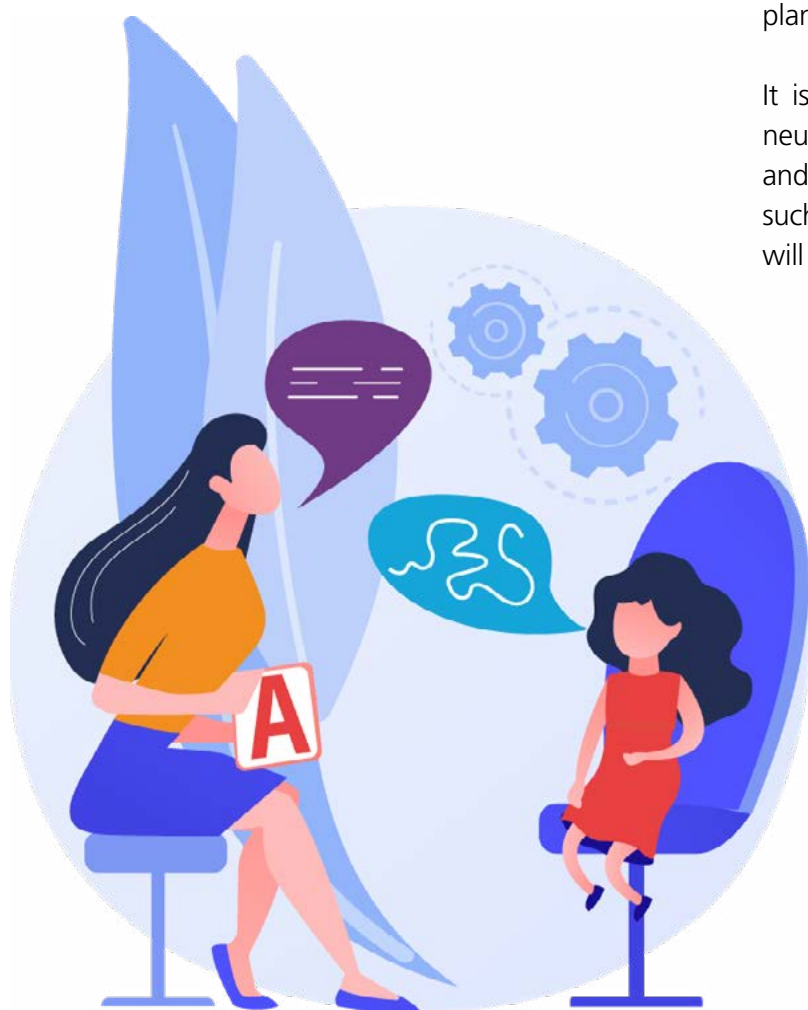
The MDT consists of professionals within GHA such as paediatricians, speech and language therapists, occupational therapists, physiotherapists, dietitians, psychiatrists and psychologists.

In order to decide whether a diagnosis is appropriate, the MDT will need to gather a variety of information relating to language, cognition, motor skills, social and emotional development. This information comes from many different sources such as parents, carers, teachers, SENCos, care workers and the child or young person themselves.

We refer to the collaborative work between professionals in GHA, Care Agency and Education as the Multiagency Team (MAT).

If parents / carers do not want GHA to liaise with the MAT, parents need to inform a member of the GHA MDT of this. Please note that the work the MAT does is crucial for assessment, diagnosis, support and review so if information is not allowed to be shared, it could result in insufficient data to reach a diagnosis and the inability to implement an appropriate support plan.

It is important to note that the diagnosis of some neurodevelopmental conditions such as AS, ADHD and Tourettes are given by the GHA. Other diagnosis such as Dyslexia and other specific learning difficulties will be identified by the Department of Education.



Definitions:

MDT (Multidisciplinary Team):
Team made up of only GHA professionals.

MAT (Multiagency Team):
Team made up of professionals from the GHA, Care Agency and Education.

+ Your Child's Journey Plan

You have concerns:

If you have concerns about your child's development you first need to make an appointment to speak with a member from the MAT (health, education or care agency professional). Direct referrals from parents or caregivers cannot be accepted for Neurodevelopmental assessment.

During your appointment, you will be asked general questions regarding your concerns. This is the opportunity to discuss and provide examples of your worries such as, social communication issues, concerns over developmental milestones, specific behavioural challenges or medical matters.

If appropriate and with your consent, your discussion points and child's details will be documented for a Neurodevelopmental Referral and sent to the relevant members of the GHA multi-disciplinary team.

Stage 1 - Neurodevelopmental Referral Process:

If at MDT triage, it is decided that neurodevelopmental assessment is not the best course of action for your child, the team will guide you to the appropriate resources, support and information.

If at MDT triage, it is decided that your child needs assessment, you may receive a pre-assessment pack. This includes a *questionnaire, an information leaflet and a consent form to allow further information to be accessed from the different agencies that may be involved with your child, such as their school. **If you need help with filling in the questionnaire, you can contact the Supported Needs & Disability Office.*

Once the documents are completed and returned, the MDT will meet to review all the information. At this point, if it is necessary, they may also request additional information from you or any agencies who know your child.

+ Your Child's Journey Plan continued

Stage 2 - Assessment:

The assessment process can be made up of a number of professionals using different assessments or tools. Appointments will be scheduled to suit your day as far as possible.

The MDT will meet to discuss all the information gathered and the results. This discussion allows for a comprehensive evaluation of your child's presentation and condition, ensuring that all aspects have been thoroughly examined and understood. Through this joint working process, the team reach a decision regarding the nature of your child's diagnosis/differences and needs.

Stage 3 – Assessment Feedback:

You will be called with an appointment to meet with the relevant members of the team for your child, to discuss findings and review this with you. At this meeting there are two outcomes that may be discussed:

1. You may be given a diagnosis for your child's neurodevelopmental condition
- OR
2. Your child's differences and needs are identified in the absence of a neurodevelopmental diagnosis

The professionals will then take the time to talk through with you the next stages and their recommendations, depending on outcome. They will be able to let you know what the options are for any further needs-led support, medical or therapy intervention that may be required.

+ Talking to Your Child

Parents often worry about whether they should talk to their child about their neurodevelopmental condition. They wonder when would be a good time and how to approach the subject.

A great deal depends on personal circumstances and you may wish to speak to healthcare professionals about this. The consensus is generally that children and young people are entitled to know about their diagnosis as early as possible, at a level they are able to understand.

If the decision is made to progress with an assessment, then the MDT asks that all young people 12 years old and over, sign a consent form, as well as their parent or carer.



+ Contact Us

For further information, please contact your GP or medical professional.

This information leaflet is produced by the:

- Occupational Therapy Team
- Speech and Language Therapy Team
- Physiotherapy Team
- Consultant Paediatricians
- Clinical Psychology Team

You can also contact the Supported Needs & Disability

Office on:

sndo@gibraltar.gov.gi

