

DEMENTIA, MENTAL HEALTH DISORDER OR INTELLECTUAL AND DEVELOPMENTAL DISABILITY: HOW DO WE TELL?

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ABSTRACT

The identification of mental health disorders and dementia in individuals with intellectual and developmental disability is complex. This is due to possible overlapping clinical presentations and the difficulty in separating the symptoms of mental health disorders and dementia from the characteristics of intellectual and developmental disability. Furthermore, the intrinsic limitations in communication and challenges faced in elucidating accurate information in the presence of these conditions lend additional difficulty. However, differentiating between these conditions is essential for establishing accurate diagnoses and instituting appropriate treatment. Moreover, even if the patient presents with a completely unrelated complaint, being aware of the base diagnosis is vital. This is especially important so that appropriate intervention plans and community resources can be activated to support the individuals and their families. Having said that, the limited time and resources that primary care doctors have access to in their clinical practice may pose questions regarding how possible it is for them to make such a differentiation. This article aims to suggest a practical approach to differentiating between these conditions in the primary care setting.

Keywords: intellectual disability, mental health, dementia, psychiatric, dual disability, developmental disability, autism, primary care

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INTRODUCTION

Primary care doctors are the first line of care in the community and will often be the first point of contact for patients. On a daily basis, they make assessments, institute treatment, and make decisions on referrals for further investigations. In the process of doing all of these, the medical interview or “history taking” is the most common task performed by doctors, and a clinician may conduct between 100,000 and 200,000 patient interviews in his or her professional life.¹ These interviews in clinical practice are so critical that Engel

and Morgan called them “the most powerful and sensitive and most versatile instrument available to the physician”.² Good interview skills contribute significantly to diagnostic accuracy, patient compliance to therapy, positive patient health outcomes, and improved patient and physician satisfaction.³

What happens then in situations where the medical interview poses difficulties for the clinician? This is particularly common in circumstances where both cognitive and communication limitations are present in the patient facing the clinician. Does the clinical consultation break down once these impairments are present? Facing such a patient in his or her consult room, the immediate thought that comes to mind for the clinician will be to question what the underlying condition causing the cognitive and communication difficulty is. Understanding the root cause will allow him or her to approach the consultation and recommend interventions more effectively. Could it be intellectual disability, autism, dementia, or a mental health disorder affecting the patient? Or could these disorders be co-occurring in the same patient? These are important questions that need to be answered. Without reliable diagnoses, appropriate management plans cannot be formulated. However, the challenge in making these assessments is very real in a busy primary care practice where time and resources may be limited. Understanding each of these conditions and how they may co-exist with one another will certainly be of help to the clinician. In the next section, we will look at how these conditions are defined.

DEFINITIONS

The Diagnostic and Statistical Manual of Mental Disorders, often known as the DSM, is a reference book on mental health and brain-related conditions and disorders, published by The American Psychiatric Association (APA).⁴ Currently, the DSM is in its fifth edition (DSM-5), marking the first significant revision of the publication since the DSM-IV in 1994. In addition to enhancements in knowledge, much of the adjustments were also driven by an endeavour to ensure better alignment with the International Classification of Diseases and its 11th edition (ICD-11), a system of mental disorder classifications developed by the World Health Organization (WHO).⁵ For the purposes of this article, we will be using the definitions from DSM and the developmental disorder that we will be focusing on is Autism Spectrum Disorder. We will now look at the DSM-5 criteria in defining four conditions: Intellectual Disability, Autism Spectrum Disorder, Mental Disorder, and Dementia.

Intellectual Disability

Intellectual disability has gone through several terminology changes over the centuries: from terms such as idiots,

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imbeciles, to mental handicap, and later, mental retardation. Today, “intellectual disability” is recognised as the term used internationally in medical and educational settings.⁶

DSM-5 defines intellectual disabilities as neurodevelopmental disorders that begin in childhood and are characterised by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living.⁷

These three domains determine how well an individual copes with everyday tasks:

- The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory.
- The social domain refers to empathy, social judgement, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
- The practical domain centres on self-management in areas such as personal care, job responsibilities, money management, recreation, and organising school and work tasks.

DSM-5 emphasises that an individual’s symptoms must begin during the developmental period and are diagnosed based on the deficits in adaptive functioning. This is distinct from DSM-IV in which a person was defined as mentally retarded if he exhibited significantly subaverage general intellectual functioning (an IQ of about 70 or below) accompanied by significant limitations in adaptive functioning, and with the onset before the age of 18.⁸

One key implication of the change is that although analysis of IQ has not been completely removed from the diagnosis of intellectual disability in DSM-5, its importance has been greatly reduced. This aims to ensure that IQ test scores are not viewed as the defining factor of an individual’s overall ability without adequately considering functioning levels.

Autism Spectrum Disorder

Similar to intellectual disability, there has been a number of changes and iterations with regards to the definition of autism over the years. From a single autistic disorder previously, DSM-IV defined three distinct developmental disorders – Autistic Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder (PDD).⁹ This distinction helped with clarifying understanding but unfortunately posed unforeseen challenges with regards to accessing support services. After careful review, the three categories have now been folded into one umbrella term – Autism Spectrum Disorder – in DSM-5.

DSM-5 defines Autism Spectrum Disorder as¹⁰:

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

- Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
- Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
- Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

- Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
- Insistence on sameness, inflexible adherence to routines, or ritualised patterns or verbal nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
- Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
- Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

C. Symptoms must be present in the early developmental period (but may not fully manifest until social demands exceed limited capacities or may be masked by learnt strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.

Mental Disorder

The definition of a mental disorder is foundational in the philosophy of psychiatry and has huge practical importance for clinicians and patients. Human behaviours once viewed as a disorder many years ago may be considered acceptable today. At which point would social and behavioural differences be considered less of a normal variation but a disorder? Is there risk of over-medicalising individuals and their behaviours that may be veering out of social norms? In view of its central importance, this question has been discussed repeatedly in psychiatric circles and successive revisions of the DSM have attempted to address it.

DSM-5 currently defines a mental disorder as “a syndrome characterised by clinically significant disturbance in an individual’s cognition, emotion regulation, or behaviour that reflects a dysfunction in the psychological, biological, or development processes underlying mental functioning”. In addition, mental disorders are usually associated with significant distress or disability in social, occupational, or other important activities. An expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder. Socially deviant behaviour (e.g., political, religious, or sexual) and conflicts that are primarily between the individual and society are not mental disorders unless the deviance or conflict results from a dysfunction in the individual, as described above.¹¹

An important point to highlight is that “mental disorder” is an umbrella term and there are many different types of mental disorders, including but not limited to mood disorders, psychotic disorders, addiction disorders, and personality disorders.

Dementia

“Dementia” is also an umbrella term, but one that refers to several neurological conditions, of which the major symptom is the decline in brain function due to physical changes in the brain. It is distinct from mental illness.

In DSM-5, dementia is categorised as a Neurocognitive Disorder (NCD) and this NCD category is further subdivided into Minor NCD and Major NCD. This NCD category encompasses the group of disorders in which the primary deficit is in cognition, which is acquired rather than developmental. This is distinctly different from the emphasis on how intellectual disability whose deficits are also cognitive in nature must occur in the developmental period.

For the purposes of our article, we will not discuss minor NCD as defined by DSM-5 but will focus on the definition of a major NCD, which correlates to dementia.

In DSM-5, a major NCD is defined by the following¹²:

- There is evidence of substantial cognitive decline from a previous level of performance in one or more of the domains listed below, based on the concerns

of the individual, a knowledgeable informant, or the clinician; and a decline in neurocognitive performance, typically involving test performance in the range of two or more standard deviations below appropriate norms (i.e., below the third percentile) on formal testing or equivalent clinical evaluation.

- The cognitive deficits are sufficient to interfere with independence (i.e., requiring minimal assistance with instrumental activities of daily living).

These cognitive deficits must not occur in the context of delirium and must not be attributable to another mental disorder.

DSM-5 also describes six cognitive domains that may be affected in NCDs, and these include learning and memory, complex attention, language, executive ability, perceptual-motor-visual perception (praxis), and social cognition.

It is important to highlight that dementia and NCDs are general terms, and do not give the underlying aetiology of the cognition decline. There are many different causes for dementia, and these will also need to be elucidated as part of making the diagnosis.

Having now reviewed the definitions of intellectual disability, autism spectrum disorder, dementia, and mental disorders, let us explore the relationships between these conditions.

RELATIONSHIPS AND CO-EXISTENCE

The brain is the most complex organ in the universe and is also undoubtedly the most important organ in the human body. It weighs just 3 percent of the human body, yet consumes 17 percent of the body’s energy for its estimated 100 billion neurons with 100 trillion connections.¹³ For such a critical organ whose pathology could affect an individual’s function so significantly, the brain interestingly only has a limited number of ways to demonstrate dysfunction or distress. These include but are not restricted to anxiety, depression, psychosis, confusion, and stereotypical behaviours. Added to this irony is that the billions of neurons use only a few hundred neurotransmitters to communicate and perform its functions. What this tells us is that regardless which part of the brain is affected and where the pathology is, there is often going to be some overlaps in the neurotransmitters involved and, in the symptomology, displayed. This understanding is important, for it helps clinicians take the first step in answering questions regarding diagnosis that patients often pose. Examples include, “Does my mother have dementia or a mental illness?” and “Is dementia and intellectual disability the same thing?”. With this concept in mind, it becomes easier to see the inter-relationship between the different conditions.

It is clear from the definitions that intellectual disability and autism spectrum disorders are developmental disorders, and the symptoms of both must begin during the developmental

period. Adaptive functioning deficits are essential in the diagnosis of intellectual disability, yet these same deficits in the social, conceptual, and practical aspects can also be affected in someone with autism spectrum disorder due to social communication and sensory deficits. These overlaps are evident, which is why in the DSM-5 definition of autism spectrum disorder, it clearly states that in order to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication for the individual should be below that expected for general developmental level of the individual if he or she has only one of the conditions.¹⁰ The challenge in the paediatric field is that these differences cannot always be detected easily, as the child's brain continues to develop and grow rapidly, making the symptoms and function of the individual susceptible to change. This is less of a problem in the adult field. The individual's presenting symptoms and characteristics should be more stable, which will make assessments less time-dependent.

What about the relationship between mental health disorders and intellectual and developmental disability? These are clinically significant and need to be recognised on two levels. First, there is a distinct overlap in symptomology. For example, in diagnosing mood disorders, patients are asked questions about their sleep, appetite, and interest levels involving their usual activities. However, disrupted appetite and reduced participation in activities in an individual with autism spectrum disorder could be related to sensory hypersensitivities and not because of depression. Similarly, some of the symptoms suggestive of psychotic disorder are seen quite commonly in individuals with intellectual disability. One example would be the self-talk that is sometimes seen in persons with intellectual disability, which can be mistaken for hallucinations if one does not understand the baseline behaviour and function of this individual.

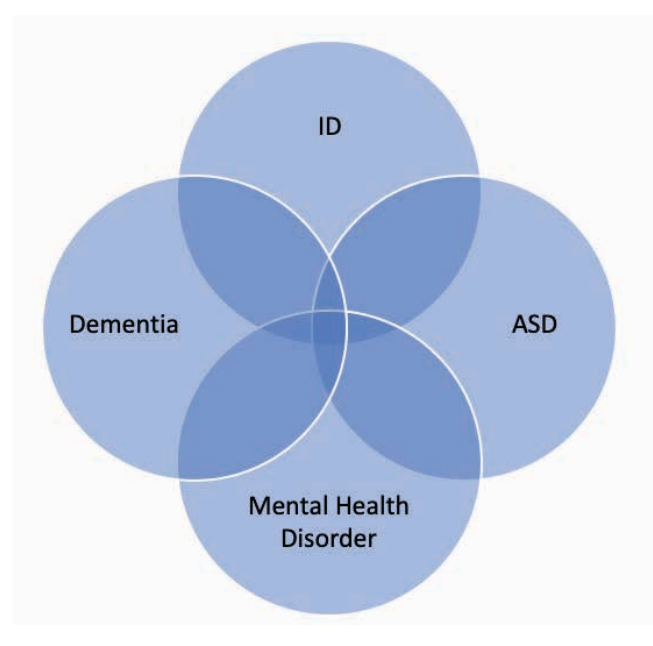
On another level, as much as clinicians need to be mindful not to assume the presence of co-morbid mental disorders too quickly, there is also the possibility of diagnostic overshadowing. This refers to the situation in which healthcare professionals misattribute symptoms to the intellectual disability rather than diagnosing a separate psychiatric disorder.¹⁴ Mental health conditions are well recognised to be more prevalent in individuals with intellectual disability, and an individual with both co-morbidities is termed to have dual disability.¹⁵ Therefore, it is vital that clinicians must strike a balance, recognising that mental health conditions are more common in this group, and yet not be too quick to make a diagnosis.

How about dementia? Dementia's key symptoms surround cognitive impairment. However, since individuals with intellectual disability have pre-existing cognitive issues, how do clinicians tell between the two? The key notable difference will be the age at which the cognitive impairment develops. Intellectual disability is developmental in nature while dementia is an acquired neurodegenerative condition

that develops later in life. In addition, the trajectory of the two are different, with intellectual disability being a chronic and static condition, whereas dementia is a degenerative one. Clinicians do face a challenge as well when a person with intellectual disability starts to present with cognitive changes. How does one diagnose mild cognitive impairment or dementia in these individuals? Unlike assessing for dementia in the general population, diagnosing dementia in the population with baseline intellectual disability is not as straightforward. It is not within the scope of this article to discuss the diagnosis of dementia in individuals with intellectual disability, but it is important to highlight that clinicians need to be sensitive to the possibility of its development in these individuals. Furthermore, in certain subgroups of individuals with intellectual disability, such as Down Syndrome, the risk of developing dementia is significantly higher and occurs far earlier in life.¹⁶

What about the overlap between dementia and mental health conditions? It is well recognised that one of the key differential diagnoses for dementia is depression. This is sometimes called pseudodementia. Individuals with depression can present with inattention, memory lapses, and difficulty with planning, all of which are also common symptoms in dementia. Moreover, an individual with dementia can also suffer from depressive symptoms, which further complicates the issue. To add more complexity, whilst the presence of cognitive impairment is necessary for the diagnosis of dementia, associated neuropsychiatric symptoms – known collectively as behavioural and psychological symptoms of dementia (BPSD) – are prevalent and can sometimes be the presenting complaints.¹⁷ These BPSD include perceptual, psycho-emotional, motor, and behavioural changes that can be similar to that seen in psychiatric disorders. Specific types of dementia, such as Frontotemporal Lobe Dementia, can also present initially with behaviour disturbances rather than cognitive changes, adding more diagnostic difficulty.

Figure 1. The relationship between the different conditions



In summary, though distinct disorders and conditions in themselves, intellectual disability, autism spectrum disorder, mental health disorders, and dementia can also co-exist in various combinations. This is best reflected in a Venn diagram (See **Figure 1**). In the next section, this article will propose a practical approach to differentiating between these conditions in a primary care setting.

A. A SUGGESTED APPROACH TO DIFFERENTIATION

Taking into consideration the definitions and inter-relationships of dementia, mental health disorders, intellectual disability, and autism spectrum disorder, how can clinicians differentiate the four when faced with a patient?

Naturally, the first course of action is to ask the patient and their family what the underlying diagnosis is, and to refer to any clinical records that may be available. However, if the family or accompanying carer is not able to provide the answer, then, in addition to carefully considering the symptomology and presentation, employing a few questions should aid the clinician in making a provisional diagnosis.

Here are four suggested questions the clinician can ask:

1. How old was the patient when the symptoms began?

This is a critical part of the patient's history that will give clinicians a very important clue as to the underlying diagnosis. Intellectual disability and autism spectrum disorder are both developmental conditions and must begin in the early years. Obtaining this history helps to confirm the diagnoses. However, if the history given is one in which symptoms only started in the late teenage years or early twenties, then these two conditions are a lot less likely, and a mental health disorder becomes much higher on the list of differentials. Dementia, on the other hand, is a neurodegenerative condition that is acquired. Therefore, if this is present, the history given should describe a decline in cognition occurring later in life, particularly in the sixties and beyond. The caveat to this is that young onset dementia is possible, and this is also especially seen in individuals with Down Syndrome.¹⁸

2. What is the patient's developmental and educational history?

Taking the time to ask a few quick questions about the patient's developmental and educational history will help the clinician glean important information and facts. Differentiating between intellectual disability and autism spectrum disorder may not always be straightforward, particularly because they often co-exist. From the developmental perspective, individuals with moderate to severe intellectual disability with or without comorbid autism spectrum disorder will tend to display developmental delays in speech and motor skills apparent within the first two years of

life. However, if the history suggests higher instances of repetitive or rigid behaviours, and more difficulties with social communication, then the possibility of autism spectrum disorder becomes higher. Asking carers about the types of allied health and therapy services may also provide greater clues. The presence of sensory difficulties will suggest the possibility of autism spectrum disorder. Patients with mild intellectual disability, on the other hand, may only display clearer symptoms in schoolgoing years. This is where the patient's educational history will come in useful. Asking which school the individual attended can be very revealing, as different schools in Singapore cater to students with different types of disabilities. If, however, the individual went through mainstream education and functioned well throughout their teenage years, it is less likely that they have an underlying developmental condition. A different diagnosis will have to be sought for their presentation.

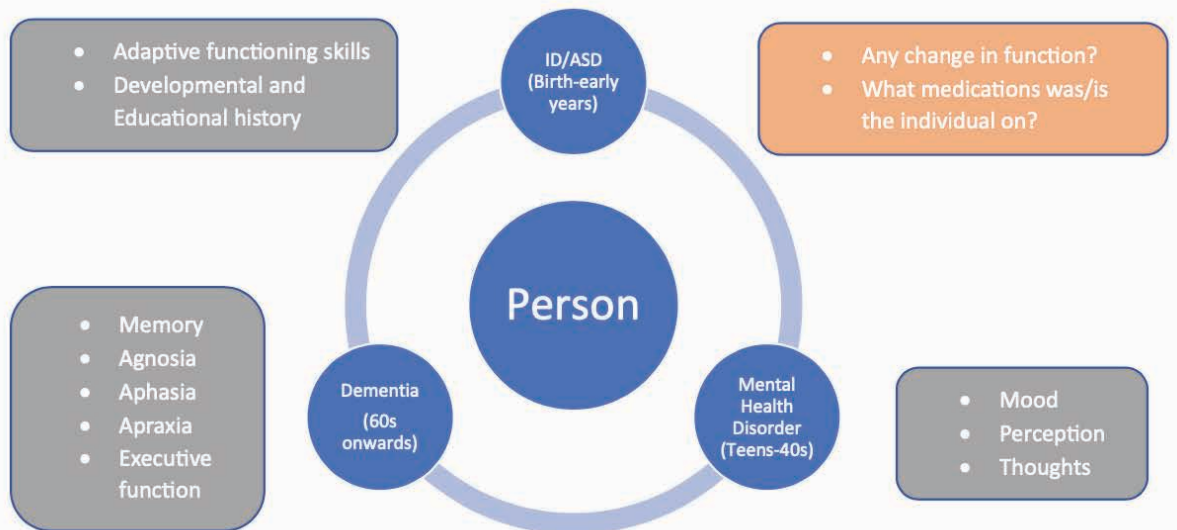
3. Have there been any changes in function over time?

The decline in function from a previous premorbid state is the hallmark of dementia. This history is therefore key if the clinician suspects the presence of a neurodegenerative process. However, in view of the possibility of various conditions concomitantly occurring, any change in function over the life course will also give important clues with regards to possible comorbidity. Intellectual disability and autism spectrum disorder are chronic conditions and remain with the individual for life. However, mental health conditions can be treated, and though function may decline at its onset, this can improve once the symptoms are well controlled. If there is a decline in function in an individual with intellectual disability later in their adult life, and a mental health condition has been excluded, then the other differential diagnosis will be that of dementia. It is also important to rule out other neurological pathologies such as cerebrovascular accidents and space occupying lesions. Overall, taking a history of any fluctuations in mental state and function across the individual's life course will give the clinician a far clearer picture regarding the individual.

4. What medications is the patient taking?

Access to medical records is extremely useful. Finding out what medications the patient previously took or is currently taking will lend important clues to the diagnosis. Though individuals with intellectual disability and autism spectrum disorder do not require medications for their underlying conditions, medications are sometimes given for comorbidities such as attention deficit hyperactivity disorder. They are also sometimes prescribed psychotropics for behaviours of concern, and this will need to be differentiated from an individual started on these medications for psychosis. One clue that aids in deciphering this is the dosage at which the medications are prescribed.

Figure 2: A suggested approach



The dosages offered for behaviours of concern may be lower than that for true psychosis. If on the other hand the medication list includes cognitive enhancers in addition to psychotropics, then this suggests that the individual may have dementia with BPSD rather than a pure mental health condition alone.

The author believes that asking these four questions will help clinicians come to a quick differential diagnosis with regards to the patient before them. It is however important to note that the suggested approach comes in the context of a clinical consultation that looks at the presenting symptomology and does not remove the need for formal diagnostic assessments if in doubt. It is also crucial to recognise that the patient sitting in the consult room facing the clinician is a whole individual and cannot be categorised into conditions in a fragmented manner. There will often be overlaps, and a significant amount of clinical judgement will need to be exercised. However, the author’s view is that this approach can help the busy clinician come to an understanding about the patient in a shorter time. It is important to emphasise though that this is an iterative process, similar to performing any other clinical assessment. The more one practises this, the more skilled one becomes in doing it (See **Figure 2**).

CONCLUSION

The identification of mental health disorders and dementia in individuals with intellectual and developmental disability and differentiating between these conditions can be challenging. The overlapping symptoms, together with the difficulties faced in conducting the medical interview due to cognitive and communication limitations, are only a few of the key contributing factors. This challenge is even more apparent in a busy primary care setting where time and resources may be limited. Yet because primary care doctors are often first line in encountering patients,

it is essential for them to make accurate assessments and suggest appropriate interventions, even without the benefit and support of complicated diagnostic instruments and investigations. This article has therefore proposed a practical approach that takes into consideration the definitions and inter-relationships between intellectual disability, autism spectrum disorder, mental health disorder, and dementia. With this, the hope is that primary care doctors will be more confident in approaching these patients in the community and in providing much needed care for them.

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LEARNING POINTS

- **The identification of mental health disorders and dementia in individuals with intellectual and developmental disability and differentiating between these conditions can be challenging.**
 - **The overlapping symptoms, together with the difficulties faced in conducting the medical interview due to cognitive and communication limitations, are only a few of the key contributing factors to challenges in diagnosis.**
 - **The Diagnostic and Statistical Manual of Mental Disorders (DSM), a reference book on mental health and brain-related conditions and disorders, published by the American Psychiatric Association (APA), clearly defines intellectual disability, autism spectrum disorder, mental disorder, and dementia as distinct conditions.**
 - **Four questions that can help clinicians differentiate between the conditions are age of the patient at onset of symptoms, developmental and educational history, changes in function, and the medication history.**
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