

navigating diagnosis

a quick-reference resource

navigating diagnosis

Navigating the process of diagnosis for neurodivergent conditions can be both challenging and empowering. Whether you're seeking clarity on your own neurodivergent identity or supporting someone through this journey, understanding the diagnostic process is crucial.

Below, we outline key aspects of the diagnostic process in both the UK and Ireland, along with considerations for individuals seeking diagnosis and post-diagnosis support.

Illustration: Megan Rhiannon 'Existing Autistic'



How to be Diagnosed

Individuals can pursue a diagnosis through various routes. Typically, this involves consulting with healthcare professionals specialising in neurodevelopmental conditions such as autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), dyslexia, dyspraxia, and others. General practitioners (GPs) can provide referrals to specialists such as psychiatrists, clinical psychologists, or neurologists who can conduct assessments and provide diagnoses.

Qualifications of Diagnostic Professions

Professionals involved in diagnosing neurodivergent conditions typically have specialised training and qualifications in fields such as psychiatry, clinical psychology, neurology, or developmental paediatrics. They may hold advanced degrees (e.g., MD, PhD, PsyD) and certifications specific to their area of expertise. It's important to seek assessments from professionals who are licensed or registered practitioners in their respective disciplines and have experience and expertise in diagnosing neurodivergent conditions. In some cases, multidisciplinary teams may be involved, particularly for complex cases or when co-occurring conditions are suspected.

assessment tools

AUTISM

Assessment for autism often involves comprehensive evaluations that may include the use of standardised tools such as the Autism Diagnostic Observation Schedule (ADOS-2) and the Autism Diagnostic Interview-Revised (ADI-R). These assessments typically involve direct observation, caregiver interviews, and behavioural evaluations to assess social communication skills, restricted and repetitive behaviours, and sensory sensitivities.

DYSLEXIA

Diagnosing dyslexia involves a comprehensive evaluation conducted by qualified professionals in psychology, education, or speech-language pathology. Common assessment tools include the Comprehensive Test of Phonological Processing (CTOPP) and standardised tests of cognitive abilities and academic achievement. Qualified professionals include clinical psychologists, educational psychologists, speech-language pathologists, and neuropsychologists, who hold advanced degrees and have specialised training in dyslexia assessment (SpLD). The diagnostic process follows professional standards and ethical guidelines to ensure accurate and reliable assessment practices.

ADHD

A diagnosis of ADHD may involve clinical interviews, behavioural observations, and standardised rating scales completed by parents, teachers, and/or the individual themselves. Common assessment tools include the Conners Comprehensive Behaviours Rating Scales (Conners CBRS), the ADHD Rating Scale (ADHD-RS), and the Vanderbilt Assessment Scale.

DYSPRAXIA

Diagnosis of dyspraxia, also known as Developmental Coordination Disorder (DCD), typically involves assessments by occupational therapists, physical therapists, or developmental paediatricians for children and young people. Evaluation may include standardised tests of motor coordination, fine and gross motor skills, and assessments of activities of daily living.

official diagnostic criteria

The language used in this section is highly pathologised language as reflective of the medical nature of diagnosis. In a social context, this type of language is preferred not to be used but is essential to diagnostic criteria.

AUTISM

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the criteria for autism include persistent deficits in social communication and social interaction, as well as restricted, repetitive patterns of behaviour, interests, or activities. Additional criteria include symptoms present in early childhood and impairment in functioning across multiple domains.

DYSLEXIA

Dyslexia is characterised by persistent difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These challenges typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading experience that can impede the growth of vocabulary and background knowledge.

ADHD

The DSM-5 outlines criteria for ADHD, including symptoms of inattention, hyperactivity, and impulsivity that persist for at least six months and significantly impair functioning. Subtypes include predominantly inattentive presentation, predominantly hyperactive/impulsive presentation, and combined presentation.

DYSPRAXIA

Diagnostic criteria for dyspraxia, or Developmental Coordination Disorder (DCD), include difficulties with motor coordination and planning that significantly interfere with academic achievement, activities of daily living, and/or social participation. These difficulties are not better explained by intellectual disability or other medical conditions.

navigating diagnosis

Who is NOT qualified to diagnose

Not all medical or educational professionals are qualified to provide formal diagnoses of neurodivergent conditions. Individuals without specific training and expertise in neurodevelopmental disorders, such as general practitioners (GPs) or educators, may not have the necessary qualifications to conduct comprehensive assessments or interpret diagnostic criteria accurately. While these professionals may play valuable roles in referring individuals for assessment and providing support, formal diagnoses should be obtained from qualified healthcare professionals with specialised training in neurodivergent assessment and diagnosis.

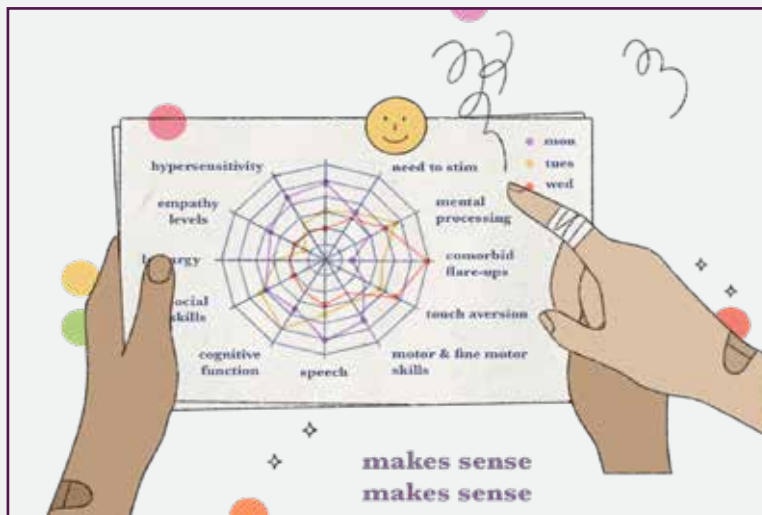


illustration: Megan Rhiannon 'Existing Autistic'

Waiting Times

Waiting times for neurodivergent assessments can vary significantly depending on factors such as geographical location, healthcare system capacity, and individual demand. In the UK, individuals may experience long waiting lists for assessments through the National Health Service (NHS), which can range from several months to over 2 years. Private assessment services often offer shorter waiting times, with assessments typically available within a few weeks to months, depending on the provider's availability.

In Ireland, waiting times for public healthcare assessments can also be substantial, with individuals often facing delays of several months to a year or more. Private assessment services may offer more expedited options, though availability can still vary depending on demand and practitioner schedules.

private diagnosis

Pros & Cons

Private diagnosis can offer several advantages, including quicker access to assessments and greater flexibility in choosing specialists and appointment times. Additionally, private assessments may provide more personalised and comprehensive evaluations, as practitioners may have more time to devote to each individual case. However, it's essential to consider the financial implications, as private assessments can be costly and may not be covered by insurance or healthcare plans. Furthermore, there are some authorities that may not accept a private diagnosis, such as the NHS, which should be taken into account before committing to a private diagnosis.

Here we list the pros and cons of seeking a private diagnosis:

Pros

Quicker Access

Private assessments often have shorter waiting times compared to public healthcare services.

Greater Flexibility

You can choose specialists and appointment times that suit your schedule.

Personalised Evaluation

Private assessments may offer more personalised and comprehensive evaluations tailored to individual needs.

Dedicated Time

Practitioners may have more time to devote to each case, leading to a more thorough and comfortable assessment.

private diagnosis

Pros

Confidentiality

Private assessments offer increased privacy compared to public services.

Choice of Professionals

You have the freedom to select professionals with specific expertise in autism.

Access to Advanced Technology

Private clinics may have access to the latest assessment tools and technology such as online patient portals.

Additional Services

Some private clinics offer additional services, such as therapy or counselling, alongside assessments (usually at additional cost).

Avoidance of Bureaucracy

Private assessments may involve less administrative hassle compared to public services.

Potential for Early Intervention

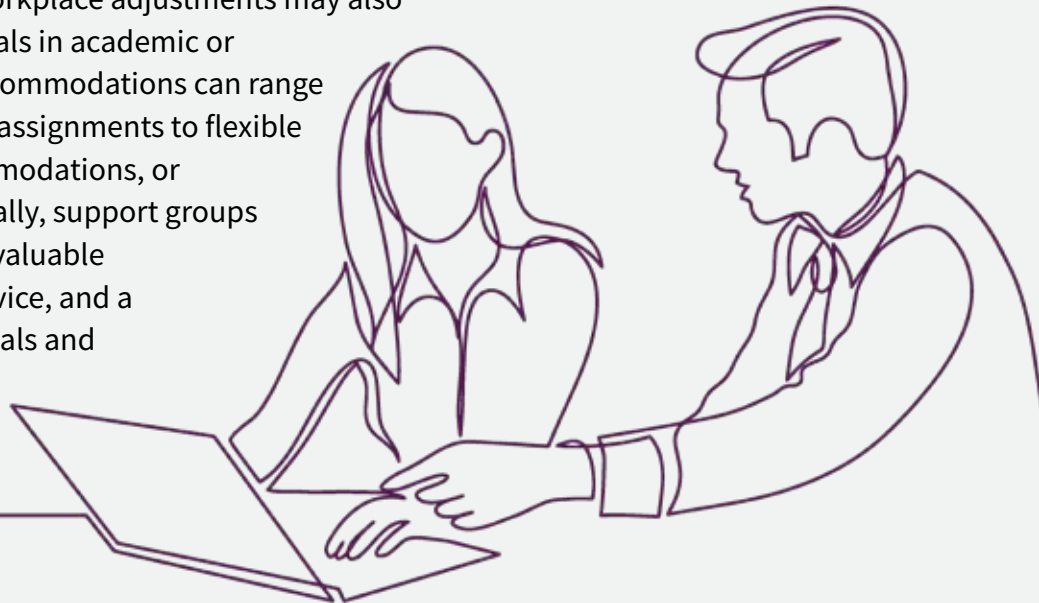
Early diagnosis through private assessment can facilitate early intervention and support.

post diagnosis

support

Receiving a diagnosis can be a pivotal moment, offering validation and clarity for individuals and their families. Post-diagnosis support is crucial in helping individuals understand their neurodivergent traits, as well as navigate the practical implications of their diagnosis in various aspects of life. This support may include access to therapies such as cognitive behavioural therapy (CBT), occupational therapy, or speech therapy, depending on individual needs and challenges.

Reasonable adjustments and workplace adjustments may also be available to support individuals in academic or employment settings. These accommodations can range from extra time on projects and assignments to flexible work schedules, sensory accommodations, or assistive technologies. Additionally, support groups and peer networks can provide valuable emotional support, practical advice, and a sense of community for individuals and families navigating a diagnosis.



diagnosis

impact for adults

For adults, a diagnosis can provide a deeper understanding of their cognitive and behavioural traits, potentially leading to self-acceptance, self-advocacy, and personal growth. Understanding one's neurodivergence can help individuals recognise their strengths, challenges, and unique perspectives, fostering a sense of identity and belonging.

A diagnosis may also open doors to tailored support services and accommodations in various aspects of life, including education, employment, healthcare, and social interactions. By seeking appropriate support and accommodations, individuals can better understand their neurodivergent traits, optimise their strengths, and achieve their goals.

However, it's essential to recognise that not everyone may choose to pursue a formal diagnosis, and self-identification is valid and respected. Some individuals may opt not to pursue diagnosis due to various reasons, including accessibility barriers, stigma, or personal preference. Self-identification allows individuals to embrace their neurodivergence on their own terms, without the need for external validation or labels.



barriers to diagnosis

Lack of Awareness and Knowledge

Limited awareness and understanding of neurodivergent conditions among healthcare professionals, educators, and the general public can hinder early identification and referral for diagnosis. Many individuals may not recognise the signs of neurodivergence or understand the importance of seeking assessment and support.

Stigma and Misconceptions

Stigma and misconceptions surrounding neurodivergent conditions can create reluctance or resistance to seeking diagnosis and support. Negative stereotypes, fear of judgment, and societal attitudes that pathologise neurodiversity may discourage individuals from disclosing their experiences or seeking assistance.

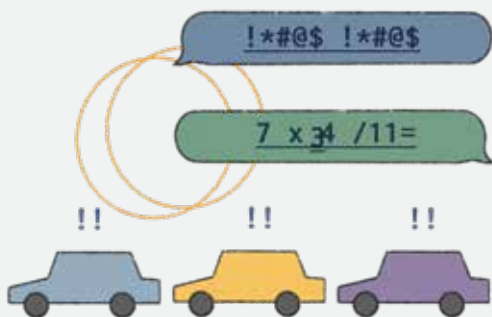


Illustration: Megan Rhiannon 'Existing Autistic'

Access to Services and Resources

Disparities in access to healthcare services, diagnostic assessments, and support resources can present significant barriers, particularly for marginalised and underserved communities. Factors such as geographic location, socioeconomic status, language barriers, and cultural differences can impact access to timely and culturally competent care.

Long Waiting Times and Limited Availability

Lengthy waiting times for diagnostic assessments and limited availability of qualified professionals can result in delays in diagnosis and intervention. Individuals may face extended waitlists for assessments through public healthcare systems, while private services may be prohibitively expensive or inaccessible.

barriers to diagnosis

Co-occurring Conditions and Complexity

Neurodivergent conditions often co-occur with other mental health conditions, learning disabilities, or medical conditions, leading to diagnostic complexity and challenges. Untangling overlapping experiences and identifying the primary neurodivergent condition may require specialised assessments and multidisciplinary collaboration.

Cultural and Linguistic Barriers

Cultural differences, language barriers, and diverse communication styles can pose challenges in the diagnostic process. Cultural stigma, mistrust of healthcare systems, and lack of culturally competent assessment tools may inhibit accurate diagnosis and engagement with support services among diverse populations.

Financial Barriers and Healthcare Costs

Financial constraints and healthcare costs can present significant barriers to accessing diagnostic assessments and support services, particularly for individuals without a national health service, adequate insurance coverage or financial resources. High out-of-pocket expenses for private assessments and therapies may limit access for many individuals and families.

Lack of Adult Diagnostic Services

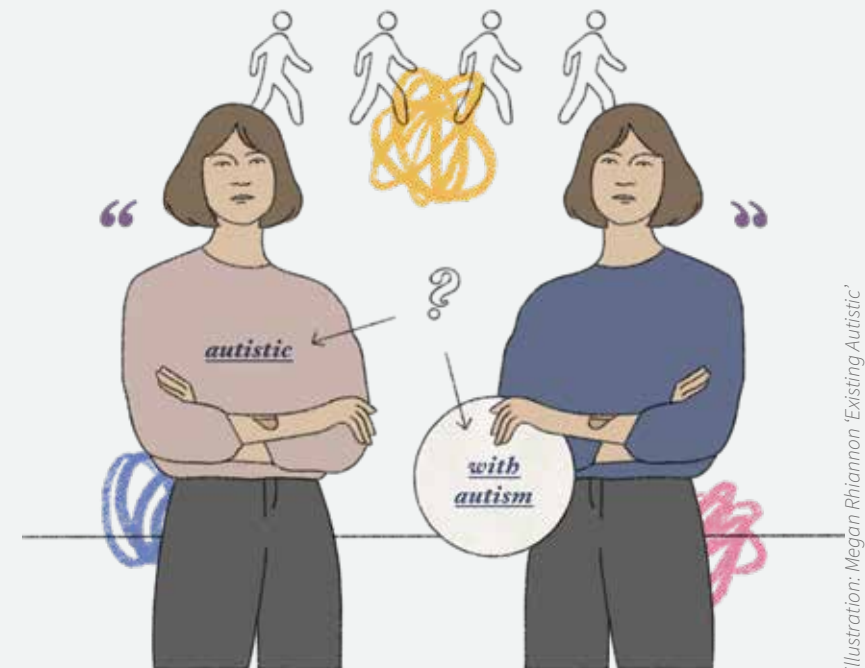
While diagnostic services for neurodivergent conditions are often available for children and adolescents, adults may face challenges in accessing assessment and support services. Limited availability of adult diagnostic services and a focus on early intervention in childhood may result in undiagnosed and unsupported neurodivergent adults.



self identification

Self-identification as neurodivergent is a profoundly personal and empowering decision for many individuals navigating the complex landscape of neurodiversity. It represents a pivotal moment of self-awareness and acceptance, where individuals recognise and honour their unique neurological traits and experiences. For many, the decision to self-identify offers a sense of autonomy and agency, allowing them to define their identity on their own terms, free from the constraints of diagnostic labels or external validation. While some may choose to seek formal diagnosis, others may opt for self-identification, influenced by a myriad of factors such as accessibility barriers, societal stigma, or personal preference.

It's important to note that while some individuals may be in the process of seeking a formal diagnosis and are on waiting lists, they are currently self-identifying. This acknowledgment underscores the complexity of the neurodivergent experience and emphasises the importance of validating and supporting individuals regardless of their diagnostic status.



self identification

pros

Autonomy and empowerment

Self-identification allows individuals to define and embrace their neurodivergent identity on their own terms, fostering a sense of empowerment and self-acceptance.

Flexibility and choice

It offers individuals the flexibility to disclose their neurodiversity as they see fit, without the pressure of formal diagnosis, enabling them to navigate their identity journey on their own terms.

Community connection

It facilitates connections with like-minded individuals within the neurodivergent community, providing support, understanding, and a sense of belonging.

Personal growth

Embracing one's neurodivergent identity can lead to increased self-awareness, resilience, and personal growth as individuals learn to navigate and embrace their unique strengths and challenges.

self identification

cons

Lack of validation

In the absence of a clinical diagnosis of a neurodivergent condition, individuals who choose to self-identify as neurodivergent may face scepticism or doubt. Their experiences may not conform to societal norms or commonly held perceptions of neurodivergence.

Limited access to accommodations

Without a formal diagnosis, individuals may face challenges in accessing accommodations and support services tailored to their specific needs, potentially hindering their ability to thrive in academic, professional, or social settings.

Medical and therapeutic support

Without a formal diagnosis, individuals may miss out on specialised medical treatments, therapies, or interventions that could help manage neurodivergent traits and improve overall well-being.

Community Connection

Although in most neurodivergent environments, self-identification is valid, not all neurodivergent environments may fully accept or validate self-identification. Some communities or online spaces may uphold a hierarchy that privileges diagnosed individuals over those who self-identify. This hierarchy can manifest in subtle ways, such as in discussions where the experiences and perspectives of diagnosed individuals are given more weight or legitimacy.

Advocacy and Rights

Following a diagnosis or as individuals self-identify, it's essential to navigate various aspects of life with a neurodivergent perspective. Understanding one's rights and advocating for oneself becomes crucial in contexts such as education, employment, healthcare, and social services.

the diagnosis journey

pre-diagnosis

Research

Individuals who suspect they may be neurodivergent can begin by researching their experiences and symptoms. Online resources, books, and reputable websites can provide valuable information.

Support groups

Joining online or in-person support groups for individuals exploring their neurodivergent identity can offer valuable insights and peer support.

Professional assessment

Seeking an assessment from a qualified healthcare professional, such as a psychologist, psychiatrist, or neurologist, could be beneficial to discuss thoughts on your neurodivergence. Referrals can be obtained through primary care physicians or mental health clinics.

mid-diagnosis

Assessment process

During the diagnostic process, individuals may benefit from keeping a journal of their experiences, symptoms, and any questions or concerns they have. This can help facilitate open communication with healthcare professionals.

Support networks

Engaging with support networks of individuals who have undergone similar diagnostic processes can provide emotional support and practical advice.

Advocacy organisations

Organisations dedicated to specific neurodivergent conditions often offer resources, guidance, and advocacy support to individuals undergoing diagnosis.

the diagnosis journey

post-diagnosis

Understanding rights

Individuals should familiarise themselves with relevant legislation, policies, and guidelines related to neurodiversity in various contexts, such as Equality Act in the United Kingdom.

Accessing accommodations

In educational or workplace settings, individuals can work with disability services offices, human resources departments, or relevant authorities to access accommodations and support services tailored to their needs.

Legal support

If faced with discrimination or denial of rights, individuals may seek assistance from legal professionals specialising in disability rights or discrimination law. Advocacy organisations can also provide guidance and support in navigating legal processes. Typically, a formal diagnosis is required for this.

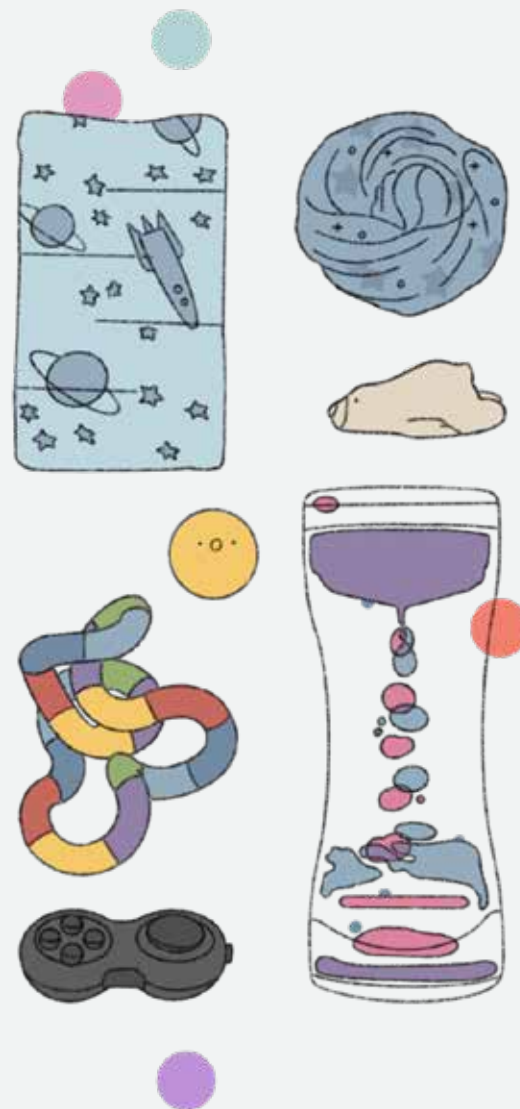


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Research & innovation

Ongoing research and innovation in the field of neurodiversity are essential for advancing understanding, diagnosis, and support strategies. As research is continually evolving, it can be beneficial for individuals to keep up to date with current and emerging knowledge. This includes research on the underlying biology, genetics, and neurodevelopmental mechanisms of neurodivergent conditions, as well as studies examining effective interventions, accommodations, and societal attitudes.

By staying informed about the latest research findings, individuals can make more informed decisions about their neurodivergent journey and access the most up-to-date support options available. Additionally, there are some newer research programs out there that may be of interest to neurodivergent people, offering opportunities to participate in groundbreaking studies and contribute to positive change and progress in the field of neurodiversity.

Summary

Navigating the process of seeking diagnosis or self-identifying as neurodivergent is a deeply personal journey, characterised by both positive and negative experiences. It is a journey marked by self-awareness, acceptance, and the recognition of one's unique neurological traits. However, it can also entail challenges such as scepticism, stigma, and uncertainty.

In this journey, knowing where to turn for support and who is qualified to help is essential. Engaging with support networks, accessing resources, and seeking assistance from qualified healthcare professionals and advocacy organisations can ensure a positive journey, empowering individuals to navigate their neurodivergent identity with confidence and resilience.

auticon is a social enterprise with the mission to **address the inequalities** in employment for **neurodivergent** adults.

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