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Persons with Intellectual Disabilities 4

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Persons with Intellectual Disabilities 4

Dr Chiang Shu Hui Grace

SFP2026; 52(2)

Intellectual disability is a development disorder that is characterised by significant limitations in intellectual functioning (learning, reasoning, problem-solving) and adaptive behaviour (social skills, conceptual skills, practical skills), which are evident in the developmental period (i.e., before the person is reaches 18 years of age). Persons with intellectual disability (PWID) usually experience health challenges and increased rates of sensory impairments, psychiatric disorders, physical disabilities, seizure disorders, and obesity.[1,2] These subsequently result in increased rates of visits to the emergency department and admissions to hospital.[3,4] To reduce such rates, PWID require improved preventive care, tailored healthcare services to meet their needs, and increased accessed to healthcare services.

Primary care physicians can play a key role in promoting the health and well-being of PWID by taking a person-centred approach to care. Primary care physicians are well-placed in the community to engage PWID and their caregivers in finding effective ways of collaborating by understanding their goals of care and values to guide healthcare decisions. They can also help to coordinate care by facilitating partnerships between PWID, caregivers, and members of the healthcare team; and monitoring the ongoing health and social needs of PWID.

Increased access to resources to improve or change conditions affecting the health status of PWID can enable them to fully engage and better integrate into society as they are not burdened with poor health. To drive this, healthcare systems must actively engage PWID and their families to improve health awareness, self-advocacy, and health literacy. Additionally, healthcare systems will also need to develop and effectively integrate networks of care amongst healthcare providers. These efforts can enable PWID and their families to take ownership of their health through better understanding and improved access to care.

This issue of the Singapore Family Physician provides an update on intellectual disabilities and how primary care physicians can better support PWID and their families.

In Unit 1, Dr Chen Shiling highlights the need for physicians to be aware of the increased complications (chronic diseases, poorer quality of life, increased morbidity, and mortality) that can occur as PWIDs age.

In Unit 2, Ms Faith Wei and Dr Tan Jian Hong provide primary care physicians with a practical framework to aid in recognising mental health conditions in PWID.

In Unit 3, Ms Deborah Quek gives primary care physicians practical tools to help bridge the communication gaps between providers and PWID during consults.

In Unit 4, Dr Vivien Lee elaborates on the importance of recognising autism and providing support for these individuals.

In Unit 5, Dr Chew Bao Li highlights reasonable adjustments that primary care physicians can adopt to better facilitate consults and provide care for PWID.

In Unit 6, Ms Joy Teo provides and overview on how primary care physicians can leverage on existing services such as the Agency for Integrated Care (AIC), SG Enable (SGE), and Family Service Centres (FSC) to better care for PWID.

In this issue, A/Prof Goh Lee Gan has also selected ten current readings on topics related to persons with intellectual disabilities.

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Distance Learning Course on "Persons with Intellectual Disabilities 4"

- Unit 1: Health and Ageing in Persons with Intellectual Disability
- Unit 2: Approach to Mental Health Conditions in Persons with Intellectual Disability
- Unit 3: Bridging Communication Gaps: Practical Tools for Everyday Consults
- Unit 4: Autism and Heath-Related Issues
- Unit 5: Reasonable Adjustments in the Clinic: What Can GPs Do?
- Unit 6: Navigating the Health and Disability Landscape Alongside Adults with Intellectual Disability: The Family Physician's Role

Unit No. 1

HEALTH AND AGEING IN PERSONS WITH INTELLECTUAL DISABILITY

Dr Chen Shiling

ABSTRACT

Persons with intellectual disability (PWID) are living longer, resulting in a growing proportion of ageing persons with intellectual disability globally. Their existing health disparities and difficulties accessing healthcare often result in poorer health outcomes, with increased morbidity and mortality. The onset of ageing, which can occur prematurely, compounds pre-existing disabilities and can lead to worsening function and quality of life. Management of life-limiting conditions also poses a unique challenge in this population with inadequate identification and treatment of palliative care needs. Addressing the needs of their caregivers is also an essential component in caring for individuals with intellectual disability, with the wellbeing of both taken into consideration when planning interventions.

Keywords: Intellectual Disability, Ageing, Health, Caregivers, Palliative, Healthcare Access, Health Disparities

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INTRODUCTION

Persons with intellectual disability (PWID) are living longer, leading to a rapidly increasing proportion of adults ageing with ID in the world.[1] This increased longevity with its accompanying needs challenges not only the individuals themselves, but also poses difficulties for their caregivers, leading to an increased demand for services that are able to address these distinct needs.[2] The care required can be particularly demanding as longevity can lead to an increase in age-related disabilities, which compound pre-existing lifelong disabilities, resulting in further challenges for this already vulnerable population.[3] Some of these age-related conditions include the development of dementia, sensory impairments, and problems with mobility.[4]

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An additional challenge is that as PWID age in family homes with ageing parents, these caregivers will have to contend with their own declining health, while coping with the increasing needs of their adult children. The holistic needs of these families ageing together will need to be taken into consideration when planning health and social interventions.

HEALTH IN PERSONS WITH INTELLECTUAL DISABILITY

PWID often face significant health disparities, with higher rates of chronic diseases while facing a number of barriers in accessing healthcare.[5] Common health conditions found in this population include epilepsy, sensory impairments, mental health conditions, gastrointestinal disorders, cardiovascular diseases, and dental issues.[6] Persons with autism spectrum disorder (ASD) also have higher prevalence of epilepsy, mental health conditions, sensory processing difficulties, and gastrointestinal conditions.[7]

There is a high prevalence of multimorbidity and polypharmacy, often defined as five or more concurrent medications, in this group compared to the general population.[4,8] Studies indicate over 20–30 percent of adults with ID experience polypharmacy, leading to increased risk of adverse drug reactions, hospitalisation, and reduced quality of life.[9] This phenomenon could be driven by high rates of multi-morbidity, complex health needs, and frequent, sometimes inappropriate, use of psychotropic medications.[10]

The barriers PWID face in accessing healthcare include lack of service provider expertise and skillsets, diagnostic overshadowing, and systematic barriers including inaccessible healthcare facilities.[11] These barriers often lend themselves to delayed or inaccurate diagnosis, leading to treatment not being instituted in a timely manner and thus negative health outcomes. This greater morbidity and mortality results in a poorer quality of life and a lower life expectancy of 15–20 years lesser than the general population.[12] These disparities are described in a review paper written by Krahn et al[13] as a "cascade of disparities" (refer to **Figure 1**).

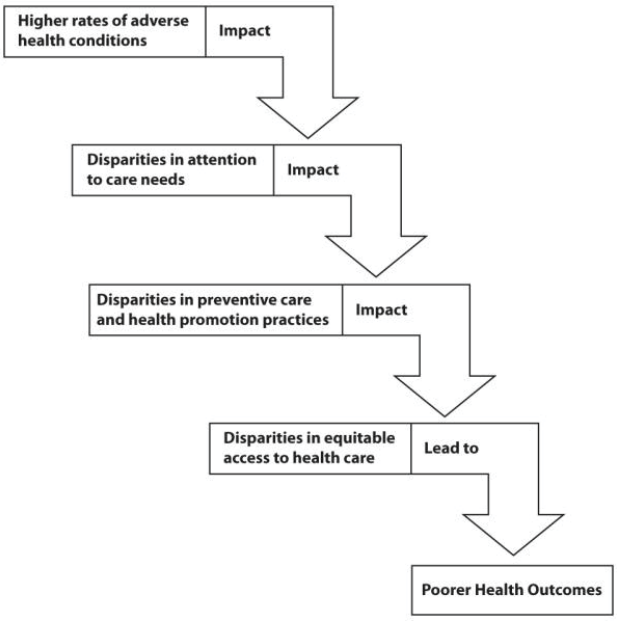

Figure 1. "Cascade of Disparities" leading to poor health outcomes in adults with intellectual disabilities (Krahn et al)[13]

Right at the top of this cascade is the observation that PWID have higher rates of adverse health conditions such as mental health conditions and neurological disorders. Some of these health issues are associated with the primary health condition, such as specific genetic syndromes, that results in the disability and cannot be prevented. Others could potentially be prevented with improved care. This distinction helps clarify existing health differences with preventable health disparities. The rest of the differences in the cascade are considered to be preventable. This could include the lack of knowledge and awareness amongst caregivers about health needs and how national health promotion programmes tend to exclude PWID.

The issues described in the cascade of disparities can also be understood alongside a concept known as the social determinants of health. It is well recognised that health outcomes are not purely determined by genetic influences and medical factors. Social determinants of health—broadly defined as the conditions in which people are born, grow, live, work, and age, and people's access to power, money, and resources—have a powerful influence on health outcomes and inequities.[14] These determinants are often grouped into core domains to inform policy and guide clinical interventions.

The Healthy People 2030 Framework has been widely adopted by the Centres for Disease Control and Prevention (CDC). It organises social determinants of health into five key domains (refer to **Figure 2**)[15]:

- **Economic Stability:** Focuses on poverty, employment status, and food security
- **Education Access and Quality:** Includes graduation rates, higher education, and early childhood development
- **Health Care Access and Quality:** Covers health insurance coverage and access to primary care and health literacy
- **Neighbourhood and Built Environment:** Includes quality of housing, access to healthy foods, water quality, and neighbourhood safety
- **Social and Community Context:** Addresses factors like social cohesion, civic participation, and experiences of discrimination or racism

Figure 2. The Healthy People 2030 SDOH Framework (Gomez et al, 2021)[15]

Applying this framework in the lives of PWID, it is evident that as a group, they face a number of negative social determinants of health. PWID are more likely to have limited education and lower incomes, and face higher risk of unemployment. Reduced social networks, poorer nutrition, and poor-quality housing also lead to negative social and living environments.[16] Negative attitudes and discrimination from society can also contribute to social exclusion and isolation, affecting both physical and mental health negatively.[17] Collectively, these problems result in inequitable access to health care, often across the life course, leading to poor health outcomes in this population group. Addressing these social determinants of health and implementing interventions to halt the cascade of disparities will be crucial to reducing inequities and improving health in PWID.

AGEING AND HEALTH IN PERSONS WITH INTELLECTUAL DISABILITY

These disparities become even more evident when PWID age. The life expectancy of PWID has increased over the years, but the concept of healthy, active ageing in this group has not been an area of focus. Common conditions experienced by the general population in ageing include

arthritis, mobility limitations, falls, sensory impairments, depression, and dementia. All these conditions are already more prevalent in PWID before the ageing process starts, but ageing can compound and complicate the pre-existing disability and health problems. For example, in an individual with cerebral palsy and ID, the mobility difficulties and visual impairment may already be present since childhood. However, with the ageing process, there could be declining balance and age-related visual problems, as well as new health conditions such as swallowing difficulties and hearing impairment. These added health issues compound pre-existing issues and therefore have a very real impact on the function and quality of life of these individuals.

Health conditions that have been extensively studied and researched in the ageing general population, such as sarcopenia and frailty, have also not received the same attention in PWID. Similar to the general elderly population, sarcopenia is a syndrome that will likely be more prominent in ageing adults with ID. Defined by declining muscle mass, muscle strength, and performance, sarcopenia has significant implications for function and disability in the general population, with its impact in PWID likely to be even more complex. Sarcopenia is also commonly described concurrently with another important geriatric syndrome, frailty. Characterised by a reduction in reserves, which in turn increases an individual's vulnerability to stressors and negative health-related outcomes, frailty is likely to hold important clinical and functional repercussions for the population of PWID as well. However, limited research has been conducted in these areas in PWID.

Once there is functional decline, rehabilitation can be more challenging as the presence of learning difficulties can make it especially difficult for PWID to compensate for worsening mobility.[18] This can lead to poorer rehabilitation results and longer recovery times, resulting in further decline, poorer psychological wellbeing, and negative quality of life outcomes.[19]

Even more concerning is that there is evidence to suggest that some of these age-related conditions occur at younger ages in PWID compared to the general population.[20] This accelerated ageing phenomenon could be driven by genetic factors, but could also be related to limited access to health services, leading to inadvertent negative health consequences and premature decline. Lifestyle and environmental factors may also contribute to this higher rate of age-related diseases and potential for secondary disability. The implication of this premature ageing phenomenon is that PWID will likely have to cope with having the challenges associated with ageing for more years of their lives compared with the general population. In the next section, we will briefly describe this in persons with Down Syndrome.

PREMATURE AGEING IN PERSONS WITH DOWN SYNDROME

Premature ageing in Down syndrome (DS) is a well-recognised phenomenon where individuals experience accelerated, age-related decline 10–20 years earlier than the general population, with a biological age reported to be approximately 19 years older than their chronological age.[21,22] A key contributing factor for this is the DYRK1A gene on chromosome 21, which individuals with DS have three copies of. This impairs DNA repair and increases cell senescence, resulting in a more rapid ageing process. Therefore, individuals with DS may present with clinical changes such as early onset cognitive decline, dermatological conditions, visual and hearing loss, endocrinological changes, as well as musculoskeletal decline.

This process may begin to become apparent in the 40s, and particularly notable is the early onset dementia of the Alzheimer's disease type. This is related to the overexpression of the APP gene, which also resides in chromosome 21, leading to the accumulation of amyloid in the brains of almost all persons with Down Syndrome by the time they are in their 40s.[23] If they live beyond age 60, the prevalence of dementia in this group has been reported to be as high as 80 percent.[24] Early cognitive changes in persons with DS bring with them numerous challenges, including diagnostic difficulties due to atypical presentations, varying baseline cognitive function, limited treatment options, and the lack of sufficient support systems customised to suit the needs of this group.

While life expectancy has increased for persons with Down Syndrome over the years, the accelerated ageing process leads to a higher burden of age-related conditions, resulting in greater morbidity. The need for increased awareness and knowledge about the health needs of this group amongst healthcare providers is evident. Together with that, there is also a clear need to develop clinical pathways for closer monitoring and timely support as individuals develop progressive health issues. Furthermore, as individuals continue to decline throughout the ageing process, conversations around end-of-life issues need to take place in a sensitive and timely manner.

PALLIATIVE CARE IN PERSONS WITH INTELLECTUAL DISABILITY

There are unique challenges faced by healthcare teams in addressing life-limiting conditions PWID and in providing quality end-of-life care for this population. Palliative care adopts a person-centred approach in supporting individuals, which involves an in-depth understanding of the individual's beliefs, values, priorities, life experiences, and preferences. This poses a distinct challenge in PWID, as their communication difficulties might result in the healthcare professional being unable to accurately gather the information they require to develop a personalised plan. This could be a particular challenge in non-verbal patients. Furthermore, PWID may encounter delayed diagnosis of life-limiting conditions due to health disparities, as well as poor identification of palliative care needs, resulting in overall underutilisation of palliative services. A scoping review looking at the barriers PWID face in accessing

palliative found that health professionals and caregivers do not recognise when it is necessary to make a referral to palliative services, and that healthcare staff need more training in pain management and anticipation of death in this group.[25]

The differing health profiles and characteristics of PWID is also a contributing factor to the suboptimal identification of needs. Studies have shown that the types of cancer more prevalent in PWID differ from the general population, showing a different profile not only in the types of cancer but also in the age at diagnosis and prognosis of the conditions. PWID have a higher prevalence of specific cancers, such as leukaemia and brain tumours, while the incidence of melanoma, prostate cancer, and breast cancer are lower compared to the general population.[26] This highlights the need for different types of screening, assessments, and interventions compared to the general population.

After diagnosis, educating individuals on their life-limiting condition(s) and the disease trajectory is key. However, this again poses challenges in this group. PWID need to be provided with accessible information to help them better understand their health conditions, and decision-making about treatment plans need to be supported. Inaccurate assumptions about the lack of capacity can lead to inadequate involvement of PWID in decision-making. As disease progresses, it is critical that individuals are supported in coping with grief and loss. This needs to be personalised and tailored to each individual. Careful ethical considerations are also crucial, as promoting the individual's autonomy must be balanced with safeguarding their best interests.

Overall, palliative care for PWID requires a tailored, person-centred approach in order to overcome significant barriers. It is also essential to remember that PWID will need to rely on their caregivers for lifelong support, and even more so as they experience declining health. This leads to more complexities in care planning and the caregivers' needs will have to be taken into consideration and attended to as well.

CAREGIVERS AND FAMILY CAREGIVING

Depending on the level of severity, PWID require assistance from their caregivers in many or all aspects of their lives. The impact of prolonged caregiving on these carers is immense and can affect their physical, mental, social, and financial health.[27] The burden of care increases as caregivers themselves age and face anticipatory anxiety over the worry of who would succeed them as carers when they are no longer able to perform the caregiver role. In the long term, this results in long periods of high carer burden, increased caregiver distress, and overall lower caregiving capacity.[28]

As PWID age, their declining function leads to this already vulnerable group becoming even more dependent and leads to even higher care burden in their families. Caregivers may then struggle to implement treatment plans for their charge, compounding the health and functional impairments found in PWID, leading to further decline in the latter's health. With an estimated 60–65 percent of adults with ID living in the community with their families, this can increase morbidity and stress for their caregivers who are ageing alongside them, and lead to premature institutionalisation.[29,30]

Overall, the phenomenon of ageing caregivers supporting their ageing children with ID in the community is one that is complex and requires intentional and specific interventions. Their health and social needs have to be assessed and addressed alongside each other, as the health and function of one will impact the other greatly. Caregivers require education, facilitation, and concrete support in order to continue caring for their adult children. However, the caregivers will themselves also require support and interventions to address their own health needs. Being able to successfully participate in activities and maintain their function is crucial for caregivers. Without such support, not only will they be unable to continue in their caregiving role, they will also suffer negative consequences themselves.

Overall, as PWID are dependent on their caregivers for their daily needs, it is imperative that healthcare professionals pay special attention to both the care recipient and the caregiver in a holistic and integrated manner. It is vital to ensure equity in accessing the required services to promote independence and positive wellbeing.

CONCLUSION

The increased longevity PWID are experiencing comes with a set of complex needs that challenges not only the individuals themselves but also poses difficulties for their caregivers and families. Existing health disparities and barriers in accessing healthcare, together with a number of negative social determinants, result in increased morbidity and mortality. Ageing and end-of-life healthcare needs are inadequately met, leading to worsening function and quality of life. Tailored and specialised assessments and interventions are required, with special focus on supported decision-making and ethical considerations. The health and social needs of ageing caregivers must also be addressed in a holistic manner, alongside that of their adult children with ID, as the care needs of both will only continue to increase. To address the complex needs of ageing PWID, it is imperative that the health and social sectors recognise the need to develop customised services, as current systems are inadequately equipped to address the unique health needs of PWID and their caregivers.

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LEARNING POINTS

- **Persons with intellectual disability face a number of health disparities and barriers accessing healthcare, leading to poorer health outcomes, morbidity, and mortality.**
- **There is a growing proportion of ageing PWID globally, with many developing ageing issues that compound on pre-existing disabilities, resulting in complex health issues and declining function.**
- **Premature ageing is a phenomenon seen in PWID, particularly in those with Down Syndrome, leading to a higher burden of age-related conditions.**
- **Palliative care needs are inadequately identified and managed in PWID due to communication limitations and insufficient skillsets in healthcare professionals.**
- **The caregivers of PWID are critical to the support of PWID. They face more challenges as they age, and will need to be supported in a holistic manner.**

Unit No. 2

APPROACH TO MENTAL HEALTH CONDITIONS IN PERSONS WITH INTELLECTUAL DISABILITY

Ms Wei Xin Yi Faith, Dr Tan Jian Hong

ABSTRACT

Persons with intellectual disability (PWID) have significantly higher rates of mental health conditions than the general population, but these conditions are frequently overlooked or misdiagnosed. Atypical presentations of mental health conditions in PWID and a lack of familiarity with needs and behaviours specific to PWID make it difficult to identify and manage these mental health conditions in this population. This paper aims to provide primary care physicians with a practical framework to identify and manage mental health conditions, particularly depressive, anxiety, and psychotic conditions, in PWID.

Keywords: Intellectual disability, Mental disorders, Depressive disorder, Anxiety disorders, Psychotic disorders

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INTRODUCTION

Persons with Intellectual Disability (PWID) are at a significantly higher risk of developing mental health conditions than neurotypical individuals.[1–3] However, mental health conditions are often underdiagnosed or misdiagnosed in PWID; one study found that 30 percent of PWID with no prior psychiatric diagnosis had an undiagnosed mental disorder.[4] A few common diagnostic challenges faced by physicians when diagnosing PWID with mental health conditions are outlined below. Refer to Psychiatric and Behavioural Disorders in Intellectual and Developmental Disabilities for a more exhaustive list.[5]

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- **Intellectual distortion.** Limited ability to understand complex or abstract questions or poor communication skills may cause PWID to give inaccurate answers to the physician's questions.[6] For example, PWID might not be able to articulate feelings of "worthlessness".

- **Diagnostic overshadowing.** Unusual behaviour in PWID might be falsely ascribed to intellectual disability instead of the co-occurring mental health condition.[7] It is important for physicians to distinguish developmentally appropriate behaviours in PWID from possible signs of a new mental disorder.

- **Atypical presentation of symptoms.** The 2025 ACE Clinical Guidelines for managing Major Depressive Disorder (MDD) and Generalised Anxiety Disorder (GAD) both acknowledge that patients with neurodevelopmental disorders might have atypical presentations of the respective conditions that may not be recognised as the symptoms stated in the DSM-5 manual.[8,9] The later sections will outline possible atypical presentations to aid physicians in better identifying such symptoms.

Even when symptoms of mental health conditions are identified in PWID, management of mental disorders in PWID is complicated by issues like medical comorbidities and caregiver burden[10,11] and must be tailored to the individual. With PWID making up an estimated 1–3 percent of Singapore's population,[12,13] general practitioners will inevitably encounter PWID in their day-to-day practice. This paper thus discusses approaches to both identifying and managing mental health conditions in PWID, with a focus on depressive, anxiety, and psychotic disorders, which are significantly more prevalent in PWID than in the general population.[1] Bipolar disorders and other neurodevelopmental disorders like ADHD are also more common in PWID,[1,14] but diagnosis and management of these conditions are beyond the scope of this article.

INITIAL ASSESSMENT OF PWID IN THE PRIMARY CARE SETTING: A GENERAL APPROACH TO PWID PRESENTING WITH BEHAVIOURAL ISSUES OR NON-SPECIFIC PHYSICAL SYMPTOMS

While behavioural issues might be the first presentation of mental disorder in PWID, a new mental health condition should not be the physician's first suspicion in PWID presenting with behavioural issues. Instead, it is important that the physician has a workflow to first consider more common causes of behavioural changes in PWID.

First, medical conditions must be ruled out. Medical conditions causing pain or discomfort, such as gastritis, constipation, or ear infections, can lead to disordered

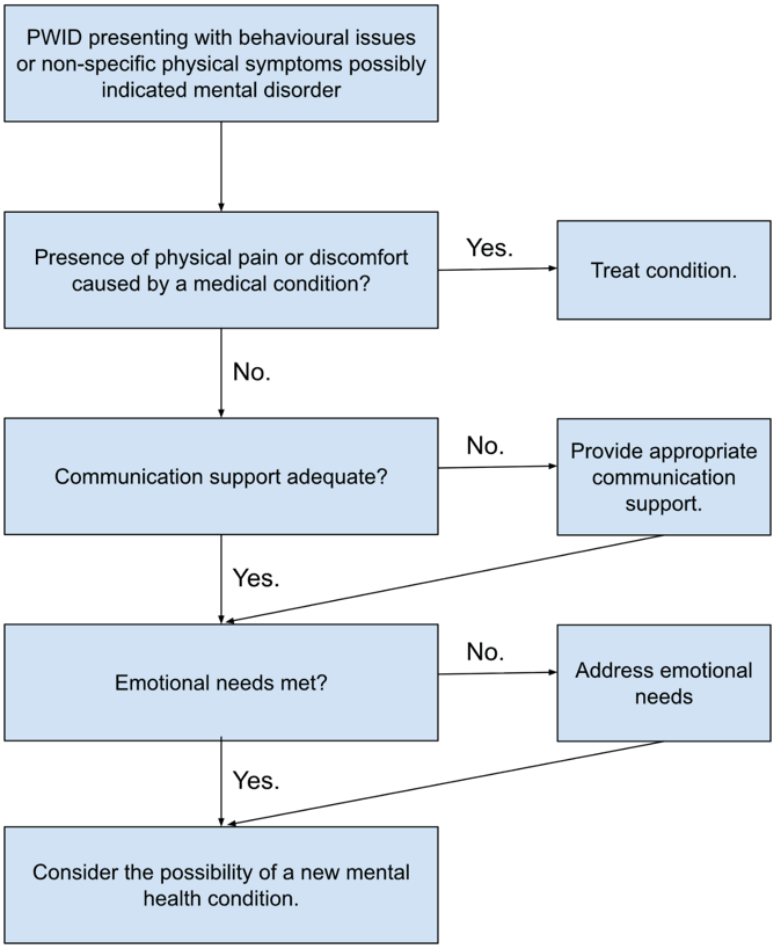
behaviour in PWID, especially in those with limited verbal communication abilities.

Second, communication support must be addressed and provided if needed. PWID who are unable to communicate their needs might resort to disordered behaviour in an attempt to communicate these needs. Hence, consider if the PWID requires communication aids like sign language, a drawing pad, or a Pictorial Exchange System (PECS).

Third, emotional needs must be considered. It is not abnormal for PWID to experience emotional distress in response to situations they encounter. It is only when the distress is persistent and results in significant functional impairment that we consider the possibility of a separate psychiatric diagnosis. Some individuals, especially those with Autism Spectrum Disorder, might have sensory modulation difficulties, leading to hypersensitivity to certain sounds, sights, or textures. Hence, it is important to consider if certain environments or situations could be causing them to feel overwhelmed, resulting in behavioural issues when they are unable to process these emotions. This is especially so when they are going through transitional periods such as moving to a new school or place of residence, or a change in caregiver like a new domestic helper. PWIDs may face greater difficulty coping with such transitions due to their disability, but can be aided by being prepared and counselled through these changes.[15]

Once all other factors have been addressed, a new underlying mental disorder can be considered. See **Figure 1**.

Figure 1. Approach to PWID presenting with behavioural issues or non-specific physical symptoms possibly indicating mental disorder



Non-specific physical symptoms, such as sleep disruption or appetite changes, might also first present in PWID with a new mental disorder. A similar principle applies; the physician must thoroughly address potential medical causes, lack of communication support, as well as sensory and emotional needs. Caregiver communication and understanding is especially important in the situation where first-presenting symptoms are reported by the caregiver and not the patient themselves, which is often the case in PWID. In such scenarios, the physician should be mindful to identify if there are any miscommunications on the caregiver's part.

IDENTIFYING DEPRESSIVE SYMPTOMS IN PWID

Depressive disorders are the most prevalent comorbid mental health conditions in PWID, with approximately 16 percent of PWID having a depressive disorder.[1] Common depressive symptoms vary in PWID based on the degree of intellectual disability (ID), as shown in **Table 1**.

Table 1. Common signs of depression in PWID by degree of ID. Adapted from *Psychiatric and Behavioural Disorders in Intellectual and Developmental Disabilities*.

Mild ID (IQ 50–69)	Moderate ID (IQ 35–49)	Severe/Profound ID (IQ <35)
• Tearfulness • Diurnal mood variation • Loss of energy • Loss of interest • Low self-esteem	• Social isolation • Weight loss • Self-injurious behaviour	• Screaming • Aggression • Self-injurious behaviour

Diagnosis of Major Depressive Disorder (MDD), the most prevalent depressive disorder, requires five out of the following nine symptoms to be present almost every day for a 2-week period, according to the DSM-5 manual.[16] However, strictly adhering to the DSM-5 description for each symptom might exclude potential cases of MDD in PWID. Common atypical presentations and possible confounding factors for each symptom listed in the DSM-5 criteria for MDD are listed below to better guide physicians in identifying symptoms of a depressive disorder in PWID.

- Depressed mood. Most common mood symptoms in PWID are reported to be sadness, irritability, and withdrawal, as opposed to solely depressed mood in neurotypical individuals.[17]
- Diminished interest or pleasure in activities. It may be helpful to find out from the caregiver what activities the patient typically enjoyed, and to note whether there was a sudden loss of interest or refusal to do such activities. This may also manifest as a lack of interest in interacting with loved ones such as trusted family members or the caregiver themselves.
- Appetite and weight changes. For an objective assessment of this symptom, it might be beneficial to ask the caregiver for serial recording of weight or diet over a determined period of time.
- Sleep disturbances. Ask caregivers for sleep patterns, including if the patient has interrupted sleep, is sleeping late, awakening early, or sleeping longer than usual. Sometimes, difficulty falling asleep in PWID might manifest as behavioural disturbances at bedtime. Hence, it is important to probe for the onset of and factors causing these bedtime behavioural disturbances and whether they are characteristic of the patient's longstanding tendencies and behaviour.
- Psychomotor agitation or retardation. New onset of behavioural symptoms such as impulsivity, tantrums, and aggression are seen significantly more in PWID with depressive disorders than in PWID without mental illness.[17]
- Fatigue or loss of energy. This might manifest as a refusal to get out of bed, or a deterioration of social and self-care skills.[18]
- Feelings of worthlessness or excessive or inappropriate guilt. PWID might express such feelings with statements like "I am bad at everything" or "nobody likes me".
- Diminished ability to think or concentrate. In PWID, this might present as a decline in adaptive functioning, or loss of previously mastered skills.[5]
- Recurrent thoughts of death, recurrent suicidal ideation, or suicide attempt. Repeated self-injurious behaviour might be seen especially in individuals with moderate to profound ID.

Use of the Glasgow Depression Scale (GDS) as a clinical tool may be useful, as it was especially developed to target unique depressive symptoms in PWID using images and language that is easily understandable.[19] In general, it is important to get a good clinical picture of the patient's baseline demeanour, functional ability, and behaviour prior to onset of their presenting symptom(s). This will help differentiate baseline exaggerations of the patient's typical tendencies from a new mental health issue.

IDENTIFYING SYMPTOMS OF ANXIETY AND STRESS-RELATED DISORDERS IN PWID

Anxiety and stress-related disorders encompass a range of conditions including generalised anxiety disorder (GAD), panic disorder, social anxiety disorder, specific phobias, and post-traumatic stress disorder. Communication difficulties, environmental factors like physical illness and abuse, and caregiver overprotection or dependence are among factors potentially contributing to the higher anxiety rates seen in PWID.[1,5]

Assessing anxiety in PWID is difficult, as PWID might not be able to accurately self-rate their anxiety or communicate subjective feelings of discomfort.[5] However, clinical tools such as the Glasgow Anxiety Scale (the equivalent of GDS for depression) may be helpful in assessing symptoms of anxiety disorders in PWID.[20]

Diagnosis of GAD, the most prevalent anxiety disorder, requires persistent and excessive anxiety for six months, together with three out of the following six symptoms present almost every day, according to the DSM-5 manual.[16] Common atypical presentations and possible confounding factors for each symptom listed in the DSM-5 criteria for GAD are listed below to better guide physicians in identifying signs of GAD in PWID.

- Feeling restless, keyed up, or on edge. If subjective reporting of restlessness by the patient is not possible, it might be more helpful to assess for physical signs of restlessness and anxiety, including excessive perspiration, teeth grinding, chewing their fingernails, or self-abusive behaviours. Other behavioural disturbances such as withdrawal, regressive or clingy behaviour, and freezing may be seen.[21]
- Being easily fatigued. In PWID, this might manifest as a refusal to get out of bed or a deterioration of social and self-care skills.[18]
- Difficulty concentrating or mind going blank. In PWID, this might present as a decline in adaptive functioning or loss of previously mastered skills.
- Irritability. Aggression and agitation, including screaming and crying unpredictably, are among the most common presentations of anxiety in PWID.[5]
- Muscle tension. Since subjective reporting of this symptom by PWID might not be possible, it might be more helpful to objectively assess physical signs of muscle tension, including an excessively upright rigid posture or tense jaw muscles.
- Sleep disturbances, including difficulty falling or staying asleep. As per questioning for sleep disturbances in MDD, ask the caregiver for sleep patterns, and find out about the progression and factors surrounding bedtime behavioural disturbances if there are any.

IDENTIFYING PSYCHOTIC SYMPTOMS IN PWID

Psychosis is a pathological mental state where there is loss of contact with reality, characterised by the presence of delusions and hallucinations, and/or disorganised thinking.[16,22] Prevalence of schizophrenia and related psychotic disorders is four to five times greater in PWID than in individuals without ID.[1,5]

Clinical features of schizophrenia spectrum disorders include positive symptoms, such as formal thought disorders and auditory hallucinations, and negative symptoms, such as apathy, social withdrawal, and anhedonia. PWID with schizophrenia spectrum disorders were found to have more prominent observable signs, more negative symptoms, and a greater degree of functional impairment compared to those without ID.[5] Positive symptoms can be difficult to identify in patients with significant impairments in communication, as they often present as behavioural changes rather than being verbally articulated. Caregivers may notice a distinct, bizarre change in their behaviour from baseline that is persistent and cannot be explained by other factors. A description of common psychotic symptoms and the associated behavioural changes in PWID with schizophrenia spectrum disorders are outlined below.

- Auditory hallucinations. In PWID, this might manifest as shouting or talking to an imaginary friend.
- Delusions of control or passivity experiences. In neurotypical individuals, patients often express beliefs that their actions, emotions, or sensations are being controlled by external forces. In PWID, these might manifest as sudden behavioural changes that the individual may claim is caused by external influence.
- Delusional perceptions. In PWID, look out for suspiciousness that is uncharacteristic of the patient's usual personality.
- Thought echo. Repetitive speech or self-talk might be a demonstration that the individual's thoughts are being repeated or echoed.[23]
- Thought insertion and thought broadcasting. These respectively refer to feelings that thoughts are being put into or taken out of their mind. These might be harder to elicit through nonverbal cues, but may be inferred from statements or behaviour suggesting that thoughts are not their own or are being accessed by others.[23]
- Formal thought disorders (including disorganised speech, loosening of associations, tangentiality, and incoherence). These might manifest as illogical connections between ideas, or speech that is haphazard and difficult to follow. These may be easily mistaken for baseline intellectual impairment if not carefully assessed.[24]
- Disorganised behaviour. This might be difficult to distinguish from behavioural disturbances commonly caused by other factors in PWID, such as communication difficulties or mood disturbances. These other factors should be thoroughly explored before being attributed to psychosis.
- Negative symptoms. Look out for sudden social withdrawal, loss of motivation to participate in previously enjoyed activities, and blunted affect. These should be distinguished from baseline intellectual disability by exploring the patient's baseline level of social interaction and typical engagement in activities they enjoy.

MANAGEMENT OF KNOWN MENTAL HEALTH CONDITIONS IN PWID

For PWID with identified mental health conditions, management is not drastically different from that of neurotypical individuals, but additional factors must be considered and addressed.

In general, for any PWID with mental health conditions, social stressors and exposure to stressful events significantly influence mental health outcomes in PWID and should be addressed.[25] Pharmacological treatment, if any, should be given as part of a comprehensive biopsychosocial

management plan and not in isolation. Caregiver support should also be addressed, as caregiver stress is common in those looking after PWID with challenging behaviour, which is common especially in PWID with psychiatric comorbidities.[25,26] The physician should look out for signs of caregiver stress, such as fatigue, sleep disturbances, and social isolation, and refer caregivers to appropriate support services if necessary. Some such services include professional counselling, community support groups (e.g., Caring SG, Caregiver Alliance), or referral to a social worker for financial support.

More specific details regarding managing depressive, anxiety, and schizophrenia spectrum disorders are highlighted in the next section.

MANAGING PWID WITH DEPRESSIVE AND ANXIETY DISORDERS

Non-pharmacological treatment such as Cognitive Behavioural Therapy (CBT) is recommended for depressive and anxiety disorders, especially in individuals with mild ID, but requires adaptations for ID such as using visual aids, simplified language, and smaller groups.[27,28] While evidence on its efficacy in individuals with severe to profound ID is limited, the primary care physician can consider making referrals to appropriate therapists for patients with mild ID before considering use of pharmacological therapy, or as a supplement to pharmacological therapy.

Principles for prescribing pharmacological therapy in PWID is similar to general population guidelines; first-line pharmacological agents for both depression and anxiety are selective serotonin reuptake inhibitors (SSRIs) and serotonin-noradrenaline reuptake inhibitors (SNRIs).[29,30] Sertraline, escitalopram, and fluoxetine are common drugs of choice, but there is no clear evidence indicating superiority of any one drug among the SSRIs and SNRIs; drug selection should be tailored to the patient based on drug interactions, side effects, and prior treatment response.[28,29] As PWID are more sensitive to side effects of psychotropics,[31] antidepressants should be started on low doses, with slow titration and close monitoring for efficacy and side effects. Beta blockers may be considered for anxiety, but there is no direct evidence for its use specifically in PWID. In general, regular and long-term use of benzodiazepines is not recommended due to the increased risk of behavioural disinhibition in PWID.[32,33]

MANAGING PWID WITH PSYCHOTIC SYMPTOMS

For PWID with new signs of psychosis identified, specialist referral to the Adult Neurodevelopmental Service (ANDS) at the Institute of Mental Health (IMH) is warranted for assessment and management.

PWID have been shown to be more sensitive to the side effects of psychotropics like antipsychotics.[31,34] In patients already on antipsychotics prescribed by a specialist, the primary care physician should be mindful to monitor for any extrapyramidal side effects, metabolic disturbances, and excessive sedation during the clinical encounter that may warrant dose adjustments.

CONCLUSION

Mental health conditions are prevalent in persons with Intellectual Disability (PWID), but often present atypically due to impairments in communication and functional abilities, leading to underdiagnoses and misdiagnoses. A structured approach to assessing PWID, including excluding medical causes, ensuring adequate communication support, and addressing emotional and environmental stressors is important and can help to reduce misdiagnoses. Recognising atypical presentations of depressive, anxiety, and psychotic disorders in PWID is essential in preventing diagnostic overshadowing and enabling PWID to receive timely intervention. The management of mental health conditions in PWID involves a biopsychosocial approach and largely mirrors that of the general population, but requires careful individualisation, including adapted psychological interventions and caregiver support.

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LEARNING POINTS

- **Mental health conditions in persons with Intellectual Disability (PWID) are prevalent but often have atypical presentations.**
- **A comprehensive assessment of PWID presenting with behavioural concerns or non-specific physical symptoms is important, and should exclude medical causes, provide adequate communication and emotional support, and consider the possibility of atypical presentations of mental health conditions.**
- **Management of PWID with mental health conditions involves a biopsychosocial approach and requires careful individualisation and caregiver support.**

Unit No. 3

BRIDGING COMMUNICATION GAPS: PRACTICAL TOOLS FOR EVERYDAY CONSULTS

Ms Deborah Quek

ABSTRACT

Persons with intellectual disability (PWID) have significantly higher rates of mental health conditions than the general population, but these conditions are frequently overlooked or misdiagnosed. Atypical presentations of mental health conditions in PWID and a lack of familiarity with needs and behaviours specific to PWID make it difficult to identify and manage these mental health conditions in this population. This paper aims to provide primary care physicians with a practical framework to identify and manage mental health conditions, particularly depressive, anxiety, and psychotic conditions, in PWID.

Keywords: Person-centred care, Intellectual disability, Clinical communication, Autonomic regulation, Primary care

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INTRODUCTION

What makes good communication? Most of us communicate effortlessly, without pausing to consider how these skills developed. For many clinicians, communication feels intuitive rather than taught. It would be unnecessary to persuade physicians that effective communication underpins good clinical care, and that the ability to elicit symptoms, explain management plans, and support treatment adherence is foundational. Yet the persistent communication gaps experienced by persons with intellectual disabilities (PWID) suggest that there is still room to build on what we already know, particularly in ways that are practical, efficient, and compatible with busy consultation rooms.

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Person-centred care demands that we see the individual before the diagnosis. In person-centred care, patients are viewed as contributors to their own health, with support calibrated to their abilities rather than being reduced to assumptions about incapacity.[1] For PWID who cannot independently assume this role, relational networks such as families, caregivers, and advocates become essential conduits of agency. This recognises patients as active partners with capabilities, preferences, and potential, rather than passive recipients of care.[1] Reviewing our attitudes towards our communication abilities and that of others becomes essential when practising person-centred care, and anchors the way we approach vulnerable and marginalised populations who face genuine barriers in their language ability that impact their understanding and expression. Some clinicians are skilled communicators, while some overestimate their ability to communicate.[2] Patients do not doubt their clinician's competency; however, poor communication can impact patient satisfaction and health outcomes.[2,3] Recognising that everyone has their own preferred style of communication, combined with personality differences calls for continued reflection and development of communication skills.[4]

THE NEED TO DEVELOP NUANCED COMMUNICATION PROFILES FOR PATIENTS

Does everyone have the right to communicate? If our answer is a resounding yes, then it is crucial to adopt and apply appropriate interventions and accommodations according to a patient's ability, instead of generalising communication profiles.

Common practice sees labels such as "verbal/non-verbal". Many patients are willing and eager to participate in managing their health when their abilities are recognised and supported.[1,5] Individuals with similar intellectual disability (ID) diagnoses may present with vastly different communication profiles. One person may speak fluently yet struggle with comprehension, while another may speak minimally, but is able to demonstrate adequate understanding when supported appropriately with visual supports. It would be wrong to make assumptions about an individual's ability to understand information simply based on their ability to read, as much as it is wrong to assume that compliance equates to understanding without considering the contextual clues that aid understanding.[5] These differences matter, and it also means that loosely generalising patients into broadly defined groups (verbal vs non-verbal, literate vs illiterate) does a disservice to our clinical practice. Adopting more precise descriptors of language helps shape the impressions that the entire healthcare team supporting the patient might have, resulting in less assumptions and more seamless care.

To integrate communication meaningfully into care, we must first clarify what communication actually is in the context of intellectual disability. Communication is often treated as: 1) a tool which clinicians already have, or 2) a problem located in the patient.

In reality, communication is a shared system. For the general population, it can be easily assumed that talking is communicating, but communication extends beyond verbal speech alone. It is a process of information exchange, and encompasses the speech and language systems that enable this process.[6] Information can be exchanged through verbal, non-verbal, visual, and contextual information. Language acquisition often unfolds through a complex interplay of biology, environment, and social interaction, long before we ever need to name it.[6] In the world of Speech and Language Pathology, the rules of language look at its form (syntax, morphology, and phonology), content (semantics), and use (pragmatics).[6] Speech involves the motor production of sounds, which includes taking into consideration the articulation of speech sounds and phonological processes that allow effective combination of these speech sounds to form words.[6] A PWID struggles with communication because the complex cognitive abilities required for speech and language do not develop along the same trajectory or speed. Naturally, their communication competency hits a ceiling. But how will they learn if they are not taught?

"When one communication partner has difficulty understanding, processing, or expressing information, the clinician assumes a greater role in shaping the interaction so that communication can succeed".[5] A person's right for bodily autonomy, making decisions about their own health, and ensuring they are set up for success in communication has to be regarded as essential when we talk about person-centred care.[1] As advocates for greater dignity for PWID, it is our responsibility to not use infantilising language, or speak as if they are not there.

COMMUNICATION AS A CULTURAL ACT

Communication is not only a clinical skill; it is a cultural act. The way we communicate, and how much we value communication, is deeply shaped by our worldview. In many East Asian cultural contexts, individuals are often understood through a relational lens rather than as fully independent actors.[7] Cultural values such as reciprocity, kinship, hierarchy, respect, and social obligation are strongly emphasised.[7,8] As a result, a person's sense of self and decision-making is commonly shaped by social roles, relationships, and shared norms, rather than by individual beliefs or preferences alone.[7] Practising physicians and caregivers with an Asian-centric worldview may value harmony and respect, and this may play out in communication being more indirect, with an emphasis on maintaining peace.[7] When communication is viewed primarily through a cultural lens of respect, restraint, or hierarchy, the focus of having PWIDs engage in autonomous communication is reduced; caregivers may default to the physician's recommendations more easily, and physicians may also unintentionally deprioritise the need for expressive tools or supported decision-making systems.[7,8]

This turns into a systemic issue. The lack of emphasis on the need for effective communication with PWID means reduced accessible communication pathways in healthcare, which further reinforces learned passivity for the PWID. The table below sets out how different cultural contexts may shape communication patterns between doctor-patient-caregiver based on existing research,[2,3,7,8] and how it can play out in the Singaporean context.

	Western-centric orientation	Asian-centric orientation	Clinical consequence in the Singaporean context
Value placed on self-expression	Expression is equated with authenticity and agency. Speaking up signals empowerment	Harmony and respect often valued over overt expression. Speaking less = maturity/ restraint	Patients or caregivers might not voice confusion, pain, or disagreement, resulting in underreported symptoms and undetected illnesses
Doctor-patient relationship	Partnership model: values patient autonomy and shared decision-making	Hierarchical: physician as authority, patient as deferential	Patients might avoid questioning instructions; doctors might underestimate comprehension needs
Family roles in communication	Emphasis on the individual's voice and choice	Emphasis on collective harmony and family decision-making	Family might mediate or override patient's preferences; direct patient engagement reduced
Communication goals in disability	Focus on independence and self-advocacy	Focus on compliance, politeness, and maintaining order	Less emphasis on functional communication systems (AAC, communication boards), especially for adults

HOW YOU SAY *WHAT* YOU SAY MATTERS

Health, when viewed through the bio-psycho-social ("BPS") lens, is familiar to family physicians, but in this framework, where does communication lie? I would argue that it sits at the intersection of an individual's biological capacity, psychological state, social context, and sensory experience. Our ability to receive information, process it, and plan a response is influenced by factors like the ability to sustain attention, discriminate input, and meaningfully organise it before formulating the motor plan needed for speech or action.[6] Speech and Language Therapists working with adults with intellectual disability often find that the golden window for learning during the early intervention stage has passed, and so teaching someone how to communicate is significantly more challenging. Despite its centrality, communication is rarely made explicit in the BPS model. It is often treated as a soft skill rather than an essential component of maintaining good health.

Language processing is highly sensitive to autonomic activation.[9] In states of heightened arousal, access to receptive and expressive language narrows, and communicative behaviours may replace verbal speech. Instead of using words to express their emotions, a PWID, when deeply frightened, may begin shouting with a loud voice. When angry, he might hit the person closest to him. The clinician should acknowledge that the individual's shouting and hitting is a form of communication, except that it is non-verbal. Therefore, the clinician should be careful not to suppress the PWID's attempts at communication, but instead employ strategies to facilitate the PWID's communication in a constructive manner. The ability to attune well ought to therefore precede information exchange. Clinically, this involves modulating pace, prosody, and verbal density, and employing strategies such as slowed speech, keyword stress, reduced utterance length, and visual referencing. These adjustments function to lower cognitive demand and facilitate social engagement.

ATTUNEMENT: REGULATION AS A PREREQUISITE FOR LANGUAGE

For Speech-Language Pathologists (SLPs), nothing is more gratifying than sharing strategies that are both effective and feasible in real clinical contexts. While SLPs often rely on visual tools and augmentative and alternative communication (AAC) systems, not every encounter allows for additional materials or set-up. The most readily available (and often most powerful) tool remains the clinician themselves. Due to the relationship between communication, behaviour, and sensory processing, there have been studies exploring attunement in providing embodied, empathetic care that positively influences behaviours and communicates beyond what verbal speech can.[10–13] From a neurological perspective, attunement looks at the alignment between internal neurological rhythms and external environmental rhythms in a way that can allow for smooth interactions.[10] Attuning between two parties, therefore, describes the mechanisms that allow for emotional and behavioural alignment that brings about mutual understanding.[11,12] A doctor's visit can be a stressful event. When stress, sensory overload, or cognitive demand overwhelms a person's capacity, non-verbal behaviours often become the most accessible form of communication. This is also why we commonly hear the phrase "behaviour as communication".

Research on affective communication highlights that meaning is conveyed not only through words, but through tone, facial expression, pacing, and body posture—particularly when emotional content is involved or when verbal comprehension is limited.[14] Psychologist Albert Mehrabian's work demonstrated that in emotionally-laden interactions, listeners rely heavily on non-verbal and paralinguistic cues to interpret intent when spoken words and delivery do not align.[14] While words are only 7 percent helpful, non-verbal body language can be up to 55 percent helpful.[14] Although this does not apply to all forms of communication, it is highly relevant in clinical encounters where anxiety, uncertainty, or cognitive load is elevated. Sometimes, less is more.

From a pragmatic language perspective, these elements—eye contact, prosody, timing, and physical orientation—are integral to how messages are received. Allied health therapy approaches such as Intensive Interaction, DIR Floortime, and neurodevelopmental therapy (NDT) similarly emphasise attunement: the process of matching a person's emotional state, energy, and pace in order to establish safety and connection. When clinicians attune effectively, they can reduce threat, build rapport rapidly, and create conditions that support engagement and understanding, even within brief consultations.

FUNCTION OVER FORM: HOW WE DESCRIBE WHAT WE SEE/HEAR

When the PWID is in a state of regulation, their communicative acts can then be interpreted more accurately by examining their function rather than their surface presentation. Repetition, intonation, and context provide essential information about whether an utterance serves to request, resist, regulate, or share. However, what they say might not necessarily represent what they mean.

Patrick (not his real name) is an adult with Mild-Moderate ID who is able to read the Bible independently, complete with hand gestures and rising intonation to stress on important points. Yet, when asked comprehension questions about what he just read, he is unable to give a reply. Would you then say he is verbal or non-verbal? Similarly, Eleanor (not her real name) is an autistic adult with Mild ID whose communication profile is characterised by verbal speech at phrasal/sentence level, but frequently uses scripts and echolalia to respond. When asked if she would like to engage in an activity, she would respond saying "No, I'm sorry Deborah, but …" or "Yes, would you like to build a campfire?". Imagine if you were trying to elicit consent for a medical procedure (like blood taking, or to conduct

a body examination), how would you know what she means? Through careful observation, data collection and analysing patterns in her responses, it was found that her understanding of responding positively was modelled or imitated from watching cartoons that she enjoyed. Saying "No, sorry Deborah but…" was consistent across multiple requests to indicate refusal.

When individuals are labelled simply as verbal or non-verbal, there is a risk that communicative intent might be misinterpreted, leading to misinformed clinical decisions. Clinical documentation should therefore move beyond whether a person can speak, or how much they speak, to consider what is communicated, in what contexts, and with what consistency. Attention should be paid to the use of scripted or echolalic responses, and to whether these communicative acts reliably convey intention and consent. Importantly, such observations do not require specialist assessment and can be gathered within routine doctor-patient-caregiver consultations. Where communication patterns remain unclear or complex, referral for formal speech and language assessment can then be considered. Non-verbal communication and body language are equally valid sources of meaning, but their interpretation should be consulted with caregiver input, given their deeper familiarity with the individual's typical communication patterns.

AUGMENT: SCAFFOLDING ACCESS UNDER LOAD

When verbal language alone is insufficient, augmentative supports provide an external scaffold for meaning-making. Visual tools reduce reliance on internal working memory and abstract reasoning, allowing individuals to engage despite cognitive or emotional strain. These supports need not be complex; their effectiveness lies in immediacy, relevance, and familiarity.[15] In the clinic room, the use of pictures and videos can be quickly looked up online, with the latter being more effective in increasing understanding.[16] In situations where the use of digital media is not accessible, a clinician can employ the use of line drawings/symbols or commonly used signs/gestures to support understanding.

CONCLUSION

Improving communication with persons with intellectual disabilities does not mean avoiding accommodations, nor does it require complex or time-intensive interventions. Rather, it calls for mindful, proportionate adaptations that are feasible in everyday primary care, and for recognising communication as a shared system in which the clinician plays an active role.

This paper highlights how culture, assumptions and imprecise labels about "communication ability" can obscure a patient's functional capacity, resulting in mismatched expectations and reduced participation. Situated within the bio-psycho-social framework, communication access is shown to be shaped by autonomic state, sensory load, relational context, and cultural expectations—not cognition alone.

For physicians working with PWID, attunement is therefore a foundational clinical competency. Regulation precedes language, and small adjustments in pace, verbal density, prosody, and visual support can meaningfully improve engagement without compromising efficiency. Ultimately, effective communication with PWID is not about doing more, but about doing differently to support dignifying person-centred care within everyday consultations.

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LEARNING POINTS

- **Communication in PWID is a shared clinical process, not a fixed patient attribute. Functional communication is shaped by cognitive capacity, autonomic regulation, sensory load, social context, and cultural expectations, and should not be inferred from labels such as "verbal" or "non-verbal".**
- **Attunement is a core clinical competency that precedes effective information exchange. A clinician's tone, pacing, prosody, and non-verbal behaviours influence autonomic regulation and directly affect a patient's capacity to understand and respond, especially under stress.**
- **Practical communication accommodations can be embedded into routine consultations. Simple adaptations—such as slowing speech, reducing verbal density, stressing key words, and using basic visual or contextual supports—can improve engagement and comprehension without increasing consultation time.**

Unit No. 4

AUTISM AND HEALTH-RELATED ISSUES

Dr Vivien Lee

ABSTRACT

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition, yet research and services have historically focused on childhood, with limited attention to middle and older adulthood. As autism prevalence rises and populations age, there is an urgent need to understand health-related outcomes and ageing trajectories among autistic adults. This article aims to synthesise current evidence on biopsychosocial health issues faced by autistic adults. Building on existing reviews, the literature was synthesised using Fernández-Ballesteros' four-domain model of ageing well: (1) health and activities of daily living, (2) cognitive and physical functioning, (3) positive affect and control, and (4) social participation. International evidence was integrated with available regional and Singapore-specific data where possible. Findings indicate that outcomes in autistic older adults are generally poor, marked by increased medical conditions, low adaptive skills, elevated risk of cognitive decline, high rates of mental health conditions, reduced social or community participation, and low quality of life. In Singapore, improved autism screening and diagnosis in childhood and rapid population ageing highlight the need for autism-informed healthcare, integrated social support systems, and longitudinal research focused on ageing outcomes in autism. Addressing these gaps is essential in promoting equitable and person-centred ageing well for autistic individuals across their lifespan.

Keywords: Persons with Intellectual and Developmental Disability, Autism Spectrum Disorder, Health

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INTRODUCTION

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition that emerges in early childhood and persists through adulthood.[1] Globally, autism prevalence has increased substantially over the past two decades, reflecting changes in diagnostic criteria, improved awareness, and expanded screening practices rather than a single causal factor. In the United States, current estimates indicate that 1 in 31 children is diagnosed with autism, compared with 1 in 150 eight-year-olds in 2000.[2–4] Similar upward trends have been observed internationally, including in Asia-Pacific regions with high socio-demographic indices.[5–7]

In Singapore, population-based and screening studies suggest that over 1 in 100 children meet the criteria for autism, with detection occurring at increasingly younger ages due to strengthened developmental surveillance and early screening initiatives.[8] However, as in many Asian societies, autism prevalence among adults—particularly middle-aged and older adults—remains poorly characterised. This is partly due to historical underdiagnosis, stigma, and limited access to diagnostic services during earlier decades.

Based on early prevalence estimates in the United States, hundreds of thousands of autistic adults are expected to enter their thirties in the coming years,[9] with many additional individuals remaining undiagnosed or receiving diagnoses only in adulthood.[10] Comparable "lost generations" of autistic adults likely exist in Singapore and across Asia, where diagnostic frameworks and autism-specific services were introduced later and unevenly across populations.

A recent meta-analysis of longitudinal outcome studies found that approximately half of autistic adults experienced poor outcomes in adulthood, measured using objective indicators such as employment, social relationships, and independent living.[11] Predictors of poorer outcomes included lower intellectual functioning, diagnostic subtype, and earlier diagnostic era, reflecting cohort effects linked to historical access to services.[11,12] While outcomes research has expanded, relatively little attention has been paid to what constitutes positive or successful ageing in autism, particularly outside Western contexts.

Using Rowe and Kahn's model of successful ageing,[13] only 3.3 percent of autistic adults aged 40 years and older in the Australian Longitudinal Study of Adults with Autism met criteria for successful ageing, despite relatively high cognitive abilities and later diagnoses.[14] These findings underscore the importance of examining autism through a lifespan and ageing framework, particularly as early intervention services were unavailable to many older autistic adults. In Singapore, structured early intervention programmes became widely accessible only in the early 2000s,[15] suggesting similar cohort effects to those observed internationally.

Health economists have highlighted the high financial costs, predicting that annual medical and nonmedical costs of ASD in the United States will be $268 billion for 2015 and $461 billion for 2025.[16] Much of this expenditure is for adults, largely because of the costs of medical care, residential or supported living accommodation, and productivity loss, by both caregivers and individuals. This is supported by data in

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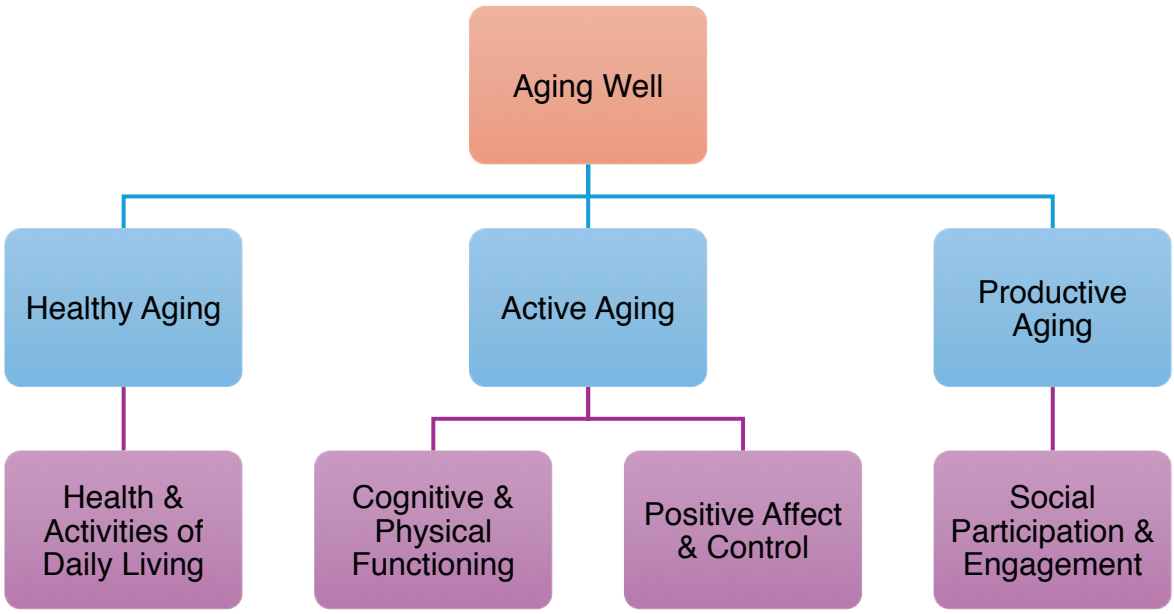
China where the lifetime cost for an individual with ASD in China was $2.65 million for those without intellectual disability (ID) and almost double at $4.61 million for those with ID. Over a lifetime, the total annual costs for middle aged and elderly (>42 years) were highest, followed by transitional adults (18–29 years) and preschoolers, both for individuals with or without ID.[17]

Over the past 80 years, changing diagnostic boundaries, increased awareness, and evolving service systems have resulted in autistic adult cohorts with diverse life experiences.[18] These cohort effects are amplified by the presence of adults who meet current the DSM-5 criteria but were never formally identified earlier in life.[10] As a result, there remains a critical gap in understanding autism in middle and older adulthood, particularly in Asian populations.

Building on prior reviews,[19–21] this narrative review applies a multidimensional model of ageing well to synthesise evidence on health-related outcomes in autistic adults, with particular attention to Singapore and Asia where possible. Using Fernández-Ballesteros' four-domain framework (refer to **Figure 1**)—health and activities of daily living; cognitive and physical functioning; positive affect and control; and social participation—this review highlights health disparities, service implications, and priorities for future research in ageing autistic populations.

Figure 1. Fernández-Ballesteros' four-domain framework on Successful Ageing (Adapted from Klein et al 2024)[68]



1. HEALTH AND ACTIVITIES OF DAILY LIVING

The World Health Organisation defines healthy ageing as the process of developing and maintaining the functional ability that enables wellbeing in older age. Functional ability is about having the capabilities that enable all people to be and do what they have reason to value.[22] In the general population, physical health strongly predicts functional independence among older adults,[23,24] a relationship that appears particularly salient in autistic populations.

Medical Comorbidities

Autistic adults are at higher risk of premature mortality than non-autistic individuals. Chronic physical health conditions are associated with premature mortality for autistic adults.[14,20,25]

International evidence consistently demonstrates that autistic adults experience higher rates of chronic medical conditions than non-autistic adults across their lifespan. Large healthcare-based studies from the United States and United Kingdom show elevated prevalence of physical health conditions across multiple systems: neurological disorders (e.g., epilepsy, cerebrovascular disease, cognitive disorders, Parkinson's disease),[26–29] cardiovascular diseases (obesity, hyperlipidaemia, hypertension, diabetes),[26–30] gastrointestinal disorders,[26–29] respiratory diseases (asthma, chronic obstructive pulmonary disease),[30] and sleep disturbances [26,27,29] among autistic adults.

Autistic adults with co-occurring intellectual disability (ID) appear to have similar high comorbidity burden as well,[29] with gastrointestinal disorders and neurological disorders being the most common.[31]

Comparable population-level healthcare data are not available in Singapore. Local clinical practice guidelines for autistic children list several common co-occurring conditions in autistic children, which include dental disorders, epilepsy, gastrointestinal disorders (e.g., constipation, reflux disease), hearing and visual impairment, obesity, and sleep disorders.[32]

Preliminary evidence also suggests that autistic females report lower rates of menopausal symptoms compared with the general population, potentially reflecting under-recognition rather than true biological differences.[33] This is important to note as the reported rate of co-occurring health conditions can be much lower in studies due to barriers to healthcare access.

Potential contributors to this increased health burden in autistic adults include genetic predisposition,[34] lifestyle factors (diet, sleep, physical activity),[35] barriers to healthcare including preventive and emergency services,[36,37] sensory and communication challenges in medical settings,[36,37] and long-term psychotropic medication use.[38]

Functional Independence

Quality of life is associated with daily living skills, especially functional independence. Autistic adults often demonstrate lower adaptive functioning relative to peers with similar age or cognitive levels,[39,40] with skills remaining stable or improving only slowly across adulthood.[41,42] Difficulties in executive function, which are common in autism spectrum disorder,[43,44] may further compromise skills required for daily living as age-related cognitive changes emerge. It has been reported that a significant proportion of older adults with autism, especially those with co-occurring ID, require some assistance with activities of daily living.[45] This reflects a growing area of societal burden with increasing numbers of ageing autistic individuals. A local qualitative study highlights concerns of caregivers of autistic adults on declining independence, future care arrangements, and limited age-appropriate care services.[46]

2. COGNITIVE AND PHYSICAL FUNCTIONING

Cognitive and physical functioning are central components of ageing well, encompassing the maintenance of cognitive abilities and the capacity to compensate for age-related changes.[47] In the general population, modifiable risk factors for cognitive decline include depression, low social engagement, physical inactivity, and certain medications.[48–50] As described below, risk factors like depression and low social participation are even more prevalent in autistic populations.[53]

Risk of Early Cognitive Decline and Dementia

Emerging evidence suggests that autistic adults may be at increased risk of early cognitive decline and dementia, including earlier onset relative to the general population, particularly those with co-occurring ID.[51] Adjusted risk for early-onset dementia was about 2.6 times higher in autistic adults compared to general population under 65.[51] This risk of dementia increases with age. The adjusted odds of having dementia was much higher at 18.8 in older autistic adults above 65.[52] Self-report studies of middle-aged and older autistic adults without ID also reveal high rates of perceived cognitive decline, often associated with higher autistic traits and depressive symptoms.[53]

Although Singapore lacks population-level data on dementia in autistic adults, national dementia prevalence is rising with an ageing population, raising concerns that autistic adults may represent an under-recognised high-risk group. Diagnostic overshadowing and limited autism-informed geriatric services may further delay recognition.

Neurological Conditions Affecting Physical Functioning

Besides dementia and cognitive impairment, autistic adults also appear to have elevated risk of neurological conditions associated with ageing, including Parkinson's disease and parkinsonism. Studies across the US and Europe report significantly higher prevalence than in the general population, with evidence of earlier onset.[26,27,54] In a Swedish cohort study involving more than 2 million individuals, it was found that the adjusted risk for Parkinson's disease was about 4.4 times higher in autistic adults.[54] While the use of antipsychotic medications and resultant side effects might partially explain this risk, findings suggest that increased vulnerability can be secondary to genetic factors.[55] Both dementia and Parkinson's disease are progressive neurodegenerative diseases compounding motor, cognitive, and autonomic dysfunction in older autistic adults.

Singapore-based prevalence studies on neurological conditions in autistic adults are not available. Local clinical practice guidelines for autistic children listed common co-occurring neurodevelopmental conditions including attention-deficit hyperactivity disorder, intellectual disability, developmental coordination disorder, impaired adaptive function, language disorder, learning difficulties, and sensory processing difficulties.[32]

3. POSITIVE AFFECT AND CONTROL

Positive affect and control refer to psychological well-being, life satisfaction, coping capacity, and sense of purpose.[56] In the general population, risk factors of mental health conditions in older adulthood can be broadly classified via biopsychosocial factors, consisting of biological factors (age, sex, physical function, health conditions), psychological factors (affect, personality traits, subjective well-being), and social factors (physical activity, sleep quality, social support, marital status, loneliness).[57] As described in this review, some of these risk factors like health conditions and poorer physical functioning and social support are even more prevalent in autistic populations.

Mental health conditions are highly prevalent among autistic adults.[25–27,29] Meta-analyses indicate lifetime prevalence rates of 42 percent for anxiety and 37 percent for depression,[58] substantially exceeding Singapore's general population estimates of between 1.6 percent for anxiety and 6.3 percent for depression.[59] Lifetime rates of psychiatric conditions are high at 66.7 percent in autistic older adults.[53] In a Netherlands cohort study, higher rates were found: 79 percent of autistic adults met criteria for any lifetime psychiatric disorder, with mood (57 percent) and anxiety

(54 percent) disorders as the most common.[53] Estimates in the meta-analysis for autistic adults with ID were lower, with current and lifetime prevalence estimates of 20 percent for anxiety and 14 percent for depression.[58] But this difference might be secondary to under-reporting due to the inability of autistic adults with ID to communicate or express their symptoms.

Singapore-based prevalence studies on mental health conditions in autistic adults are not available, but local clinical practice guidelines for autistic children listed several common co-occurring mental health conditions, including anxiety disorder, depressive disorder, bipolar disorder, eating disorder, gender variance and dysphoria, obsessive compulsive disorder, oppositional defiant disorder, schizophrenia, and Tourette syndrome and tic disorder.[32] Without targeted and suitable mental health supports, ageing autistic adults in Singapore may face compounded risks of isolation and reduced well-being.

Table 1 illustrates a summary of research data on physical and mental health conditions amongst autistic adults. Although the local population is different from international population, the prevalence of health conditions in Singapore has also been included for reference when possible.

Table 1. Summary of Data on Physical and Mental Health Conditions amongst Autistic Adults

Condition	Croen et al. 2015 (US adults vs controls)[26]	Hand et al. 2020 (US adults ≥65 vs controls)[27]	Bishop-Fitzpatrick & Rubenstein 2019 (US adults)[29]	Lever & Geurts 2016 (Netherlands adults)[53]	Hollocks et al. 2019 (Meta-analysis)[58]	Vivanti et al. 2021 (US adults vs controls)[51] 2025[52]	Yin et al. 2025 (Swedish adults cohort)[54]	Singapore general population adults
Epilepsy	11.9% vs 0.7%; OR 16.3	26.4% vs 1.9%; OR 18.9	25%	—	—	—	—	0.4% (69)
Dementia/ cognitive disorders	2.3% vs 0.5%; OR 4.4	Cognitive disorders 25.2% vs 4.9%; OR 8.4	4.9%	—	—	4% ASD only; 5.2% ASD + ID; 1% control; HR 2.6) <65 years old OR 18.1 ASD; OR 8.6 ASD + ID ≥65 years old	—	8.8% above 60 years old[70]
Parkinson's Disease/ Parkinsonism	0.9% vs 0.03%; OR 32.7	6.6% vs 1.2%; OR 6.1	—	—	—		0.05% vs 0.02%; RR 4.4	0.3% above 50 years old[71]
Cerebrovascular disease	1.1% vs 0.6%; OR 2.12	14.9% vs 9.1%; OR 1.7	—	—	—	—	—	0.28%[72]
Sleep disorders	17.6% vs 9.6%; OR 1.9	1.4% vs 0.7%; OR 2.2	85.3%	—	—	—	—	Poor sleep 27.6%[73]
Gastrointestinal conditions	34.7% vs 27.5%; OR 1.35	51.2% vs 17.6%; OR 5.2	49.7%	—	—	—	—	—
Cardiovascular disease	37.0% vs 23.0%; OR 2.54	54.2% vs 37.1%; OR 2.1	49.0%	—	—	—	—	—

Hypertension	25.6% vs 15.6%; OR 2.19	66.5% vs 51.2%; OR 2.0	27.3%	—	—	—	—	33.8%[74]
Diabetes	7.6% vs 4.3%; OR 2.18	36.6% vs 27.4%; OR 1.6	21.7%	—	—	—	—	9.1%[74]
Hyperlipidaemia	22.8% vs 15.1%; OR 2.1	65.5% vs 54.4%; OR 1.6	30.1%	—	—	—	—	30.5%[74]
Obesity	33.9% vs 27%; OR 1.4	14.4% vs 10.3%; OR 1.4	—	—	—	—	—	12.7%[74]
Any psychiatric disorder	54%	—	72.0%	79% lifetime	—	—	—	13.9% lifetime (mood, anxiety, alcohol use disorders only)[59]
Depression/ mood disorders	25.8% vs 9.9%; OR 2.9	35.9% vs 9.1%; OR 5.6	28%	57.2% mood disorders (major depression 53.6%)	37% lifetime pooled prevalence	—	—	6.3% lifetime[59]
Anxiety disorders	29.1% vs 9.1%; OR 3.7	37.2% vs 8.8%; OR 6.2	43.4%	53.6%	42% lifetime pooled prevalence	—	—	1.6% lifetime[59]
Schizophrenia & psychotic disorders	Schizophrenia: 7.8% vs 0.4%; OR 22.2 Other psychosis: 6.3% vs 0.6%; OR 11.8	17.8% vs 0.8%; OR 25.3	10.5%	—	—	—	—	0.9%[75]
Suicidality/ self-harm	1.8% vs 0.3%; OR 5.1	3.6% vs 0.3%; OR 11.1	—	—	—	—	—	0.006%[76]
ADHD	11.1% vs 2%; OR 5.3	2.5% vs 0.1%; OR 22.4	8.1%	30%	—	—	—	2–7%[77]

OR – odds ratio
RR – relative risk
HR – hazard ratio
Figures rounded up to 1 decimal place

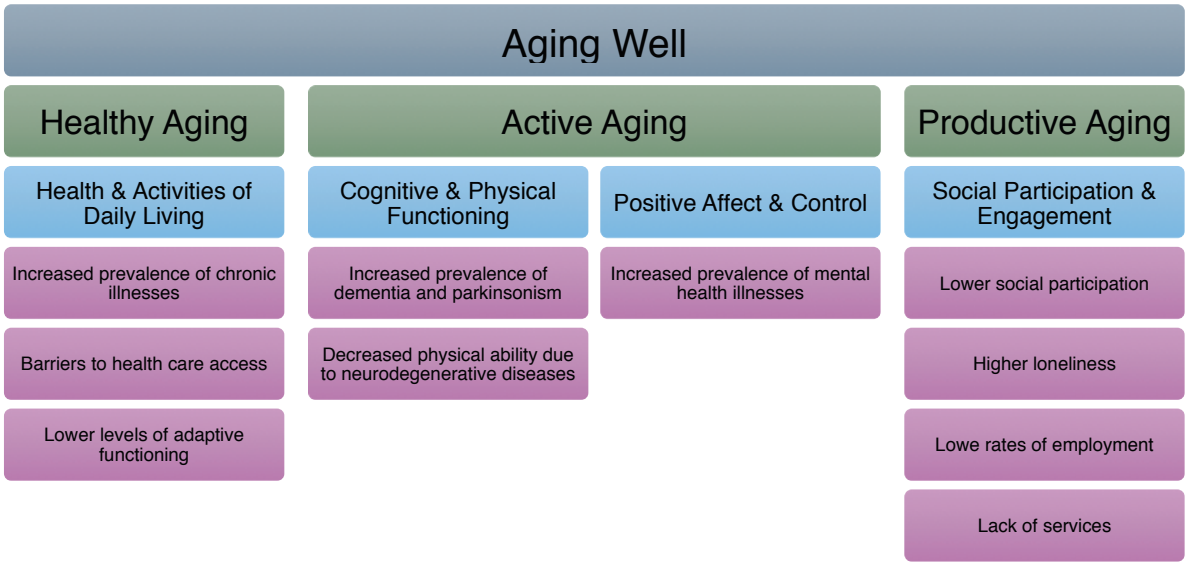
4. SOCIAL PARTICIPATION

Social participation—including employment, volunteering, and community engagement—is a key determinant of health in older adulthood.[60] Loneliness is associated with increased morbidity and mortality, and may exert effects comparable to traditional physical risk factors.[61]

Autistic adults consistently report lower levels of social participation and higher loneliness than non-autistic peers.[62] There are several reasons for loneliness across the lifespan for autistic adults. First, difficulties with social interaction and communication are common in autistic adults. Second, once autistic individuals grow up and leave the social setting of schools, the workplace becomes a major source of social interaction. Yet, employment rates amongst adults remain lower compared to other disability groups.[63,64] Lastly, support services for autistic individuals significantly decrease when they reach adulthood.[65]

In Singapore, demand for adult services exceeds supply, highlighting limited capacity and options in terms of respite care, residential care, day activity centres, and employment support services. There is a "service cliff" phenomenon whereby autistic individuals lose access to services once they leave the school setting.[66] In a local qualitative study, concerns of autistic adults dropping out of services, living at home for a prolonged period without meaningful engagement, losing the skills that they had acquired in school, and exhibiting challenging behaviours were raised.[66]

Figure 2. Barriers to Ageing Well in Autistic Adults



CONCLUSION

Autism is increasingly recognised as a lifelong condition with complex health-related implications, extending into middle and older adulthood. Evidence from international studies indicates elevated risks across physical health, cognitive functioning, mental health, and social participation domains. A summary of barriers to ageing well is illustrated in **Figure 2**. Quality of life among autistic adults is shaped by health status, social functioning, perceived support, supported employment, and leisure programmes.[67] Across their lifespan, people with autism experience a much lower quality of life compared to people without autism.[67]

In Singapore, rapid population ageing, improved autism detection, and evolving service systems create both challenges and opportunities to support autistic adults in ageing well.

Future research should prioritise longitudinal studies in our local populations, autism-informed healthcare models, and policies that integrate health, social, and community services across the lifespan. Addressing these gaps is essential to ensuring equitable, person-centred ageing outcomes for autistic individuals in Singapore.

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LEARNING POINTS

- **Autism is a lifelong condition with complex health-related implications throughout the lifespan.**
- **Autistic adults experience poorer ageing outcomes across multiple domains (physical health, cognitive functioning, mental health, and social participation)**
- **Autistic adults have higher mortality and morbidity compared to general population.**
- **Across their lifespan, people with autism experience a much lower quality of life compared to people without autism.**
- **It is important to study the health of autistic adults and address gaps to ensure provision of person-centred care for autistic individuals in Singapore.**

Unit No. 5

REASONABLE ADJUSTMENTS IN THE CLINIC: WHAT CAN GPs DO?

Dr Chew Bao Li

ABSTRACT

Persons with intellectual disabilities (PWID) and autism spectrum disorders (ASD) face significant barriers to accessing healthcare, often resulting in unmet medical needs and health disparities. General practitioners (GPs) play a crucial role in providing equitable primary healthcare through reasonable adjustments—modifications to standard practices that enable PWID to access services effectively. This article explores practical strategies for busy GPs across various practice settings to implement reasonable adjustments, ranging from pre-visit planning to post-consultation. These include appointment scheduling flexibility, environmental modifications, communication adaptations, leveraging technology, and collaborative care approaches. By understanding the unique needs of PWID, health outcomes can be significantly improved whilst optimising practice efficiency and creating an inclusive healthcare environment that benefits both patients and healthcare providers.

Keywords: intellectual disabilities, autism spectrum disorder, reasonable adjustments, healthcare accessibility, inclusive healthcare, communication strategies, primary care

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INTRODUCTION

Persons with intellectual disabilities (PWID) represent approximately 1–3 percent of the global population.[1] Prevalence rates are likely similar in Singapore, although there are no official local statistics publicly available to date.[20] Studies consistently demonstrate that PWID have significantly poorer health outcomes compared to the general population, with higher rates of preventable diseases, increased mortality, and reduced life expectancy.

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Similarly, individuals with autism spectrum disorders (ASD) face substantial healthcare challenges, with many reporting fear, embarrassment,[2] and other negative experiences in healthcare settings. Barriers to healthcare access include communication difficulties, sensory processing difficulties (SPD), and anxiety about medical procedures. As a result, these patients are more likely to have undiagnosed conditions, receive suboptimal preventive care, and experience medication errors. Patients may also face inaccurate assumptions about their capacity to make healthcare decisions. Locally, the Enabling Masterplan 2030 (EMP2030) has also acknowledged that more can be done to enhance access to mainstream healthcare for persons with disabilities in addition to current progress, and that persons with disabilities and their caregivers continue to report attitudinal and communication barriers when accessing healthcare, particularly for PWID and individuals with ASD.[3]

In National Healthcare Group (NHG) Polyclinics, there were a total of 892 unique adult (>18 years of age) patients with diagnosis code of intellectual disability, ASD, Down Syndrome, cerebral palsy, Patau's syndrome, Edwards' syndrome, delayed social and emotional development, and global developmental delay attending for health encounters in 2023 and 2024. Some clinics had more than 600 attendances from this patient group in 2024, with one clinic having 811 attendances in 2024—translating to an average of 1–3 patient attendances daily.[21]

GPs may lack familiarity and confidence[4] in treating these populations, leading to inadequate care or multiple specialist referrals that might not be value-added. A systemic scoping review conducted by the University of Sydney, Australia reported that patients faced discrimination or insensitivity from GPs, alongside uncertainty among some GPs about their role, with some incorrectly assuming that the clinical responsibility to provide primary healthcare for PWID lies with paediatricians or specialists.[4] Locally, a survey of private GPs also revealed that only one-third of respondents were confident of having sufficient knowledge of health conditions associated with PWID and ASD.[5] Acknowledging that overcoming these challenges is the first step towards implementing effective reasonable adjustments and delivering respectful, patient-centred care, the EMP2030 aims to promote inclusivity by increasing the number and strengthening the capability of healthcare professionals trained to effectively communicate with and care for persons with disabilities.[3]

The concept of reasonable adjustments advocates for healthcare providers to modify their standard practices to ensure equitable access for persons with disabilities. For busy GPs managing high patient volumes in private clinics or polyclinics, implementing these adjustments can seem

daunting. However, many effective adjustments are simple, low-cost modifications that can significantly improve patient experience and health outcomes whilst potentially reducing consultation complexity and duration.

This article draws upon current evidence as well as experiences of a novel pilot in NHG Polyclinics (Ang Mo Kio) for adult PWID and ASD patients—the SPARk (Supporting PWID with Accessible Resources and k(C)are) Clinic—to provide practical guidance for GPs across different practice settings on implementing reasonable adjustments. The focus is on evidence-based strategies that can be integrated into existing workflows with minimal disruption of practice efficiency. There will also be a focus primarily on adults with PWID and/or ASD as healthcare access and service delivery for adults present distinct challenges from paediatric care. While children and adolescents with PWID and/or ASD often receive coordinated care through established workflows including specialised developmental services and educational support systems, adults frequently face care transitions, reduced support services, and greater expectations for independent mainstream healthcare navigation.

PRE-VISIT: PREPARATION AND PLANNING

Understanding the Patient Population

Intellectual Disability

Intellectual disability is defined by the DSM-5[6] as having significant limitations in intellectual functioning and adaptive behaviour, manifesting before age 18. The severity ranges, with most individuals (about 85%) having mild intellectual disability (IQ 50–70). Common associated conditions include epilepsy, sensory impairments, mental health disorders, and physical disabilities.

PWID often experience challenges with abstract thinking, problem-solving, and absorbing new information. They may have difficulty understanding complex medical terminology, following multi-step instructions, or expressing their symptoms clearly. However, it is crucial to recognise that intellectual and language abilities vary among individuals, and many PWID can actively participate in their healthcare decisions with appropriate support.

Autism Spectrum Disorders

Autism spectrum disorders are defined by the DSM-5 as having persistent deficits in social communication and interaction, alongside restricted, repetitive patterns of behaviour. Sensory processing difficulties (SPD) are common, with individuals potentially experiencing sensitivity to light, sound, touch, or other stimuli.

Many individuals with ASD prefer predictability and routine and may find unexpected changes distressing. They may communicate differently, requiring more time to process information or preferring written or visual over verbal communication. Some patients may have both ASD and intellectual disability.

Appointment Scheduling

As far as possible, PWID and patients with ASD should ideally be seen as scheduled appointments as opposed to walk-ins to limit impact on other patients and optimise pre-visit planning and visit outcomes. Multiple publications have identified that insufficient consultation time to overcome communication barriers and manage the complex issues of PWID and patients with ASD is a major factor impacting on the accessibility of GPs.[4] Subject to resource availability, consider offering longer appointment slots for PWID, typically 20–30 minutes instead of the standard 10–15 minutes. This additional time allows for slower-paced communication, explanation of procedures, and addressing any emotional or behavioural challenges. For SPARk Clinic, first visits are scheduled into 30-minute appointment slots, with 20-minute slots for subsequent follow-up visits.

Schedule appointments at times when the clinic is less busy, such as late afternoon slots, and avoid days where patient load is projected to be higher (such as Mondays and post-public holidays). This reduces waiting times and environmental stressors like crowded waiting areas, which are major causes of anxiety and stress for patients.[2] The SPARk Clinic currently runs fortnightly on Wednesday afternoons (2–5 pm).

For patients with ASD who may thrive on routine, offer consistent appointment times and days whenever possible.

For regular patients with visit itineraries requiring assessments at multiple stations in the clinic, keeping to a routine sequence might be helpful. For instance, always arranging first for their blood pressure to be taken at the vitals station, then heading to the lab for venipuncture, then having his/her BMI checked outside the consult room before awaiting for GP consultation in the waiting area. If the same itinerary is scheduled and assessments are performed in the same order every time the patient visits the clinic, this will help the patient acclimatise to the steps more quickly.[7]

Arranging for the same GP or clinic to attend to the patient at each visit as far as possible is reassuring for these patients, and helps healthcare professionals continuously build rapport and develop a better understanding of the patient's communication styles and medical and social history.[2,5] This is even more crucial given the potential for complex biopsychosocial issues evolving as these patients age, and is also in keeping with Healthier SG's "One Resident, One Doctor" initiative.[7]

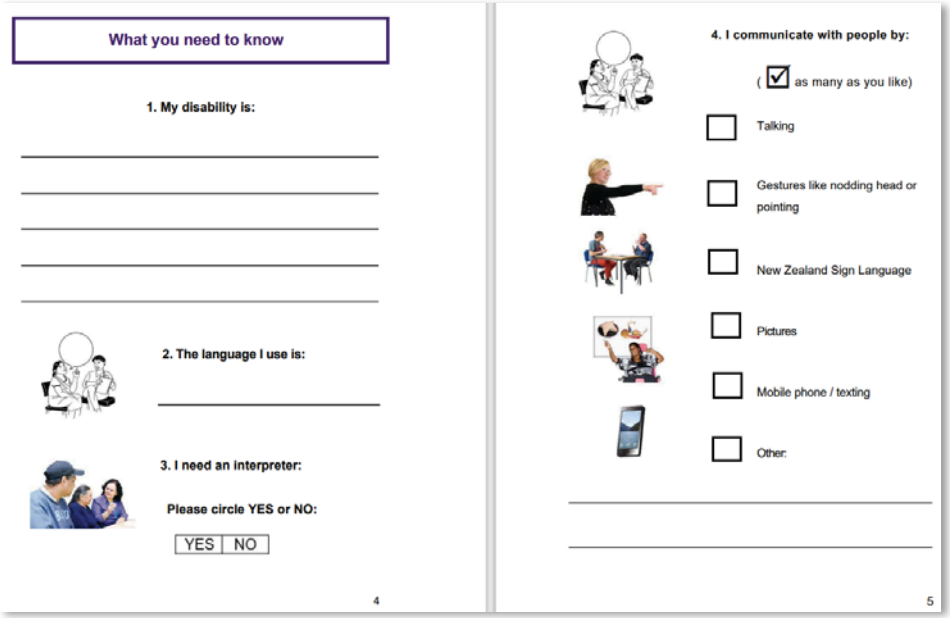
Information Gathering

For first-time patients, find out about the reason for encounter, medical history, communication preferences, and support needs if such information is accessible beforehand. This may be done via reviewing previous consult notes, referral letters, or step-down care memos; pre-visit questionnaires sent to patients or their caregivers, or pre-visit telephone conversations with a coordinating

staff member of the clinic. For instance, in SPARk Clinic, a Care Coach both engages patients and caregivers pre-visit; and assists with appointment coordination and reminders.

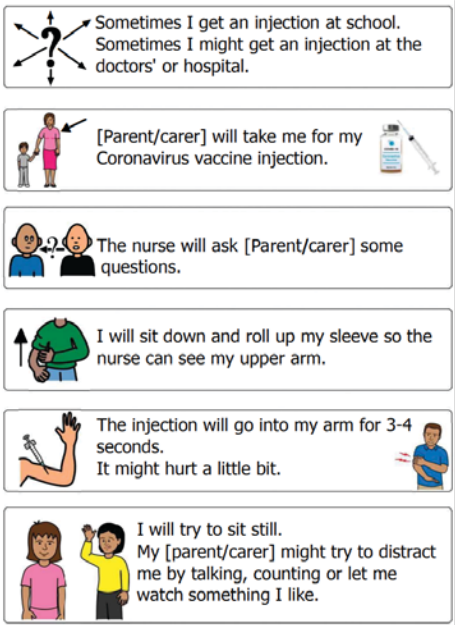
Take note of information in the patient's Health Passport (sometimes also termed a Hand-Held Health Record) (refer to **Figure 1**) if this is available pre-visit. Locally, health passports have been neither officially implemented nor widely adopted yet, although some PWID or individuals with ASD receiving services from some organisations (e.g., Movement for the Intellectually Disabled of Singapore (MINDS)) might have one. As per international guidance, this is a useful patient-owned, portable, and accessible document that provides healthcare staff with essential information to support the delivery of personalised care and improve patient safety including in emergency situations.[19] It also empowers PWID and individuals with ASD to communicate what they want healthcare staff to know about them. The passport usually includes salient details about the patient such as medical alerts and communication needs, and may be maintained in physical, digital, or combined formats.[19] If patient does not presently own a Health Passport, they may be encouraged to create a basic one at subsequent clinic visits with readily available online templates.

Figure 1. Example of information within a Health Passport (with Communication Passport integrated)[8]



Prepare social stories (refer to **Figure 2**) for common procedures and workflows that can be sent to patients and caregivers for pre-visit viewing and preparation. This is a visual tool with simple language and pictures that can help patients understand what to expect in a structured, sequential, step-by-step manner. Many resources are available online, or you can create simple materials specific to your clinic workflows.

Figure 2. Example of a social story on receiving vaccinations[9]



Environmental Modifications

Replace harsh fluorescent lighting with softer, warmer alternatives where possible. Consider installing dimmer switches to allow for lighting adjustment based on individual patient needs.

Some patients may have altered temperature perception. Ensure the clinic maintains a comfortable temperature and have blankets available for patients who might feel cold during examinations.

Strong scents may be distracting or distressing for some patients. Avoid air fresheners and use air purifiers if necessary.[7]

Provide various seating options where possible, including chairs with arms for patients who need additional support. Designate a quiet room (this can simply be an unused consult room) and/or quiet zones with comfortable seating away from high-traffic areas for patients who prefer less sensory stimulation while waiting for his/her turn. For instance, the SPARk Clinic is located at a less crowded corner cluster on the 5th floor of the polyclinic. Noise-cancelling headphones can also be provided for patients who find them helpful.

Offer sensory tools such as fidget toys, stress balls, or textured objects; or simple books that patients can read whilst waiting. These items should be easily disinfected or replaced regularly for infection control purposes.

Implement clear signage using both text and visual symbols to help patients navigate the clinic. Consider sharing a visual map of the clinic layout with patients before their visit.

A referral to an Occupational Therapist (OT) may be considered for specific patients who have persistent challenges with SPD, for a more comprehensive assessment to identify contributing factors and help them adapt to an unfamiliar environment and social setting. This can be in the form of questionnaires or validated assessments of sensory integration.[10]

DURING THE VISIT: ADAPTIVE COMMUNICATION AND MANAGEMENT

Managing Anxiety and Distress

Allow caregivers to be present in the consultation room whenever appropriate. Recognise early signs such as restlessness (e.g., increased fidgeting), increased repetitive behaviours, changes in breathing patterns, or verbal expressions of discomfort to reduce the chance of escalation. Implement calming techniques such as deep breathing exercises, using sensory tools, counting, or focusing on preferred objects or topics. Some patients may benefit from brief breaks during longer consultations or procedures.

The attending clinician's self-regulation is also essential in reducing emotional transference to patients; if one is anxious, there is a high chance that the patient will become anxious as well.[10]

Communication Strategies

Verbal

As detailed in the next article by Teo J, the initial minutes of a consult should place emphasis on engagement and rapport-building rather than rapid information acquisition.[7] The primary objective should not be to obtain as much history as possible in a limited time, but rather to establish sufficient rapport to encourage patients to eventually return for continuity of care. This may involve starting with open-ended questions and allowing time for them to express what is currently on their mind, even if it is not directly related to the history of presenting complaint or reason for encounter.[7]

Rather than completing the full history-taking in a single visit, aim to spread information gathering across a few visits. Strong rapport fosters trust, which is essential for obtaining accurate history. As trust develops, the efficiency of information gathering naturally improves.[7]

Speak slowly and clearly, using simple language and avoiding medical jargon. Break complex information into smaller, manageable chunks, and check understanding by asking the patient to repeat back key information in their own words at regular intervals. Stating the patient's name before each question can help maintain the patient's attention.[7]

Use concrete rather than abstract language. For instance, instead of asking *"where does it hurt?"*, one can ask *"Can you point to the place that hurts?"*. Providing binary answer choices to limit cognitive load may also be helpful, such as *"Is your pain in your stomach or your chest?"* or *"Do you spend more time inside or outside your house?"*[7]

Allow extra time for patients to process information and formulate responses. Giving at least 10 seconds for a patient to respond to one's questions is suggested. Repeating and rephrasing questions after allowing adequate response time might be necessary.[7] Resist the urge to repeat questions immediately or conclude that the patient hasn't understood the questions.

For those with accompanying caregivers or family members, make a deliberate effort to engage first with the patient, even when reliable responses may not be possible. After this initial engagement, it is then appropriate to explain to the patient that you will be speaking with their caregiver or family members to obtain a corroborative history.[7]

Non-Verbal

Be mindful of non-verbal communication, as many individuals with ASD might have difficulty interpreting facial expressions, body language, or tone of voice. Maintain a calm, neutral expression and avoid sudden movements that might be startling or misinterpreted.

Use visual supports such as pictures (refer to **Figure 3**—this is what SPARk Clinic utilises) that patients can point to, diagrams, or written words to supplement verbal communication. Besides history-taking, visual supports can

also be helpful when explaining procedures, medication instructions, or follow-up care requirements to patients with limited verbal communication.

Figure 3. Example of a visual support image[11]

Physical Examination and Performing Procedures

Explain each step of the examination or procedure before performing it and ask for permission before proceeding to touch the patient. Some individuals might prefer to touch the stethoscope or other equipment first to become familiar with the sensation. As abovementioned, using social stories and demonstrating physical exam steps on a mannequin prior to the examination has also been shown to be helpful[2] and alleviates some of the associated apprehension.

Consider alternative examination positions if standard positions cause distress. Some patients might feel more comfortable sitting rather than lying down, or might need to maintain visual or touch contact (such as holding a hand) with a caregiver throughout the examination. Use a gradual approach for examinations that might be uncomfortable or anxiety-provoking, such as those involving intimate areas. Start with less invasive steps of the examination and build up to steps that require a higher tolerance threshold as the patient becomes more comfortable. Be prepared to pause or stop if the patient becomes distressed.

Building strong rapport and trust, as abovementioned, will boost one's success rate in carrying out less well-tolerated procedures, such as venipuncture or vaccinations.[7]

Supporting Decision-Making Capacity

All patients (regardless of disability or impairment) should be assumed to have the capacity to make healthcare decisions unless there is clear evidence to the contrary. Patients feel empowered when actively involved in decision-making and when they have a clearer understanding of their diagnosis and treatment.[2] Many PWID can make informed decisions about their healthcare when information is presented appropriately and when they are given adequate time and support.

A healthcare professional's choice to discuss clinical management decisions only with a patient's caregiver is frequently driven by perceptions of increased efficiency. However, depending only on caregiver reports might lead to important information being overlooked or misunderstood as caregivers, while knowledgeable, cannot fully convey the patient's personal experiences or perspectives.[7]

Use supported decision-making approaches rather than substituted decision-making whenever possible. This involves providing information in accessible formats such as easy read[12] materials (refer to **Figures 4 and 5**), which combine short, easily understood sentences with simple, clear images to help explain various topics, allowing time for consideration, and encouraging the patient to express their preferences and values.

If patients have legal guardians or appointed deputies, continue to include the patient in discussions and respect their preferences where possible. The goal is to maximise patient autonomy.

Figure 4. Example of an easy read educational leaflet on consent and capacity[13]

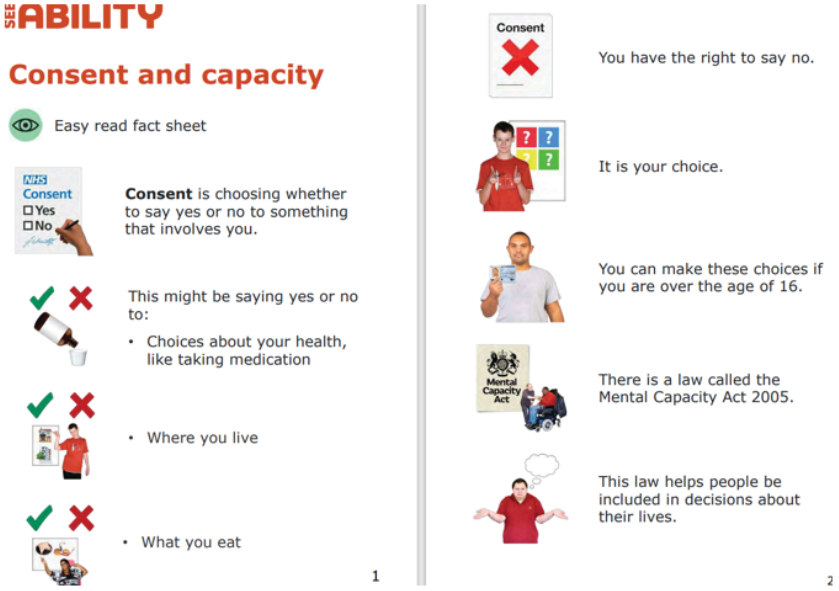
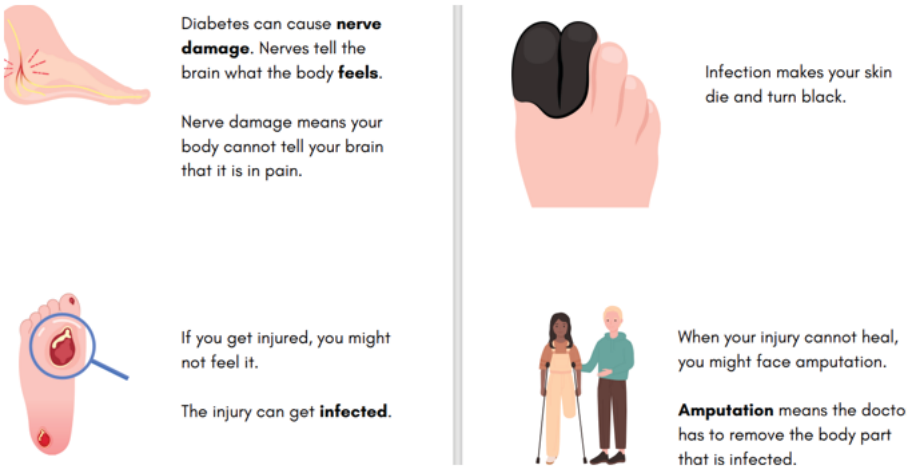


Figure 5. Example of an easy read educational leaflet on diabetic neuropathy[11]



Medication Management

If there are no changes to dosing regimens, accommodating medication collection on a separate occasion or facilitating home deliveries of low-risk chronic prescriptions post-consult can mitigate the need for in-person waits at the pharmacy.[4]

Simplify medication regimens where possible, considering factors such as the patient's ability to remember doses, handle packaging, and understand dosing instructions. Provide clear, written medication instructions using simple language and visual aids. For instance, instead of saying "take this medication regularly", specify "take one tablet every morning with breakfast". Consider personalised medication charts that include pictures of the medications and clear timing instructions. Caregivers should also be updated on medication instructions, with patient consent whenever appropriate.

Monitor for medication side effects more closely, as PWID and patients with ASD might have difficulty recognising or communicating adverse reactions. More frequent follow-up appointments might need to be scheduled when starting new medications and clear red flag instructions should be provided to both patients and caregivers.

Caregiver Support and Stress Assessment

Recognise that caregivers of PWID and ASD often experience significant stress, social isolation, and their own physical and mental health challenges that might impact the quality of care they can provide. Supporting caregivers is an investment in the patient's long-term wellbeing and will prevent crisis situations that require more intensive intervention.

Allocate part of the consultation time to assess their wellbeing and capacity in addition to the patient consult, such as screening for caregiver stress and burnout using validated questionnaires such as the Zarit Burden Interview (ZBI). At the SPARk Clinic, these are administered with the support of nursing Care Managers as required. Schedule appointments for both the patient and their caregiver to be within the same clinic session if necessary. This approach helps GPs contextualise biopsychosocial issues for both

parties while also reducing the time burden on stressed caregivers, who would otherwise need to make separate visits to the polyclinic for their own medical appointments. To date, among the 51 patients followed up at the SPARk Clinic since its inception in July 2024, two elderly caregivers with physical and mental health conditions are also receiving regular follow-up care through the service, in addition to their adult children with intellectual disability or ASD.

A Medical Social Worker (MSW) referral may be useful in some cases to further explore both caregiver and patient's social setup and facilitate referrals to community support services.

OTHER CONSIDERATIONS

Interdisciplinary Coordination

Develop a network of knowledgeable referral sources consisting of healthcare professionals in the public or private sector who have experience working with PWID and ASD individuals. This can include psychiatrists, neurologists, psychologists, social workers, speech therapists, and occupational therapists. This can aid in timely referrals, co-management of cases, or transfer of care in complex medical or behavioural conditions that might be unmanageable in primary care.

Regular multidisciplinary team meetings for complex cases—for instance, every 2–3 months at the SPARk Clinic—bring relevant healthcare providers together to develop comprehensive care plans. This collaborative approach can prevent fragmented care, address issues using the biopsychosocial model, and ensure all team members understand their roles and responsibilities.

Technology and Digital Health Solutions

Accessible Health Information

In the current era of artificial intelligence (AI), AI-based image generation tools are a novel means of easily developing simple visual health education resources, including the aforementioned easy-to-read leaflets and visual support images. Publicly available online video-sharing platforms can offer an additional means of delivering health information such as social stories through audiovisual media, although information sources might need prior curation to ensure accuracy.

Assistive technology apps for smart devices such as Proloquo2Go, iCommunicate, and Speech Assistant AAC can assist in patient communication and engagement. Virtual reality (VR) clinic tours are being developed for patients to improve preparation and enhance confidence for healthcare visits, such as an AI-based immersive VR application being developed by UNSW, Australia.[14]

Consider tele- or video-consultations for follow-up appointments if clinically appropriate, as some patients might feel more comfortable in familiar home environments. According to a UK survey, approximately one-third of people with a disability do not have basic digital skills. Thus it is important to consider that any digital solutions should be accessible and user-friendly for varying levels of technological literacy and not exclude patients who live in digital poverty.[15]

Clinic Management Software (CMS) Adaptations

Use a digital flagging system in your CMS or alert section in patients' case notes, easily accessible to all staff, to identify patients who may benefit from reasonable adjustments and to highlight basic context about a patient including important support needs or communication preferences. This complements the utility of a health passport. This digital flag should be updated regularly depending on changes in patients' preferences and circumstances.[16]

Create standardised templates for consultation notes and referrals (such as Smartphrases in NHG Polyclinic's EPIC NGEMR) that can auto-populate patients' medical history and essential details from the patient's health passport, such as communication needs and SPD, for efficient documentation and handover of care when necessary.

Staff Training and Development

Building Competency and Confidence

Invest in staff training that covers topics such as disability awareness, communication strategies, legal requirements, and practical skills for implementing reasonable adjustments. For instance, IDHealth currently offers a modular e-learning course to enhance healthcare professionals' approach in caring for PWID.[17] Allow time for staff to attend or organise Continuing Medical Education (CME) events by various healthcare professionals and disability organisations (e.g., MINDS, AWWA, Happee Hearts Movement, Institute of Mental Health (IMH)'s Adult Neurodevelopmental Service (ANDS)) to keep up-to-speed with best practices.

Regular team meetings also provide opportunities to answer queries, share experiences and develop collective expertise. Ensure all staff members—including clinic assistants, nurses, and administrative personnel, and not just doctors—understand their roles and responsibilities in providing team-based inclusive care.

Quality Improvement and Service Evaluation

Implement systems to measure the effectiveness of reasonable adjustments and overall accessibility of your practice. This may include patient satisfaction surveys, feedback forms, and regular reviews of patient outcomes and experiences.

Share successful strategies and lessons learnt with fellow healthcare providers via professional networks, conferences, or publications whenever possible. Contributing to the broader knowledge base locally and/or internationally helps improve awareness and care for PWID and individuals with ASD across the healthcare system.

CONCLUSION

Implementing reasonable adjustments for PWID and patients with ASD should be viewed as part of our duty of care and clinical responsibility as primary healthcare professionals[18] in advocating for inclusive healthcare in Singapore and in keeping with EMP2030 objectives. Whilst not exhaustive, the strategies outlined here suggest that many effective adjustments are simple, low-cost modifications that can significantly improve patient experience and health outcomes.

As our healthcare system continues to evolve towards more patient-centred care, the principles and practices outlined in this article will become increasingly important for all GPs. From a macroscopic perspective, it is also our hope that local policymakers fund advocacy as a legitimate part of the healthcare model and regard advocacy as part of clinical responsibility—akin to investing in better health outcomes, lower costs, enhanced professional satisfaction, and stronger national development—all of which will pay dividends in the long run.[18]

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LEARNING POINTS

- **Reasonable adjustments are often simple, low-cost modifications that can significantly improve healthcare access for PWID and patients with ASD. Many effective adjustments such as longer appointment times, communication strategies, environmental modifications, and CMS flagging are not resource-intensive but can have substantial positive impacts on patient experience and health outcomes.**
- **Effective communication requires time, patience, flexibility, and the use of multiple modalities including visual aids, social stories, easy-read materials, and concrete verbal language. GPs should allow extra processing time, avoid medical jargon, and check understanding frequently whilst respecting individual communication styles and preferences. The aim is to build strong rapport and trust to encourage patients to return for continuity of care. Supported decision-making approaches rather than substituted decision-making should be used whenever possible.**
- **Collaborative care approaches that involve multidisciplinary teams are essential for providing comprehensive and effective healthcare to PWID and patients with ASD. Working with caregivers, allied health professionals, and specialists can provide valuable insights and improve care coordination.**

Unit No. 6

NAVIGATING THE HEALTH AND DISABILITY LANDSCAPE ALONGSIDE ADULTS WITH INTELLECTUAL DISABILITY: THE FAMILY PHYSICIAN'S ROLE

Ms Joy Teo

ABSTRACT

People with intellectual disability (PWID) and their caregivers often struggle to make their way through the various processes necessary to seek and obtain the help they need to manage their health and well-being. This article proposes that family physicians can play a central role as a relational anchor for them as they are a natural touchpoint in the community who are able to journey with the patient and caregiver throughout their life course. The physician's role is not to master a list of services, but to know whom to call in times of need. Their relationship with the patient and caregiver, and detailed knowledge of who they are and what they value is the basis for this decision. Physicians should be familiar with the contact details of the agency for integrated care (AIC), SG Enable (SGE), and Family Service Centres (FSC) in their neighbourhood.

Keywords: Health and social integration; Healthcare services; Disability services; intellectual disability health

SFP2026; 52(2): 41-45

INTRODUCTION

As Singapore ages, maintaining the health of the nation has become a priority. HealthierSG was launched in July 2023 to encourage stronger relationships with family physicians, health screening, vaccinations, and increased physical activity.[1] Health is also recognised today as far more than just physical wellness. There is much more support now for mental health issues as their prevalence has increased in both the young and old.[2] Beyond biological and psychological health, there is also recognition that an individual's relationships with their immediate family and wider community play a significant part in a person's overall wellbeing. This lends support to the biopsychosocial model of health[3] and the now the often-heard phrase "health and social integration".[4] There is much discussion about how services delivered by the healthcare system and social services need to be pulled together to meet needs. Models of care continue to be proposed and piloted. For example, between January and March 2026, a pilot to test collaboration between a group of general practitioners and a social service agency aiming to provide stronger support to patients with more complex medical and social needs has begun.[5]

It is an unfortunate but well-established fact that people with intellectual disability (ID) suffer from poor health and many health inequalities.[6] The multi-morbidity burden is higher than the general population and polypharmacy is common.[7,8] This situation is a function of genetic predispositions, early ageing, and increasing life expectancy, which often brings along age-related chronic conditions.[9,10] Living longer also implies a potential reduction in the ability of caregivers to provide care and thus negatively affect the health and well-being of the care recipient with ID. In addition, PWID also suffer from many of the negative social determinants of health.[11]

In his or her early years, the child or adolescent with ID may regularly visit a paediatrician (purview of Ministry of Health) and access early intervention and special school services (purview of Ministry of Education). At 18 years old, the individual with ID leaves the special school system and enters the "adult disability services" space, which is overseen by the Ministry of Social and Family Services (MSF) and managed by SG Enable. These services include vocational training and job placement services as well as day activity centres for those who are unable to find employment. It is at this time that the individual will also need to be discharged from the care of his or her paediatrician if still under their care. Currently there is no identified medical specialty that takes over the care of adults with ID. It is possible for individuals with ID to be unknown to the healthcare system until he or she presents with significant and severe health issues. In the later years of life, health services like home personal care services and dementia day care may be needed. Such services fall under the administration of Agency for Integrated Care (AIC).[12]

It should now be apparent that supporting the health of PWID is often more complex than doing so for the general population. As their needs vary over their lifespan, they often require supports and services that fall within the jurisdiction of different public service spheres. While a variety of services are available, for care to be optimal, integration of services is necessary.

This paper proposes that family physicians are in an ideal position to journey with individuals with ID throughout their lifespan, drawing on supports and services within the

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healthcare, disability, and social service sectors to optimise the health of their patients. Family physicians in this role do not merely provide a service, but a constant, trusted relationship that individuals with ID and their families can turn to in times of distress, transitions, and change in their lives. The author proposes that they are the pillar of community-based healthcare, not because they can service all the patient's needs, but because they are the relational anchor that provides a link to other service providers to form a supportive ecosystem for PWID. Care for PWID in the community thus becomes the litmus test for community-based care for all. This paper aims to reframe the health and disability services landscape through the relational role of a family physician.

WHAT DO PATIENTS WITH ID AND THEIR CAREGIVERS WANT AND NEED?

Research into doctor-patient relationships and what is expected by PWID and their caregivers of their general practitioner appear to prioritise good communication and connection between patient and doctor.[13] In Singapore, Happee Hearts Movement (HHM) commissioned the NUS Saw Swee Hock School of Public Health in 2023 to evaluate its specialised clinical service for adults with ID, IDHealth. The service evaluation showed that caregivers and patients appreciated care that was tailored to individual needs, care that met needs beyond medical issues, care built on a trusting relationship with patients, and care that facilitated participation in the community.[14] While IDHealth is a specialised service and consists of an interdisciplinary team, such care need not be unique to this service.

The nature of a family physician's role allows them to become familiar with their patients as they interact with them over years, watching their growth and monitoring their health. Unlike in tertiary care where there is often the pressure to discharge patients and care is episodic, the family physician in primary care can build trusting relationships with their patients over the course of a lifetime. This allows time to grow in understanding of a patient's communication style, lifestyle preferences, health risks, and family dynamics. Tailored care requires such depth of knowledge.

To meet the unique biopsychosocial health needs of the patient, in addition to deep knowledge of the patient and family, the family physician needs to be able to translate the patient's request or need into language that service providers understand. Patients and caregivers rarely request for services. They present with problems that sound more like "I cannot go for my specialist appointment, because there is nobody to watch my son at home", "I am so stressed about what will happen when I die", and "He shouts and hits me and my helper after every meal", rather than "Can you help me apply for day activity centre services?", "I need help with future care planning", and "I think he might need dental services". The next section suggests how existing health and disability services can be leveraged to help address common concerns that caregivers of patients with ID might raise.

LEVERAGING HEALTH AND DISABILITY SERVICES

"I cannot go for my specialist appointment because there is nobody to watch my son at home."

In this and similar scenarios, caregivers are reporting barriers to caring for their own health, or limitations in participation in community because their adult child with ID is not engaged in meaningful activity during the day. In Singapore, the special education system ends when the individual is 18 years old. Upon graduation, students enter one of three pathways. They could be placed in open employment or vocational training for open employment, enter a sheltered workshop, or are identified to be suitable for day activity centres, depending on their functional ability. Despite allocation to services on graduation, it is not uncommon that students meet with long wait times to enter these services and ultimately end up unengaged at home. There is also a group of students who do not meet the requirements for services or drop out of services due to difficulty with transition. Caregivers thus must spend their days supervising their adult child at home.

Enabling Services Hubs (ESHs) were developed and launched beginning in 2023, to support PWID closer to their homes.[15] Their services target people with disabilities who are not enrolled in adult disability services and include social and recreational activities and courses for persons with disabilities as well as caregiver support programmes. There are currently three ESHs in Singapore, located in Tampines West, Punggol, and Jurong. ESHs are managed by SG Enable and staff there are able also to provide information and referral to other adult disability services (e.g., case management, respite, sheltered workshop, day activity centres). Therefore, to address issues of meaningful engagement or support for caregivers, ESHs are an appropriate referral point for information, care navigation, and linkage to relevant adult disability services.

"I am so stressed about what will happen when I die."

Worry about how their adult and ageing children with ID will be cared for when they are no longer able to is a constant burden for many parents. There are many factors that need to be considered when making plans for this eventuality. Housing and daily living needs, financial needs, need for meaningful engagement and relationships, as well as health and medical needs of the PWID must be considered. In this process, not only should the concerns of the caregiver be heard, but even more so the voice of the PWID.

Family physicians can contribute to this future care planning process in three ways. First, they can be the point person for the medical and health needs of the PWID. Instituting regular health checks can serve to nurture a trusting relationship that will assist with prevention and timely intervention for health issues. Second, with a strong trusting relationship developed, family physicians may be the best person to advise caregivers and, where appropriate, patients with ID to make advanced care plans and identify suitable

health spokespersons as well as appointing donees under the Lasting Power of Attorney (LPA). When necessary, family physicians would also be in a good position to assist with the mental capacity assessment for the application of a deputyship. Third, family physicians could encourage and direct PWID and their caregivers to seek assistance with future care planning. If the individual with ID is already within a disability services (e.g., sheltered workshop), the social worker in the service would be the most appropriate person to reach out to for assistance. If the individual is not within a disability service, he or she may seek assistance through an ESH.

"He shouts and hits me and my helper after every meal."

Behaviours of concern (BOC) are "culturally abnormal behaviour(s) of such an intensity, frequency, or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities."[16] BOC are a common reason for caregivers reaching out for help. BOC occur when the PWID has unmet needs. The behaviour is a form of communication; an expression that there is pain, discomfort, or distress. Taking a biopsychosocial approach, it would be appropriate for the family physician to first rule out or address likely biophysical causes for distress. For support to identify and address other psychological or social factors that may be contributing to the BOC and further analyse the situation, referral to services like the disability case management programme (DCMP) via SG Enable would be appropriate.

When BOC are very severe, and significant harm is being caused to self or others, the family physician may consider referral to the Adult Neurodevelopment Service (ANDS) in the Institute of Mental Health (IMH). The ANDS team is a psychiatrist-led multidisciplinary team that specialises in addressing mental health and behavioural issues in adults with ID and autism spectrum disorder (ASD). When BOC are assessed to likely involve a complex interplay of factors, including complex medical conditions, mental health issues, unhealthy living environments, and strained relationships, a referral to IDHealth, an interdisciplinary community-based healthcare team for adults with ID, is appropriate.

"My daughter used to be independent with everything but nowadays I must help her with showering, toileting, and dressing. I'm so tired. I have no time for myself."

As a caregiver ages along with the individual with ID, caregiver capacity reduces while caregiving needs increase. In such situations, caregivers may need support with daily caregiving tasks and general management of the household. Such supports can be obtained through schemes and services administered through the agency for integrated care (AIC). One of these schemes includes the Home Caregiving Grant—monthly financial assistance to help cover the costs involved with caregiving. Such grants are meant to enable caregivers to employ full or part-time help to manage household tasks or caring for their adult child with ID. One of the care services available through AIC is the home personal care service. This service provides trained care staff to the home to assist the caregiver with activities such as engaging the care recipient in mental stimulation activities or simple exercises, assistance with medication, respite, and assistance with daily living activities that may include self-care. Other care services include the household services scheme, which provides part-time help with domestic chores or basic elder-minding services, and the medical escort and transport scheme, which provides transport and/or a companion for medical appointments. In addition, caregivers with high levels of stress may also require and benefit from the support of community mental health teams. These teams are in every neighbourhood in Singapore.

The ageing individual with ID can also benefit from services designed for the elderly in the general population such as day care services and active ageing centres.[12] Participation in activities at these centres helps to keep the individual physically, mentally, and socially engaged. The caregiver is simultaneously provided with time to rest. Access to these services is also via AIC.

In these examples, the needs expressed by the patient with ID and their caregivers can be categorised into three main areas. They are: meaningful engagement, behaviours of concern, and caregiver stress. **Figure 1** illustrates how services from both the health sector (administered by AIC), the disability sector (administered by SG Enable), and the social service sector can be activated to meet these needs. While AIC and SGE manage numerous services, family physicians need only to know how to make referrals to AIC or SG Enable, who will then take over the process of further assessing the patient and caregiver needs and subsequently making the appropriate referral. For social services, it would be helpful for the family physician to become familiar with contacting the nearest family service centre (FSC), which would be able to assess and manage the case or make recommendations to other social services such as the social service offices (SSO), national anti-violence helpline (NAVH), and protection specialist centre (PSC). Each neighbourhood has its own FSC, SSO, and PSC.

Figure 1. Patient and caregiver needs and relevant services

Patient with Intellectual Disability and Caregiver Needs

Meaningful Engagement

Health Services (AIC)	Disability Services (SGE)
Older patients	Younger patients
Active aging centres	Day activity centres
Senior day care	Sheltered workshops
Household services scheme	Vocational training and job pla
	Enabling service hubs

Behaviours of Concern

Health Services (AIC)	Disability Services (SGE)
More severe BOC, involving mental illness, complex medical conditions, psychosocial factors	Less severe BOC, fewer and less complex medical issues
IDHealth (HHM)	Disability case management programme (DCMP)
Adult Neurodevelopmental Service (IMH)	Family empowerment programme (FEP)

Caregiver Stress

Health Services (AIC)	Disability Services (SGE)	Social Services
To address caregiver mental health and relieve practical care burden	To address stress due to reasons that include lack of engagement of patient, BOC and/or overall concern for future	To address immediate financial needs , psychoemotional support and intervention for caregiver and family and suspected abuse or violence.
Home personal care	Disability case management programme (DCMP)	*Family service centres*
Respite	Respite	Social service offices
Mental health teams	Day services (e.g., day activity centres, sheltered workshops etc.)	Protection specialist centres

CONCLUSION

Support for PWID and their caregivers in the community may require various professionals, schemes, and programmes that fall within the health, disability, and social sectors. Manoeuvring through the eligibility criteria and processes to obtain these cross-sector services can be confusing and overwhelming for PWID and their caregivers. The task of the family physician is firstly to translate the concerns and needs of the patient and caregiver into the language of the service sectors, and secondly to be able to link the patient and caregiver to the right people who can meet their needs.

Family physicians may journey with a patient and his/her caregiver throughout their lives. They can be a constant relational anchor through life's many changes and transitions, helping to activate other community partners to meet the varied, sometimes complex needs of their patients.

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LEARNING POINTS

- **Care for PWID may often require support from services within the healthcare, disability, and social service sectors.**
- **Family physicians can play the role of relational anchor for patients with intellectual disability and their caregivers in the community.**
- **Based on relationship and deep knowledge of the patient and caregiver, the family physician leverages services to meet their needs.**
- **To help them fulfil this role well, the family physician should be familiar with the contact details of the agency for integrated care (AIC), SG Enable (SGE), and the Family Service Centre (FSC) in their neighbourhood.**

ASSESSMENT OF 30 MCQS

FPSC NO : 132
MCQS ON PERSONS WITH INTELLECTUAL DISABILITIES 4
SUBMISSION DEADLINE: 7 APRIL 2026, 12 NOON

INSTRUCTIONS
- **To submit answers to the following multiple choice questions, you are required to log on to the College Online Portal (https://lms.wizlearn.com/cfps/)**
- **Please contact sfp@cfps.org.sg if you have not received an email on the new LMS account.**
- **Attempt ALL the following multiple-choice questions.**
- **There is only ONE correct answer for each question.**
- **The answers should be submitted to the College of Family Physicians Singapore via the College Online Portal before the submission deadline stated above.**
- **There will be NO further extension of the submission deadline**

1. The barriers persons with intellectual disability (PWID) face in accessing healthcare include:

A. Communication limitations
B. Lack of expertise and skillsets in healthcare professionals
C. Diagnostic overshadowing
D. All of the above
E. None of the above

2. The life expectancy of PWID is:

A. Shorter than before
B. Longer than before
C. Same as the general population
D. Same as before
E. Longer than before but shorter than the general population

3. Premature ageing in PWID is related to:

A. Genetics
B. Environmental factors
C. Caregiver factors
D. A and B only
E. A, B, and C

4. Palliative care in PWID is:

A. Challenging due to communication limitations
B. Well addressed as palliative physicians are very holistic
C. Less complex as they have no mental capacity
D. Not related to ethical issues
E. Not different from providing palliative care for the general population

5. Providing good healthcare for PWID does NOT involve:

A. Promoting autonomy and providing support in decision-making
B. Leaving their caregivers out of it so they can rest
C. Understanding that their health profiles are different from the general population
D. Equipping healthcare professionals with additional skillsets
E. Ensure that there is sufficient time for clinical consultations

6. A 32-year-old man with moderate intellectual disability presents with new-onset agitation and aggression. What should be the most appropriate first step in the primary care assessment?

A. Start an antipsychotic medication
B. Assess for the possibility of a new psychiatric disorder
C. Exclude medical causes of pain or discomfort
D. Reassure his caregiver that behaviour challenges are normal and expected in PWID
E. Refer to a psychiatrist

7. Which of the following best describes diagnostic overshadowing in PWID?

A. Over-diagnosis of psychiatric disorders in PWID
B. Attributing behavioural changes solely to intellectual disability
C. Inability to distinguish depression from anxiety in PWID due to overlapping symptoms
D. Use of caregiver reports for diagnosis instead of the patient's self-report
E. Failure to use DSM-5 diagnostic criteria

8. Which of the following is an atypical presentation of depression in a person with severe intellectual disability?

A. Persistent screaming and aggression
B. Diurnal mood variation
C. Expressed feelings of worthlessness
D. Excessive rumination
E. Verbalised low mood

9. In assessing anxiety in a non-verbal adult with intellectual disability, which of the following is most helpful?

A. Asking the patient to self-rate anxiety severity
B. Using standard anxiety scales designed for the general population
C. Observing behavioural signs such as agitation or self-injury
D. Relying solely on DSM-5 symptom descriptions
E. Avoiding formal assessment due to communication difficulties

10. Which of the following principles BEST reflects appropriate pharmacological management of depression or anxiety in PWID in primary care?

A. Benzodiazepines are first-line for managing behavioural issues as it enables rapid symptom control
B. Higher doses of antipsychotics can be given as PWID are less sensitive to its effects
C. Beta blockers are first-line in treatment of anxiety disorders
D. Medications should be prescribed without caregiver involvement
E. SSRIs or SNRIs may be used with low starting doses and slow titration

11. Which mechanism best explains why slowing speech and reducing verbal load can improve engagement in PWID?

A. Increased auditory processing speed
B. Enhanced lexical retrieval
C. Reduced cognitive load and autonomic threat response
D. Improved expressive syntax
E. Increased working memory capacity

12. Which statement best reflects a person-centred communication stance in primary care?

A. Communication ability is primarily determined by IQ
B. Caregivers should speak on behalf of PWID
C. Behaviour should be addressed before communication
D. Communication is a shared responsibility between partners
E. Time constraints make adaptations impractical

13. PWID use repeated phrases or scripted speech when responding to questions. What is the MOST appropriate clinical approach?

A. Redirect questions to the caregiver
B. Interpret responses literally
C. Discontinue attempts at direct communication
D. Assume lack of understanding
E. Focus on the function of the communication within context

14. Why are visual supports particularly effective during states of emotional or sensory dysregulation?

A. They increase vocabulary exposure
B. They bypass the need for expressive speech
C. They reduce reliance on higher-order language processing
D. They improve articulation accuracy
E. They eliminate behavioural responses

15. Why is attunement particularly important when communicating with PWID during medical consultations?

A. It ensures compliance with medical instructions
B. It precedes language access by supporting autonomic regulation
C. It allows clinicians to shorten consultations
D. It replaces the need for verbal explanations
E. It is mainly relevant for paediatric patients

16. Regarding cognitive decline and dementia in autistic adults, which statement is most accurate?

A. Dementia risk is similar to the general population
B. Dementia occurs only after age 65 in autistic adults
C. Autistic adults have a lower risk of dementia due to neuroplasticity
D. Autistic adults have increased risk of early-onset dementia
E. Dementia prevalence in autistic adults is unknown

17. Which mental health prevalence estimate best reflects findings in autistic adults?

A. Anxiety ~5%, depression ~10%
B. Anxiety ~20%, depression ~14%
C. Anxiety ~42%, depression ~37%
D. Anxiety ~1.6%, depression ~6.3%
E. Anxiety ~10%, depression ~12%

18. Which factor most likely contributes to the under-recognition of physical and mental health conditions in older autistic adults?

A. Reduced prevalence of chronic illness with age
B. Diagnostic overshadowing and communication barriers
C. Higher health literacy among autistic adults
D. Overuse of preventive healthcare services
E. Increased symptom reporting in primary care

19. According to studies of older autistic adults, which condition listed below shows the highest risk compared with non-autistic controls?

A. Hypertension
B. Diabetes mellitus
C. Gastrointestinal disorders
D. Schizophrenia and psychotic disorders
E. Obesity

20. Which of the following is a modifiable risk factor for cognitive decline that is particularly common in autistic adults?

A. Age
B. Smoking
C. Gender
D. Head injury
E. Depression

21. Jannah, a 28-year-old woman with mild intellectual disability, arrives at your clinic for chronic review of her Type 2 diabetes mellitus, accompanied by her mother. During the consultation, Jannah appears anxious and keeps looking at her mother before answering questions. Her mother frequently interrupts to "correct" Jannah's responses. What is the most appropriate approach?

A. Direct all questions to her mother to expedite the consultation
B. Ask her mother to wait outside to reduce interruption and ensure patient confidentiality
C. Terminate the consultation and reschedule when Jannah can attend alone
D. Acknowledge Jannah's autonomy by directing questions to her first and allowing time for her responses, before speaking to her mother
E. Use only written communication to avoid her mother's interference

22. When scheduling appointments for patients with ASD, which adjustment is most likely to reduce anxiety and improve the consultation experience?

A. Providing consistent appointment days and timings, and allowing longer consultation periods
B. Offering shorter 10-minute appointments to minimise patients' discomfort
C. Advising them to walk-in whenever they feel comfortable and ready—No appointment required
D. Requiring all patients to wait in a communal waiting area for socialisation
E. Scheduling appointments with different GPs each visit

23. A Social Story for PWID and patients with ASD is a:

A. Clinical case study of intellectual disability and/or ASD for educational purposes
B. Set of rules used to manage challenging behaviour in clinical settings
C. Visual tool with simple language and pictures in a step-by-step sequence that helps patients know what to expect during a clinic visit
D. Validated assessment tool used to explore patients' social background
E. Educational leaflet on PWID and patients with ASD, targeted at the general population

24. Jim, a 35-year-old man with ASD and moderate intellectual disability, becomes visibly distressed during physical examination for a presenting complaint of knee pain, rocking back and forth and covering his ears. His father mentions that he is sensitive to touch and loud noises. What is the most appropriate immediate response?

A. Continue the examination quickly to minimise duration of distress
B. Pause the examination, lower your voice, and explain each step before proceeding
C. Ask his father to restrain Jim so you can complete the examination safely
D. Refer Jim to A&E as the examination is unlikely complete
E. Administer sedation to help Jim tolerate the examination

25. Which approach best demonstrates the principle of supported decision-making for PWID?

A. Doctors should make all healthcare decisions on behalf of the PWID to ensure optimal outcomes
B. Providing information in accessible formats and supporting the patient in expressing their preferences
C. Requiring a legal guardian to make all medical decisions
D. Refer to a psychiatrist to facilitate consent-taking
E. Limiting treatment options to reduce decision-making burden

26. Which of the following best describes the role of the family physician in caring for adults with intellectual disability in the community, as proposed in this paper?

A. Acting as the primary coordinator who directly manages all medical and social services
B. Serving mainly as a referral gatekeeper to specialist and disability services
C. Providing episodic medical care while social services address non-medical needs
D. Functioning as a relational anchor who links patients and caregivers with appropriate services
E. Transferring care to specialist services once complexity increases

27. Which of the following best explains why adults with intellectual disability might remain unknown to the healthcare system until significant health issues arise?

A. Adult disability services provide comprehensive medical care
B. There is a clearly defined medical specialty for adult intellectual disability
C. Transition from paediatric to adult care may occur without an identified medical provider
D. People with intellectual disability are fearful of seeing doctors
E. Caregivers prefer to manage health issues independently

28. An adult with intellectual disability has been staying at home since graduating from special school. He is not enrolled in any adult disability service and spends most days watching television. His mother reports exhaustion and difficulty attending to her own medical appointments.

Which is the MOST appropriate initial referral to address both the individual's and caregiver's needs?

A. Referral to Adult Neurodevelopment Service (ANDS) at IMH
B. Referral to a sheltered workshop
C. Referral to a family service centre (FSC)
D. Referral to an acute hospital social worker
E. Referral to Enabling Services Hub (ESH) via SG Enable

29. A caregiver reports that her adult son with intellectual disability has recently begun shouting and hitting others at home. He has a history of epilepsy and chronic constipation but has not had a medical review in over a year. According to the approach outlined in Figure 1 (refer to pg 44), what is the MOST appropriate first step?

A. Immediate referral to psychiatric services
B. Initiation of behavioural modification strategies
C. Review and management of possible medical contributors to distress
D. Referral to disability case management programme (DCMP)
E. Commencement of antipsychotic medication

30. A 70-year-old mother caring for her 45-year-old daughter with intellectual disability reports increasing fatigue and difficulty managing daily caregiving tasks. She is concerned about her own health but has no immediate plans for institutional care. Which of the following is the MOST appropriate initial referral pathway to support this caregiver?

A. Adult disability day activity centre
B. Agency for Integrated Care (AIC) for caregiver support and home care services
C. Institute of Mental Health outpatient clinic
D. Acute hospital geriatric service
E. Protection Specialist Centre (PSC)

FPSC 131 "Lifestyle Medicine" Answers to 30 MCQs

1.	B	11.	A	21.	E
2.	A	12.	E	22.	C
3.	C	13.	C	23.	C
4.	D	14.	B	24.	A
5.	C	15.	C	25.	B
6.	B	16.	D	26.	A
7.	C	17.	A	27.	B
8.	B	18.	C	28.	D
9.	E	19.	E	29.	A
10.	A	20.	C	30.	E

READINGS

A SELECTION OF TEN READINGS ON TOPICS RELATED TO
PERSONS WITH INTELLECTUAL DISABILITIES 4

A SELECTION OF TEN READINGS ON TOPICS RELATED TO PERSONS WITH INTELLECTUAL DISABILITIES 4

FPSC132 – SATURDAY, 31 JAN 2026 & SUNDAY, 1 FEB 2026: 2.00pm–5.15pm
All are available as Free full text

Selection of readings made by A/Prof Goh Lee Gan

READING 1. ASSOCIATION BETWEEN TRIGLYCERIDE-GLUCOSE INDEX, BLOOD PRESSURE STATUS, AND CHD RISK

Liu H,[1,#] Wang Y,[1] Wang T,[1] Jiang C,[1] Wu H,[1] Wu J,[1] Li Y.[1,2,#] Association Between Triglyceride-Glucose Index, Blood Pressure Status, and Coronary Heart Disease Risk Among Chinese Adults With Disabilities: 10-Year Disability Health Survey Cohort Study. JMIR Public Health Surveill. 2025 Nov 3;11:e78068. PMID: 41183379.

doi: 10.2196/78068. PMID: 41183379. Free full text.

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ABSTRACT

BACKGROUND: The triglyceride-glucose (TyG) index and blood pressure (BP) status are key indicators associated with coronary heart disease (CHD). However, limited research has focused on individuals with disabilities.

OBJECTIVE: This study explores the potential combined effects of the TyG index and BP status on CHD risk in groups with varying disability characteristics.

METHODS: This study analysed data from the Shanghai Disability Health Survey, conducted between January 2012 and December 2022. Participants were then categorised into three BP status groups: nonelevated BP, elevated BP, and hypertension. Cox proportional hazards regression models were used to assess the associations between BP status, the TyG index, and CHD incidence. Additionally, the mediating, interaction, and combined effects of these factors on CHD risk were examined. A stratified analysis was performed based on participants' disability characteristics, including disability type and severity, to explore potential variations in the associations.

RESULTS: Among the 21,628 participants, the mean age was 53.30 (SD 10.57) years, and 50.89% (11,007/21,628) were male. In a follow-up of 77.45 months, CHD events occurred in 2,312 participants (10.69%). The TyG index and BP status were independently associated with an increased risk of CHD. Mediation analysis showed that TyG explained 20.5% (95% CI 13.6% p–22.0%) of the BP and CHD association. Significant multiplicative interactions were identified (hazard ratio [HR] 1.41, 95% CI 1.02–1.94), and joint analysis indicated the highest CHD risk in those with both hypertension and elevated TyG (HR 1.92, 95% CI 1.52–2.42). Stratified analyses revealed stronger mediation in participants with physical disabilities (22.6%, 95% CI 9.0%–60%) or visual disabilities (16.6%, 95% CI 4.8%–51%), while this was not significant in those with hearing or speech (P=0.07) or intellectual or mental disabilities (P=0.13). By disability grading, the mediated proportion was 22.3% (95% CI 9.2%–59.4%) in mild or moderate and 18.8% (95% CI 15.7%–29%) in severe or very severe groups. Joint associations showed consistently higher CHD risk across most disability classifications, with particularly elevated risk in people with intellectual or mental disabilities (HR 3.51, 95% CI 1.89–6.50).

CONCLUSIONS: BP and the TyG index were significantly associated with CHD risk in individuals with disabilities, with TyG mediating a part of this association and showing stronger effects in physical and mild to moderate disabilities. Significant interactions between BP and TyG further highlight their combined impact, underscoring the need for integrated interventions targeting both factors.

READING 2. INTELLECTUAL FUNCTIONING AND DISABILITY IN SINGAPORE'S LEGAL LANDSCAPE

Teo AZJ,[1] Sng DLJ,[2] Tan SWL,[2] Xiang LX.[2] Examining intellectual functioning and disability in Singapore's legal landscape. Int J Law Psychiatry. 2025 Nov–Dec;103:102137. PMID: 40829359.

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ABSTRACT
Individuals with intellectual disabilities constitute a significant portion of those managed within the criminal justice system. Courts are increasingly challenged with determining appropriate sentencing. Additionally, many of these individuals have complex social and medical backgrounds, necessitating a multidisciplinary approach to assess their legal and moral culpability. Consequently, these factors impact sentencing outcomes, including decisions regarding incarceration versus rehabilitation programmes. This current study utilises all available court judgements involving intellectual functioning and disability recorded on LawNet (Singapore's legal database) from 1985 to 2024 to examine their relationship with sentencing considerations. Broadly, this study reviews sentencing considerations related to individuals' intellectual functioning and the legislation in place to support this population. Specifically, this study further scopes into examining the outcomes of judgements that had the offender undergo an intellectual ability assessment, and its relation to current legislative frameworks' responses to the complex process of judicial decision-making. Hence, this study examines the challenges faced in tailoring legislative frameworks to the complex nature of intellectual functioning and disability in Singapore's legal arena.

READING 3. CHALLENGES IN PROVIDING PARENTING SUPPORT

Tanaka E,[1] Sugiura K,[2] Hodes MW,[3] Feldman MA.[4] Challenges in Providing Parenting Support for Parents With Intellectual Disabilities in Japan. J Appl Res Intellect Disabil. 2025 May;38(3):e70068. PMID: 40462213.

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ABSTRACT
BACKGROUND: While there is now considerable research on parenting by PWID, most of this research comes from Western countries. A dearth of information exists about families headed by parents with intellectual disabilities from other countries. This paper summarises the state of research and practice in Japan, related to existing knowledge in the field.

METHOD: We conducted a review of Japanese research and media information about parents with intellectual disabilities, relating the situation in Japan to existing research from primarily Western countries.

RESULTS: Evidence obtained suggests that Japan is only recently making progress in dispelling eugenics mythology about sexuality and parenting in PWID and recognising the need for specialised supports.

CONCLUSIONS: We make eight recommendations for future research, policy, and practice in Japan, including ending discriminatory practices, funding needed supports, and educating and training workers and professionals in evidence-based supports.

READING 4. EARLY DEVELOPMENTAL LEVELS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

Song C,[1] Han T,[1] Hu L,[1] Shao N,[1] Wang Z,[1] Jin Y,[1] Chen T,[1] Zhu Z.[2] Early developmental levels of children with autism spectrum disorder with different adaptive behaviours: a retrospective analysis. J Zhejiang Univ Sci B. 2024 Nov 15;25(11):1031–1038. PMID: 39626884.

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ABSTRACT

The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) (American Psychiatric Association, 2013) defines autism spectrum disorder (ASD) as a complex neurodevelopmental disorder that begins in early childhood and is accompanied by social communication deficits and repetitive stereotyped behaviours.

According to the monitoring data released in 2021 in the United States, the prevalence of ASD in children was as high as 2.27%; that is, one in 44 children had autism (Maenneret al, 2021). China publicly reported this figure to be around 0.7% (Zhou et al, 2020).

The current view is that children with ASD are generally impaired in their adaptation ability (McDonald et al, 2016; Hodge et al, 2021; Operto et al, 2021). Adaptive behaviours comprise the conceptual, social, and practical skills that enable individuals to adapt to the environment, which play an important role in daily life (McDonald et al., 2019). "Adaptive behaviour" was first described by Doll (1936). Subsequently, abnormalities in adaptive behaviour were included in the criteria for intellectual disability for the first time (Heber, 1961). The American Association on Mental Retardation (AAMR) has refined and specified this term several times. Researchers hold different opinions on the structure of social adaptive capability. Greenspan and Granfield (1992) divided social adaptive capability into social understanding and social interaction.

However, an increasing number of scholars considered that the concept of adaptive behaviours in children was constructed via multiple dimensions. The most representative one among them was the Vineland Adaptive Behaviour Scales (VABS) proposed by Sparrow et al (1984). This scale illustrates that adaptive behaviour includes communication, daily living skills, socialisation, and motor skills. Harrison and Oakland (2003) developed an Adaptive Behaviour Assessment System (ABAS) by applying the theory of adaptive behaviour proposed by AAMR and the American Association on Intellectual and Developmental Disabilities (AAIDD). This system shows that adaptive behaviour has three adaptive composites, namely, conceptual composite (including communication, learning function, and self-management), social composite (including leisure and social skills), and practical composite (including community application, home living, health and safety, and self-care). As there are different requirements for the social adaptive capability of children from different cultural backgrounds and various regions, Chinese scholars have translated the Normal Development of Social Skills from Infant to Junior High School Children (S–M) scale compiled by Japanese scholars into Chinese, which is now widely used in China (Zhang et al, 1995). The impairment of adaptive function in children with ASD includes multiple dimensions, such as socialisation, communication, and daily living skills (Kanne et al, 2011), and the degree of impairment can predict the prognosis and outcome in real life, including education acquisition and independent living ability (Farley et al, 2009).

Therefore, adaptive behavioural capacity is considered to be a key intervention point that directly affects the individual and social outcomes of autistic children (Veenstra-VanderWeele et al, 2017; Bölte et al, 2019).

READING 5. EXPERIENCES OF WORKING WITH SUPPORT WORKERS IN SERVICES FOR ADULTS WITH INTELLECTUAL DISABILITIES IN HONG KONG

Xun K,[1,2] Jiao R,[3,4] Deng Y.[5] Social Workers' Experiences of Working With Support Workers in Services for Adults With Intellectual Disabilities in Hong Kong. J Appl Res Intellect Disabil. 2024 Nov;37(6):e13301. PMID: 39370132.

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ABSTRACT

BACKGROUND: Services for adults with intellectual disabilities in Hong Kong have a hierarchical staffing structure. Professional social workers, who performed as mid-level employees, work with frontline support workers to deliver services to clients.

METHODS: This qualitative study explored social workers' experiences of working with support workers through in-depth interviews with 13 participants.

FINDINGS: The study revealed that social workers perceived a significant variation between themselves and support workers in terms of working motivation, values, and attitudes towards clients with intellectual disabilities. Despite the hierarchical relationships, social workers and support workers share the power of service decision-making. Social workers used firm and gentle approaches to facilitate changes in practices to uphold service values. These findings were compared with Western literature on this topic, indicating similarities and differences.

CONCLUSION: The organisations need to facilitate an effective collaboration between social workers and support workers to enhance the quality of services for adults with intellectual disabilities in Hong Kong.

READING 6. INEQUALITIES CHANGES IN HEALTH SERVICES UTILISATION AMONG MIDDLE-AGED AND OLDER ADULT DISABLED PEOPLE IN CHINA

Jin S,[1,2,#] Wu J,[1] Lin J,[1] Zhang S,[1] Ali M,[1] Fa R,[1,#] Chen S,[1,#] Qian D.[1,2,#] Inequalities changes in health services utilization among middle-aged and older adult disabled people in China: based on CHARLS 2011–2018. Front Public Health. 2024 Oct 1;12:1434106. PMID: 39411495.

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ABSTRACT

BACKGROUND: Multiple intersections, including socioeconomic inequalities, influence health equity for disabled people and sub-populations. However, this association has not been sufficiently analysed among Chinese-impaired persons. This study aimed to investigate the health services utilisation and inequalities in middle and older adult persons with disabilities and subgroups.

METHODS: The China Health and Retirement Longitudinal Study (CHARLS) database in 2011, 2013, 2015, and 2018 were used. Health services utilisation was measured by outpatient, inpatient, and self-treatment service utilisation. Types of disabilities were classified into six categories. The pooled cross-section regression, concentration index, horizontal inequity index, and concentration index decomposition were used to evaluate inequalities and explore their main contributing factor.

RESULTS: The utilisation and non-utilisation of healthcare services showed variations across years ($p<0.05$). The CIs and HIs for inpatient health service utilisation were positive for all years and disability types. The total CIs of inpatient utilisation were the highest (0.248). The highest disparities in utilisation of inpatient services were for physical disabilities (0.4515 for CI in 2011), and the highest in self-treatment services were for intellectual disability (0.1538 for CI in 2011). The expenditure factor was the main contributor to inequalities. Chronic disease, educational level, and health insurance factors also contribute to the utilisation inequalities.

CONCLUSION: Policies should promote medical insurance and assistance for disabled people with serious impairment and poor. It is crucial to improve the provision of basic medical services, including meeting the demand for varied disabilities and the accessibility of facilities and equipment to enhance the access and well-being of people with disabilities.

READING 7. FACTORS RELATED TO REGULAR DENTAL CHECK-UPS IN ADULTS WITH INTELLECTUAL DISABILITIES IN JAPAN

Nonoyama T,[1] Nonoyama K,[2] Shimazaki Y.[3] Factors Related to Regular Dental Check-Ups in Adults With Intellectual Disabilities in Japan. Int Dent J. 2024 Oct;74(5):953–959. PMID: 38461096.

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ABSTRACT
BACKGROUND: We investigated the factors associated with regular dental check-ups among adults with intellectual disabilities in Japan, with the aim of increasing the attendance rate of regular dental check-ups, which are important for maintaining the oral health of persons with intellectual disabilities.

METHODS: A questionnaire survey focused on oral health was conducted with 971 adults with intellectual disabilities in Japan. The survey included questions related to disability diagnosis, severity of intellectual disability, residence type, and several oral-health factors, including proxy-reported number of teeth, presence of a family dentist, frequency of regular dental check-ups, tooth-brushing habits, and availability of a dental hygienist at a facility. Logistic regression analysis was used to determine the association between regular dental check-ups (dependent variable) and independent variables. Odds ratios (ORs) and 95% confidence intervals (CIs) were calculated.

RESULTS: In a multivariate analysis, sex, diagnosis of disability, severity of intellectual disability, residence type, and the presence of a family dentist were significantly associated with regular dental check-ups. The ORs for nonregular dental check-ups were significantly higher for adults with Down syndrome, those with mild disability, and those living at home with family; the respective mean ORs (95% CIs) were 2.3 (1.2–4.4), 3.3 (1.3–8.4), and 1.8 (1.1–3.0). The absence of a family dentist had a particularly strong association with a lack of regular dental check-ups, with a mean OR (95% CI) of 15.0 (8.7–26.0).

CONCLUSIONS: Regular dental check-ups among adults with intellectual disabilities in Japan were associated with sex, diagnosis of disability, severity of disability, type of residence, and the presence of a family dentist.

READING 8. PREVALENCE OF MILD COGNITIVE IMPAIRMENT AND ITS ASSOCIATION WITH MALNUTRITION IN OLDER CHINESE ADULTS IN THE COMMUNITY

Wang LY,[1,2] Chen HX,[2] Hu XY,[2] Hu ZY,[3] Zhou CF.[4] Prevalence of mild cognitive impairment and its association with malnutrition in older Chinese adults in the community. Front Public Health. 2024 Aug 14;12:1407694. PMID: 39206002.

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ABSTRACT

OBJECTIVE: This study aims to characterise the prevalence and associated factors of cognitive impairment in older adults within Chinese community settings.

BACKGROUND: Research exploring the interrelation between malnutrition and cognitive impairment in the older adult community-dwelling population is scarce. The impact of nutritional status on cognitive function in ageing adults has not been definitively established.

METHODS: A cross-sectional survey was conducted in one urban and one rural community in Chengdu, China, from October 2022 to March 2023. The sample included 706 older adults. Logistic regression was utilised to determine independent risk factors for mild cognitive impairment (MCI).

RESULTS: The study found a significant prevalence of MCI at 32.0% among the older adult population. Among those suffering from malnutrition, 55.6% were affected by MCI. The logistic regression analysis indicated that malnutrition risk (OR=2.192, 95% CI 1.431 to 3.357, p<0.001), rural residence (OR=1.475, 95% CI 1.003 to 2.170, p=0.048), age (70–79 years old; OR=2.425, 95% CI 1.611 to 3.651, p<0.001; ≥80 years old: OR=4.773, 95% CI 2.571 to 8.859, p<0.001), male (OR=1.584, 95% CI 1.085 to 2.313, p=0.017), middle education level (OR=0.986, 95% CI 1.627 to 5.482, p<0.001), and ADL dependence (OR=1.810, 95% CI 1.158 to 2.827, p=0.009) were significantly associated with the occurrence of MCI.

CONCLUSION: The findings indicate a widespread occurrence of MCI in community-dwelling older Chinese adults. The association between malnutrition, as measured by the Mini Nutritional Assessment-Short Form (MNA-SF), and cognitive decline is evident. Older adult individuals with nutritional risk, advancing age, rural residence, male sex, moderate education, and ADL dependency are at increased likelihood of developing MCI. Longitudinal research is needed to clarify the temporal relationships between MCI, demographic factors, and whether improvements in nutritional status or ADL can reduce the incidence of MCI in this population.

READING 9. IMPACT OF INCOME AND FINANCIAL SUBSIDIES ON ORAL HEALTH CARE UTILISATION AMONG PERSONS WITH DISABILITIES IN SINGAPORE

Tan SHX,[1] Gao X,[1,2] Lee GKY,[2] Goh CE,[2] Tong HJ,[2] Chuang JCP,[3] Ang KY,[3] Lim DGX.[4,5] Impact of income and financial subsidies on oral health care utilisation among persons with disabilities in Singapore. Community Dent Oral Epidemiol. 2024 Jun;52(3):336–343. PMID: 38644526.

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ABSTRACT

BACKGROUND/AIM(S): Globally, studies have shown that the dental disease burden among persons with intellectual and/or developmental disabilities (IDD) is high and can be attributed to lower utilisation levels of dental services. The aim of the study was to assess the influence of income and financial subsidies on the utilisation of dental care services among persons with IDD in Singapore.

METHODS: Between August 2020 and August 2021, a cross-sectional study was conducted via centres offering Early Intervention Programme for Infants and Children, special education schools, and adult associations in Singapore serving persons with IDD. A sample of 591 caregivers of children and adults with IDD completed the survey. Data on sociodemographic information, oral health behaviours and dental utilisation were collected. Financial subsidy status was assessed by the uptake of a government-funded, opt-in Community Health Assist Scheme (CHAS) for low-income families that provided a fixed subsidy amount for dental services in the primary care setting. Statistical analysis was carried out using univariable, multiple logistic regression, and modified Poisson regression. Propensity score matching was carried out in R version 4.0.2 to assess the impact of financial subsidies on oral health care utilisation among persons with IDD.

RESULTS: Compared to those with lower gross monthly household incomes, the adjusted prevalence ratios of having at least one dental visit in the past year, having at least one preventive dental visit in the past year, and visiting the dentist at least once a year for persons with IDD with gross monthly household incomes of above SGD$4,000 were 1.28 (95% CI 1.08–1.52), 1.48 (95% CI 1.14–1.92), and 1.36 (95% CI 1.09–1.70) respectively. Among those who were eligible for CHAS Blue subsidies (247 participants), 160 (62.0%) took up the CHAS Blue scheme and 96 (35.4%) visited the dentist at least yearly. There was no statistically significant difference in the utilisation of dental services among individuals enrolled in the CHAS Blue subsidy scheme among those eligible for CHAS Blue subsidies.

CONCLUSION: Higher household income was associated with a higher prevalence of dental visits in the past year, preventive dental visits in the past year, and at least yearly dental visits. CHAS Blue subsidies alone had limited impact on dental utilisation among persons with IDD who were eligible for subsidies.

READING 10. HEALTH SUPPORT OF PEOPLE WITH INTELLECTUAL DISABILITY AND THE CRUCIAL ROLE OF SUPPORT WORKERS

Nijhof K,[1,2] Boot FH,[3,4] Naaldenberg J,[5,6] Leusink GL,[5,6] Bevelander KE.[5,6] Health support of people with intellectual disability and the crucial role of support workers. BMC Health Serv Res. 2024 Jan 2;24(1):4. PMID: 38167137.

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ABSTRACT

BACKGROUND: People with intellectual disability have a poorer health status than the general population. In the Netherlands, support workers play a key role in meeting health support needs of PWID. Research on how PWID and their support workers experience the support worker's role in preventing, identifying, and following up health needs of PWID is scarce. To enhance health support of PWID, it is crucial that we understand how health support is delivered in everyday practice. Therefore, this study investigated experiences of PWID and support workers with the health support of PWID.

METHOD: Data collection consisted of six focus group (FG) discussions with between four and six participants (N=27). The FGs consisted of three groups with support workers (n=15), two groups with participants with mild to moderate intellectual disability (n=8), and one group with family members as proxy informants who represented their relative with severe to profound intellectual disability (n=4). The data was analysed thematically on aspects relating to health support.

RESULTS: We identified three main themes relevant to the health support of people with intellectual disability: 1) dependence on health support, 2) communication practices in health support, and 3) organisational context of health support. Dependence on health support addresses the way in which support workers meet a need that PWID cannot meet themselves, and communication practices and organisational context are identified as systems in which health support takes place.

CONCLUSION: This study investigated experiences with the health support of PWID from the perspectives of PWID and support workers. We discuss the dependence of PWID and the complexity of health support in everyday practice. We provide practical implications that can strengthen support workers in the provision of health support for PWID in everyday practice. The findings of this study emphasise the need for intellectual disability care-provider organisations to establish policies around consistency in support staff to make it easier to identify and follow up health needs, and an environment where support staff can develop their expertise concerning communication practices, lifestyle choices, and identifying and following up health needs.

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  Describe the selection of the subjects clearly, including eligibility and exclusion criteria and a description of the source population. If the study was done involving an exclusive population, for example in only one sex, authors should justify why, except in obvious cases (e.g., prostate cancer). Authors should define how they determined race or ethnicity and justify their relevance.
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- **Statistics (if applicable):** Describe statistical methods that can be easily understood and verified by the reader. Use technical terms in its proper place, and where possible quantify readings and indicate errors of uncertainty and confidence intervals.

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  Where there are more than six authors, the first three should be named and then followed by "et al".

  Example:
  Moussavi S, Chatterji S, Verdes E, Tandon A, Patel V, Ustun B. Depression, chronic diseases, and decrements in health: results from the World Health Surveys. Lancet. 2007 Sep;370(9590):851–8. https://doi.org/10.1016/S0140-6736(07)61415-9.

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Tables should be submitted on a separate page. Label them in Roman-numeric sequence [I, II, III, etc] and ensure they are clear and with explanatory legends as required. Give each column a short or abbreviated heading. Place Table explanations in the footnotes, not in the heading. Explain in footnotes all non-standard abbreviations that are used in each Table.

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Concluding Paragraph
Summarise your main findings and its clinical implication, preferably in a single paragraph and no more than 3-4 sentences. Link the conclusions with the goals of the study but avoid unqualified statements and conclusions not adequately supported by the data. In particular, distinguish between clinical and statistical significance, and avoid making statements on economic benefits and costs unless the manuscript includes the appropriate economic data and analyses. Avoid claiming priority or alluding to work that has not been completed. State new hypotheses when warranted, but label them clearly.

Learning Points (for invited Family Physician Skills Course article)
Include a minimum of three (3) Learning Points as a take-home message for readers.

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The Case Records of Family Medicine is a newly created series to encourage submissions from Family Medicine teaching programmes and for Family Medicine departments to submit cases of learning value to the *Singapore Family Physician*. Cases discussed during peer review learning and Family Medicine grand ward round teachings are just some examples of submissions that are suitable for this

series. Authors planning to submit their case studies to the Case Records of Family Medicine section should structure their article according to these headings:

Title
The title should define the key focus of the case study.

Case Presentation
The author(s) will provide a pertinent summary of the medical and/or psychosocial issue pertaining to the health or disease management of the case. It should cover the situation and relevant background of the case. Author(s) should conceal the identity of the subject and/or related or accompanying personnel; abbreviation should be used instead, if necessary.

Diagnoses/Problems identified
The assessment of the diagnoses/problems identified will constitute a problem list and will serve as a focus for the management of the case. If the case was a diagnostic dilemma, the author(s) should showcase the diagnostic challenges and their work in narrowing to the correct diagnosis and/or differential diagnoses.

Management of the case
This section covers the approach to the management of the case by the author(s).

Literature review on latest evidence/guidelines (related to diagnosis and/or management)

The author(s) should provide a literature review of current evidence/guidelines, if any, of the basis of the case's diagnosis/management, or to highlight the gaps of knowledge if such evidence is lacking.

The author(s) will provide a concise summary of the lessons learnt from this case study.

Clinical Practice pointers (up to three (3))
The author(s) will suggest ways to apply the new knowledge in clinical practice or to highlight the limitations of its applications, if any.

RECOMMENDED FORMAT FOR PRISM (Patients' Revelations as Insightful Studies of their Management) SECTION

Authors planning to submit their case studies to the PRISM section should structure their article according to these headings:

Title
The title should be framed into a question to define the key focus of the case study.

Patient's revelation: What happened?
The author(s) will provide a concise description of the setting in which the subject raised his/her medical or psychosocial issue pertaining to their health or disease management. It should cover the background, encounter, and interaction of patient with the healthcare professional (doctor, nurse, or allied healthcare professional).

Author(s) should conceal the identity of the subject and/or related or accompanying personnel: abbreviation should be used instead, if necessary.

Gaining insight: What are the issues?
The issue(s) raised by the patient should be framed into question(s). The question(s) will constitute a problem list and will serve as a focus for the management of this subject.

Study the management: How do we apply in our clinical practice?
This section covers the approach to the management of the subject by the author(s). The author(s) should provide a literature review of current evidence, if any, of the basis of the subject's management, or to highlight the gaps of knowledge if such evidence is lacking. The author(s) will suggest ways to apply the new knowledge in clinical practice or to highlight the limitations of its applications, if any.

Conclusion
The author(s) will provide a concise summary of the lessons learnt from this case study.

The article submitted to the PRISM section should be written by no more than three authors. Each article should not exceed 2,000 words. Photographs or charts may be included but should conform to the specific instructions for any other articles submitted to *The Singapore Family Physician*.

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