

PERSONS WITH INTELLECTUAL DISABILITIES AND AUTISM SPECTRUM DISORDERS

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ABSTRACT

People with intellectual disability and autism spectrum disorder are vulnerable to the same spectrum of mental and physical illness as the general population. Due to unique challenges, they remain at risk of health inequalities resulting in elevated mortality from preventable causes. This article aims to equip the primary physician with greater familiarity and understanding of the varied needs for this sub-group of patients and hence supporting them to lead healthier lives.

Keywords: Autism spectrum disorder, Assessment, Intellectual disability, Mental health, Primary care, Physical health, Singapore

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INTRODUCTION

At the time of writing the population of Singapore was 5.4 million¹. The worldwide prevalence of intellectual disability is estimated to be 10.37/1000². While there is no current data about Autism Spectrum Disorders (ASD) in Singapore, worldwide, we are experiencing an increase in the number of people affected by ASD; in the USA 1 in 88 children are affected by autism³.

Given that each General Practitioner (GP) in Singapore sees an average of around 1000 patients a month⁴, the number of people with developmental disabilities a GP sees is estimated to be definitely more than 10 per month.

International studies show that this group remains at risk of health inequalities, both in third world and first world health contexts, resulting in elevated mortality from preventable causes. There are 5 factors that lead to health inequalities for this group described by Emerson and Baines (2010)⁵:

1. Adults with Intellectual Disabilities are more likely to be exposed to the social determinants of poor health including poverty, poor housing, unemployment and social disconnectedness.
2. There is an increased risk of health problems that are associated with the specific genetic and/or biological causes of learning disabilities.
3. Impaired communication skills and reduced literacy limits the ability of people with intellectual disability to report

problems and symptoms to others, to seek help, to understand and access health education and health information

4. There are increased personal health risks and behaviours such as poor diet and lack of exercise, which can be due to intrinsic factors of the individual or the restricted opportunities available both within institutions and the community.

5. There is a worldwide deficiency relating to access to healthcare provision for individuals with intellectual disabilities.

Of these only points 2-4 are potentially modifiable by adapting our practice within the primary care context.

This paper aims to help practitioners to tackle these barriers by equipping the reader with the following:

- A familiarity with the terms Intellectual Disability and Autism Spectrum Disorders
- An understanding of the physical and mental health problems commonly encountered in clinical practice
- An overview of the medical and behavioural assessments of persons with intellectual disability

OVERVIEW OF TERMS: INTELLECTUAL DISABILITY AND AUTISM SPECTRUM DISORDERS

Definition

Intellectual disability is defined by the World Health Organization (WHO) as

“a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development. Disability depends not only on a child’s health conditions or impairments but also and crucially on the extent to which environmental factors support the child’s full participation and inclusion in society.”

The use of the term intellectual disability in the context of the WHO initiative “Better health, better lives” also included both those with autism who have intellectual impairments and those who due to placement in institutions or family rejection, acquire developmental delays and psychological problems.

(Source: WHO (2010) Better health, better lives: children and young people with intellectual disabilities and their families. 26 November 2010)

(1) Intellectual Disability

Intellectual Disability is a diverse condition that encompasses a very broad range of presentations. The condition is therefore

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TABLE 1. A CLINICAL PICTURE OF ADULTS WITH INTELLECTUAL DISABILITY

Mild IQ 50-69 (85-87%) 'Equivalent' to 9 - 12 years	<u>Communication</u>: Some delay in language acquisition, most individuals are able to use speech for everyday purposes, for example to hold conversations, and to engage in the clinical interview. <u>Independent living skills</u>: Most individuals will achieve full independence in self-care (eating, washing, dressing, bowel and bladder control) and in practical and domestic skills. Main difficulties are seen in academic schoolwork, and many have particular problems in reading and writing. Potential benefit from education designed to develop their skills and compensate for their handicaps. <u>Employment</u>: Most of those with milder intellectual impairment are potentially able to maintain employment including unskilled or semi-skilled manual labour. <u>Socio-emotional</u>: There can be noticeable emotional and social immaturity, which can lead to difficulties for example inability to cope with the demands of marriage, or child-rearing, or difficulty fitting in with cultural traditions and expectations, will be apparent. Aetiology of mental retardation is more commonly unknown/idiopathic for this group this group
Moderate IQ 35-49 (6-10%) 'Equivalent' to 6 - 9 years	<u>Communication</u>: There is marked delay in developing comprehension and use of limited language. There is wide variation in language within this group, with some individuals able to participate in simple conversation and others only being able to communicate their basic needs. <u>Independent living skills</u>: There is also a delay in achievement of self-care and motor skills often requiring supervision throughout life. Completely independent living in adult life is rarely achieved. Progress in academic work is limited, but a proportion of individuals learn the basic skills needed for reading, writing, and counting. Educational programs can provide opportunities for them to develop their potential and to acquire some basic skills <u>Employment</u>: It is possible to maintain work doing simple practical work, if the tasks are carefully structured and skilled supervision is provided. <u>Socioemotional</u>: Most individuals are fully mobile and physically active and the majority show enjoy social development by developing contact with others, to communicate with others, and, engaging in simple social activities Aetiology for intellectual disability and co-morbidities become more common with increasing severity of Intellectual Disability and decreasing IQ.
Severe IQ 20-34 (3.5%) 'Equivalent' to 3 - 6 years	This category is broadly similar to that of moderate mental retardation in terms of the clinical picture. However, in addition many individuals with severe intellectual disabilities suffer from a marked degree of motor impairment or other associated deficits, indicating the presence of possible damage to, or, abnormal development of neurological system. Such individuals are usually dependent on others for all basic skills such as self-care.
Profound IQ less than 20 (1%) 'Equivalent' to below 3 years	The IQ in this category is estimated to be less than fewer than 20, which means in practice that affected individuals are severely limited in their ability to understand or comply with requests or instructions. <u>Communication</u>: Comprehension and use of language is limited to, at best, understanding basic. Most language is limited to non-verbal understanding of basic commands or making simple requests. <u>Independent living skills</u>: Individuals may be able to undertake the most basic and simple visuo-spatial skills of sorting and matching may be acquired, and the affected person may be able with appropriate supervision and guidance to take a small part in domestic and practical tasks. Most individuals are immobile or severely restricted in mobility, incontinent, often there is little or no ability to care for their own basic needs, and require constant help and supervision.
(Adapted from ICD-10 Guide for Mental Retardation 1996)	

sub-classified into Mild, Moderate, Severe and Profound severity. Adaptive function rather than IQ alone increasingly determines the severity of Intellectual Disability and this is reflected by the changes in the DSM5 6 classification system. Adaptive function refers to an individual's ability to interact with their environment independently and comprises skills such as communication, reading, writing, arithmetic, reasoning, knowledge, memory, empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships. Further to this are impairments in self-management in areas such as personal care, job responsibilities, money management, recreation, to name but a few and organizing tasks⁷. Clearly each individual with ID will present with a unique constellation of abilities and impairments. Please see table 1 for clinical picture ID.

Individuals with intellectual disabilities often show specific impairments that appear disproportionate to their overall level of functioning, for example there may be a difference between verbal and nonverbal IQ as determined by psychometric

testing. This may lead to the consideration of specific learning disabilities such as dyslexia, social communication disorders or Autistic Spectrum Disorder.

(2) Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) are classified within the DSM-5⁸. The alternative classification system, ICD-10⁹, codes these conditions under the umbrella term Pervasive Developmental Disorders and includes conditions such as Childhood Autism, Atypical Autism, and Asperger's Syndrome. At the time of publication, the systems of classification were being revised, with the forthcoming ICD-11 and the recent publication of the DSM-5. For this reason the following text will be based on DSM-5 classificatory system. The key features of ASD are: impairment of social communication and interaction, restricted, repetitive patterns of behavior, interests or activities present since early childhood and causing significant impairment in the social occupational or other important areas of functioning. Please see table 2 for the DSM-5 diagnostic criteria for ASD.

TABLE 2. DSM-5 DIAGNOSTIC CRITERIA FOR AUTISM SPECTRUM DISORDER

A Persistent deficits in communication and social interaction		B Restricted repetitive patterns of behavior, interests or activities	
Examples:		Examples:	
1. 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		1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases)	
2. Deficits in nonverbal communicative behaviors 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		2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (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).	
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers		3. 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).	
4. Hyper- or hypo reactivity 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 first present in early childhood	D Symptoms cause clinically significant impairment in social, occupational and other areas of functioning	E Impairments are not better explained by intellectual disability or global developmental delay.	

Individuals with ASD can have normal intelligence though many also have Intellectual Disability. This can present difficulties when making a diagnosis of ASD in people with Moderate to Profound Intellectual Disability, who often share many of the impairments and behaviours described in ASD, but which are also proportionate to an individual's overall level of functioning. In this case the diagnosis is less likely to be ASD.

PHYSICAL AND MENTAL HEALTH PROBLEMS COMMONLY ENCOUNTERED IN CLINICAL PRACTICE

People with Intellectual Disabilities are at elevated risk of most physical and mental health diagnoses encountered in medicine.

Common physical health co morbidities for people with ID are epilepsy with a prevalence of between 20-50%, the prevalence increases with severity of Intellectual disability, coronary Heart disease 14-20% and respiratory disease 46-52%. Furthermore there is a marked increase in sensory impairment such as hearing

impairment affects 40% of adults with ID and visual impairment is 8 times more common than in the general population. A recent Singaporean study¹⁰ of adults with ID resident in Singapore showed that among adults with ID, 15.9 % had hypertension (compared to a national average of 16.7%), 7.5% had diabetes mellitus type 2 (12.1% national average) and 17.6% (18% national average) had a history of dyslipidemia. Mental health diagnoses are similarly over-represented in people with intellectual disabilities, in particular affective disorders, schizophrenia and dementia. (See Table 3 for further details).

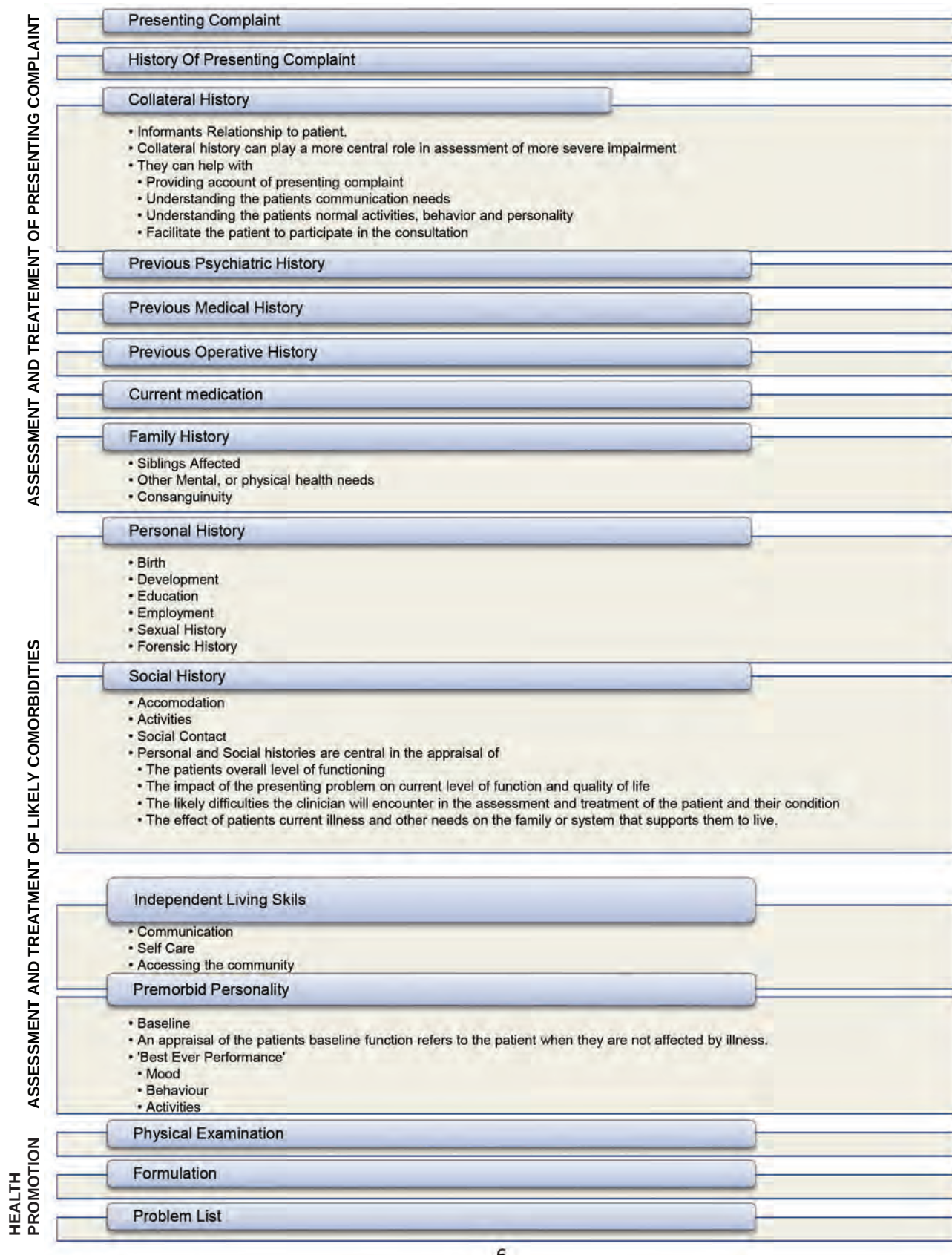
THE ASSESSMENT OF PERSONS WITH INTELLECTUAL DISABILITY (FIGURE 1)

The assessment of an individual with intellectual disability can be more complex than other assessments however the objectives of the consultation remain the same as for any other patient these are first, the assessment and treatment of the presenting complaint, second the assessment and treatment of any likely co morbidities, and thirdly health promotion¹⁵.

TABLE 3. PHYSICAL AND MENTAL HEALTH

Physical health	Wee et al 2013 (Singapore) ¹¹	Lin et al 2004 (Taiwan) ¹²	Emerson and Baines 2011 (UK) ¹³	Cooper et al 2007(UK) ¹⁴
Epilepsy		23.5		
Coronary Heart disease		7.5	14-20%,	
Respiratory disease		3.1	46-52%.	
Hearing impairment affects		8.5	40%	
Vision		16.5		
Hypertension	15.9%	0.5%		
Diabetes Mellitus type 2	7.5%			
Dyslipidemia	17.6%			
Mental health any type				40.5
Autism				7.5
Psychotic disorder		4.5		4.4
Affective disorder				6.6
Anxiety disorder				3.8
OCD				0.7
ADHD				1.5
Personality disorder				1.0
Sleep disorder				0.6

FIGURE 1. CLINICAL ASSESSMENT



The reasons for the added complexity are many and can arise from many sources, including those that are intrinsic to the individual, their physician and their environment. It is helpful to gain an understanding of these difficulties to better inform the assessment process and the consequent differential diagnosis.

The key barriers to the clinical assessment of people with Intellectual Disability were described previously by Sovner¹⁶ and elaborated upon by several other key authors. These barriers are usually described within the context of the psychiatric assessment of mental illness. Here we consider the impact of

these barriers in the family practitioner's assessment of people with Intellectual Disabilities within a primary care setting. For a more detailed description of these process see Psychiatry of Intellectual Disability: A Practical Manual ¹⁷.

(1) Communication impairment

Communication uses the combination of hearing, language, and speech in order to send, receive and understand messages. Communication in the average population occurs through five key modalities: listening, watching, speaking, reading, and writing. Among people with Intellectual disability the rate of development and final achievement levels of communication may be slower and more limited than that of the general population. Generally communication skills improve with increase in IQ. This means that individuals with mild intellectual disability may be able to understand and express themselves independently but might find difficulties understanding the written word for example. An individual with moderate Intellectual disability may have a more restricted understanding of vocabulary in both receptive and expressive language. There is also an increase in the frequency of visual and hearing impairments, as severity of intellectual disability increases, which further inhibit effective communication with people with intellectual disabilities.

Learning point: Many measures can be taken to enhance communication with people with Intellectual Disabilities. Provide written material in an accessible format using language and pictures that are appropriate to the developmental level of the individual. Frequently written information provided by drug companies for example is written in complex language format, such information is often not accessible for many adults in the population including those with intellectual disabilities.

(2) Intellectual distortion

Intellectual distortion occurs when the individual's cognitive development limits their ability to comprehend abstract concepts such as idioms. As such symptoms may be difficult to elicit because of these deficits for example when interviewing an individual about the autonomic features of anxiety idioms and phrases such as 'butterflies in the stomach', 'dry mouth' might not be understood and the patient may therefore respond inaccurately.

Learning point: Consider your patient's developmental level when assessing the patient. Is he able to comply with your instructions e.g. "point to where the pain is" An individual with severe or profound intellectual disability may not be able to localize pain, this does not mean that an individual is unable to perceive pain. Often behavioral change can be caused by physical discomfort such as toothache, earache, or constipation. As such a thorough physical examination is an indispensable part of any assessment of an individual with Intellectual Disability.

(3) Psychosocial masking

Psychosocial masking is the phenomena where by an individual's limited social experiences impact upon the content of the

symptoms that they express. This is seen frequently in psychiatric assessments, for example in mania. Mania is characterized by elevated mood and frequently associated with delusions of grandeur, within the general population a typical grandiose delusion may be that an individual believes they are a senior academic with multiple degrees. For individuals with mild intellectual disabilities delusions may appear to be subtler, for example, the belief that the individual has many friends, can drive a car or wishes to be an air-hostess. As an interviewer, it is easy to miss such symptoms of elated mood and assume that these are reasonable ambitions and beliefs.

Learning point: Difficulties differentiating between a grandiose delusion and a reasonable ambition or belief may be reduced, in part, by testing the individual's understanding of their statements and seeking a collateral history from the family to identify if these beliefs and preferences are long standing or if they are intermittent or new which would point towards the possibility of a change in mental state suggestive of mental illness.

(4) Cognitive disintegration

Cognitive disintegration refers to the impact of a decreased ability to tolerate stress, which can lead to anxiety-induced decompensation presenting as frank psychosis. This phenomenon relates to the Yerkes-Dobson observation that performance generally improves with stress until performance reaches a plateau. If stress continues to increase eventually productivity reduces precipitously and is associated with the experience of anxiety. For a more detailed description of these processes see Gentile and Gillig (2010) Psychiatry of Intellectual Disability: A Practical Manual ¹⁸.

Learning point: In people with ID it has been postulated that the threshold at which productivity declines may be lower and triggered by stressors such as a change in care giver, the death of a relative, pain, or another stressor. It is important therefore to take a thorough history that incorporates thorough consideration of socio environmental and psychological factors that could increase stress experience by an individual.

(5) Baseline exaggeration

Baseline exaggeration refers to changes in the severity or frequency of chronic maladaptive behavior associated with the onset of an illness. Many individuals with Intellectual Disabilities have behaviours that deviate from that expected of an individual without intellectual disability, for example sensory seeking behaviours such as rocking or self talking which do not indicate mental or physical illness per se. Often families will attend clinic and describe these behaviours as long standing and details about changes in these behaviours can be missed.

Learning point: A history of an increase in frequency, duration or severity of a baseline behavior can be an indication of change in mental or physical health and should be investigated.

(6) Diagnostic overshadowing

Diagnostic overshadowing is the tendency in the clinician to overlook symptoms of one disorder by attributing them to

another. This has been described in relation to the tendency to overlook symptoms of mental illness and attributing them to intellectual disability. It is possible for this phenomenon to occur in any condition and as clinicians doctors must be aware of the potential to make this kind of error and seek support from peers either through clinical supervision, support or reflective practice to minimize the risk of this type of diagnostic error.

Learning point: Consider the developmental level of the individual when examining a patient with intellectual disability.

(7) Misdiagnosis of developmentally appropriate phenomenon

Misdiagnosis of developmentally appropriate phenomenon, described by Hurley in 1996, occurs when a diagnosis is made based on behaviours that are inappropriate to an individual's chronological age but are proportionate to their cognitive ability. An example of this is the diagnosis of antisocial personality disorder in an individual with severe intellectual disability. In this scenario, diagnostic criteria for antisocial personality disorder include lack of feelings of guilt; a typically developing child acquires the cognitive ability to understand and express guilt at the age of 6 years, whereas an individual with severe intellectual disability is functioning at the age equivalent of a child between the ages of less than 6 years.

Learning point: In situations such as these, it is useful to request a detailed assessment of adaptive and intellectual function to better understand the validity of the proposed diagnoses.

(8) Suggestibility and Acquiescence

Suggestibility refers to the increased likelihood of believing another person's information and adapting behaviour

accordingly. For example, during police interrogation, an individual maybe offered a hypothetical scenario to help them explain their case better, however, the individual may then adopt the hypothetical scenario as their own thus increasing the risk of them providing an inaccurate history. Acquiescence is related to the above concepts of passing and suggestibility. It relates to the increased likelihood of providing an answer according to perceived social desirability, so called yea-saying, for example, when the doctor asks "Are you feeling better now?".

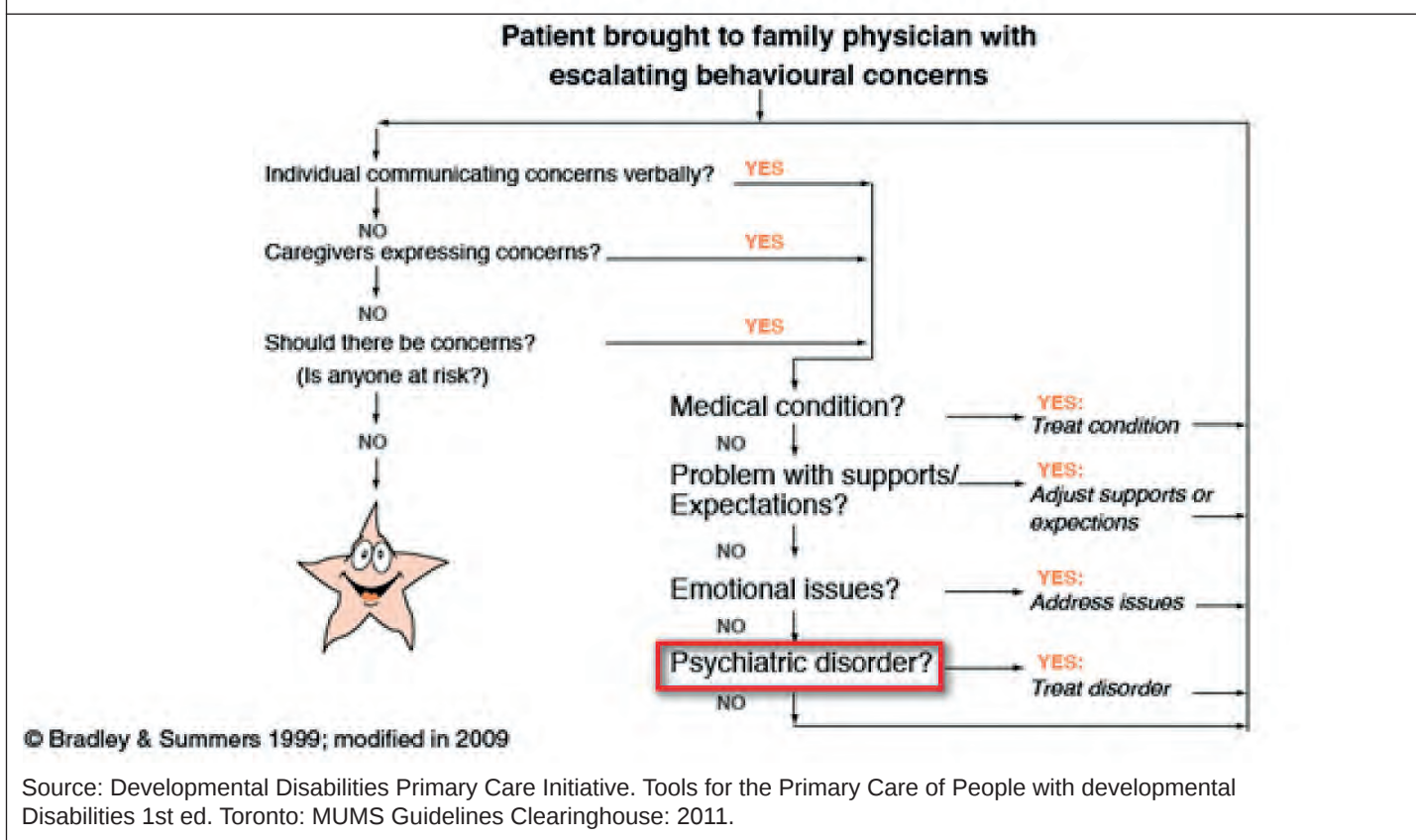
Learning point: It is difficult to assess suggestibility and acquiescence during a brief clinical interaction. 'Bedside tests' include eliciting the individual's responses to absurd statements, contradictory paired-statements and concurring paired-statements.

(9) Behavioural Correlates

Behavioural correlates are the behavioural manifestations of symptoms that the patient may or may not be able to report themselves. An example of this is dry mouth; the patient is unable to describe this symptom to the doctor, however the carer reports that the individual with ID drinks more water than previously. Another example of this is self-harm. Banging ear with fist suggests ear infection in an individual who is unable to verbalise pain.

Learning point: Be mindful that behaviours are often exhibited as a communication of an underlying physical symptom for example and individual banging his ear with his fists suggests ear infection in an individual who is unable to verbalise pain.

FIGURE 2. AN APPROACH TO A PATIENT WITH DEVELOPMENTAL DISABILITIES AND BEHAVIOURAL CONCERNS



AN APPROACH TO A PATIENT WITH DEVELOPMENTAL DISABILITIES AND BEHAVIOURAL CONCERNS (FIGURE 2)

A person with a Developmental Disability often presents to the General Practitioner with behavioural problems, such as aggressive or self-injurious behaviours. Figure 2 shows a simple approach one can take to formulate the reasons for the behavioural issues so that appropriate interventions can be carried out. Besides symptoms such as pain that may present as behavioural correlates as stated above, problem behaviours can also be brought about by a relative lack of support for the disability, such as a noisy or over-stimulating environment for someone with sensory modulation issues. In addition, people with a developmental disability are also as, or more, sensitive to the psychological impact of losses, transitional or traumatic events as people without disability, and problem behaviours can be the result of an emotional response or maladaptive coping strategies to these. For example, someone who has had a traumatic experience with being physically or sexually abused could hit out easily at people who remind him or her of the past perpetrators. Finally, problem behaviours could be a result of psychiatric comorbidities such as a psychotic disorder, anxiety or depression. Being aware of the above issues in clinical assessment could help in accurately diagnosing these, and for someone with a mild disability; it should be similar to diagnosing psychiatric conditions as in the general population. For someone with a more severe disability or if difficulties persist, it might be more helpful to seek the opinion of a psychiatrist when it comes to this stage of assessment.

CONCLUSION

This paper demonstrates that people with Intellectual disability are vulnerable to the same spectrum of physical and mental illness as the rest of the population at large. We have also seen that the way people with Intellectual Disabilities express their symptoms or manifest the signs of disease are diverse and can be atypical. This means that assessing clinicians are required to be vigilant, thorough and astute in their appraisal of patients with intellectual disabilities who present to their surgery. Working in this way practitioner will gain greater familiarity with the viewpoint of people with intellectual disabilities about their patients' own health and appraisal of quality of life. Equipped with this knowledge health care providers can maximise the individual's health and opportunities to demonstrate the many valuable contributions that this group can make to their families and our community in Singapore.

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LEARNING POINTS

- Many measures can be taken to enhance communication with people with Intellectual Disabilities by ensuring written material is presented using language and pictures that are appropriate to the developmental level of the individual.
 - Consider your patient's developmental level when assessing the patient. Is he able to comply with your instructions e.g. "point to where the pain is" An individual with severe or profound intellectual disability may not be able to localize pain, this does not mean that an individual is unable to perceive pain. Often behavioral change can be caused by physical discomfort such as toothache, earache, or constipation. As such a thorough physical examination is an indispensable part of any assessment of an individual with Intellectual Disability.
 - Difficulties differentiating between a grandiose delusion and a reasonable ambition or belief may be reduced, in part, by testing the individual's understanding of their statements and seeking a collateral history from the family to identify if these beliefs and preferences are long standing or if they are intermittent or new which would point towards the possibility of a change in mental state suggestive of mental illness.
 - In people with ID it has been postulated that the threshold at which productivity declines may be lower and triggered by stressors such as a change in care giver, the death of a relative, pain, or another stressor. It is important therefore to take a thorough history that incorporates thorough consideration of socio environmental and psychological factors that could increase stress experience by an individual.
 - A history of an increase in frequency, duration or severity of a baseline behavior can be an indication of change in mental or physical health and should be investigated.
 - Consider the developmental level of the individual when examining a patient with intellectual disability.
 - In situations where it is not clear whether antisocial behaviour is due to antisocial personality or severe intellectual disorder, it is useful to request a detailed assessment of adaptive and intellectual function to better understand the validity of the proposed diagnoses.
 - It is difficult to assess suggestibility and acquiescence during a brief clinical interaction. 'Bedside tests' include eliciting the individual's responses to absurd statements, contradictory paired-statements and concurring paired-statements.
 - Be mindful that behaviours are often exhibited as a communication of an underlying physical symptom for example an individual banging his ear with his fists suggests ear infection in an individual who is unable to verbalise pain.
-