Intellectual disability (ID) is a significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), beginning before adulthood with a lasting effect on development.\(^1\) Patients with ID are seen in all specialties, yet one finds little to no focused training regarding their care in most undergraduate medical programs.\(^2\) This leads not only to ignorance of medical students, but creates barriers for this population in accessing adequate healthcare.\(^3\) In surveying physicians, they felt they lacked adequate training to equip them to care for patients with ID.\(^3\)

**WHY INTELLECTUAL DISABILITY (ID) TRAINING IS RELEVANT**

In an average family physician practice of 7,500 patients, 25 individuals (0.33\%) will have intellectual disabilities.\(^4\) The prevalence of severe and profound ID is 3-4 per 1,000 births (0.3-0.4\%).\(^4\) Within this group of patients, there are clear negative health trends that can be attributed to their illness, but also to the quality of care received. While life expectancy overall is improving, people with ID continue to have a reduced life expectancy compared with the population as a whole.\(^4\) For example, life expectancy for the general population in developed countries is typically 81 years for women and 76 years for men.\(^5\) In the ID population, life expectancy negatively correlates with increased severity of the disability: individuals with mild to moderate level disability have a life expectancy of approximately 65 years, and with severe disability it is even further reduced.\(^5\) The top causes of mortality include respiratory disease (pneumonia, inhalation, choking), heart disease (congenital), cancer (esophageal, stomach, and gall bladder cancer and leukemia), accidents and injuries, and seizures.\(^7\)

People with ID suffer from a range of morbidities with differing trends compared to the general population. There is a higher prevalence of lifestyle-related health problems such as obesity, poorer levels of physical fitness and nutritional problems, issues with poly-pharmacy, multiple complex chronic disorders, twice the risk of hospitalization, incontinence, increased prevalence of dental disease, and greater risk of psychiatric illnesses.\(^6,8\) Conversely, health problems related to smoking, alcohol, and use of illegal drugs are less prevalent.\(^7\) Difficulties with communication are common, and can lead to under-recognition of common disorders, and thus rely heavily on a third party to advocate their needs.\(^6\) Some problem behaviours, such as self-injury and pica, are more specific to people with ID and may be associated with particular genetic syndromes.\(^7\) Thus people with ID suffer from morbidities in unique patterns, and unfortunately, the identification and treatment of disease is often more complex (Table 1). This contributes to ongoing health inequality, chronic ill health, and premature death.

For many people with intellectual disabilities, poor health may impair their ability to achieve the best possible quality of life. The attainment and maintenance of health, at a level comparable to the general population, should be the goal. To achieve this, it is important for future physicians to understand the challenges that this population faces in accessing health services, as well as the unique patterns of health needs. Resources such as a health checklist or informative interview guide can be useful tools for physicians. Individuals with...
intellectual disabilities can pose unique challenges to conducting a medical consult, and medical trainees can benefit from training on how to interview patients with ID. The following are some suggestions of interview strategies that could be taught, taking into consideration the unique needs of ID patients in accessing healthcare.

**Table 1. Main Deficits in Provision of Health Services for Intellectually Disabled Patients**

<table>
<thead>
<tr>
<th>A. Untreated, yet treatable, medical conditions.</th>
</tr>
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<tbody>
<tr>
<td>Most individuals have a wide range of health needs, which would normally be raised with a general practitioner. These include simple conditions such as overproduction of ear cerumen to more serious problems such as major cardiac arrhythmias.</td>
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<table>
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<tr>
<th>B. Untreated specific health issues related to the individual’s disability.</th>
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<tbody>
<tr>
<td>There is a need to systematically manage health needs associated with the patient’s disability or syndrome. For example, thyroid screening must increase for patients with Down syndrome who have a higher prevalence of hypothyroidism.</td>
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<tr>
<th>C. Less generic health promotion.</th>
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<tbody>
<tr>
<td>This population receives less benefit from health promotion measures compared to their non-disabled counterparts.</td>
</tr>
</tbody>
</table>

**PREPARING FOR THE FIRST ENCOUNTER**

**Offer the First Appointment**

It can be helpful to give your ID patient the first morning appointment at the clinic, as some people with ID have difficulty with crowds, lack of space or waiting for extended periods of time.

**Offer Double Consultation Time**

Take your time with the person with intellectual disabilities. People with intellectual disabilities need to be encouraged and empowered to speak for themselves. As with any patient, try and determine the level of understanding he/she has at your first meeting.

**Contact Caregiver Prior to Appointment**

It is useful to ask caregivers to bring any previous reports or results of assessments/tests to the appointment. Also, find out how the patient communicates: if the person uses a communication device, remind the caregiver to bring it to the consultation. Finally, if not already noted in their records, inquire about who is the patient’s guardian or substitute decision maker.

**STRATEGIES FOR INTERVIEWING**

**Make the Individual Comfortable**

Ensuring patient comfort can be accomplished by suggesting that someone familiar (i.e. the caregiver) remain present during the interview or by encouraging the use of “comforters” such as the patient’s favourite item. Introduce yourself as the doctor or medical student so the patient and caregiver knows who is informing or questioning them. It may be helpful to briefly re-introduce yourself at the beginning of each contact, as many people have trouble remembering faces and names. Spending some time explaining the process of consultation before you start can help reduce anxiety caused by previous experiences. It is also important to clearly explain and show them what you are going to do before proceeding with any physical exam or test. Advance warning of potential pain, irritation or uncomfortable procedures is also essential.

**Speak to the Patient with ID First, then the Caregiver if Necessary**

A unique challenge faced when interacting with patients with ID is that they are often accompanied by a caregiver. It is important to speak to the person with ID first and then check with the caregiver if something is not clear. Sometimes the supporter can dominate the interview and answers all questions for the patient. However, the person with ID should be allowed to answer for themselves unless they ask their supporter for help.

**Tips for Gathering and Sharing Information**

Communication challenges can be one of the most difficult aspects of caring for patients with ID. When talking with the patient, use simple language that they can understand and that correlates to their level of ID, for example, wording that can be understood by a six-year-old may be appropriate for someone with moderate ID. Communication through diagrams and written words is often clearer to patients than spoken language, or can be a useful supplement. You can use prepared materials (e.g. photos or drawings) to help the patient describe what they are experiencing, or what has happened previously. Concepts of time can be very difficult for patients with ID. Some patients may have little idea of measures of time like weeks or months, and may struggle to distinguish questions about a single event from questions about duration of a condition. This may challenge you to think of unique ways to explain things, for example, “take this medicine with breakfast and supper” versus “twice a day”. Finally, it is important to keep explanations simple. In checking patients’ comprehension, it is often insufficient to simply ask, “Do you understand what I just told you?” Many patients will simply say “yes” in order to be agreeable, even though they have not understood everything. It may be helpful to invite patients to say in their own words what they have heard.

**Negotiating Consent**

Patients with ID who have lived in institutions may be unaccustomed to making personal choices, although they may be competent to do so. It can be useful to establish whether patients have experience making decisions in daily life.
When explaining treatments, be aware that patients may have a concrete interpretation of the procedures that you are proposing. For example, it might be hard to imagine how one sees inside one’s bowel in a colonoscopy. Also, a person with ID may think only about the temporary pain of a procedure, and not be able to understand future benefits including the health problems that it prevents. You might need to present these in visual form—either using pictures or showing patients the procedural instruments.

**DOCUMENTATION**

**Treatment Plans**

As with all patients, good documentation is very important when dealing with individuals with ID who often have complex medical scenarios. Adherence to treatment plans can be improved by providing written instructions for any health advice, especially since support workers can change frequently, and the person may receive care in several settings. It is also important to review a medication list to see if there are any drug interactions or poly-pharmacy that could be reduced.

**Maintaining Personal Health Records**

Because an intellectual disability is life-long, many different health professionals may be involved with the patient’s care over time. Contributing to an individualized personal health record held by the caregiver can have many benefits, such as avoiding using medications or treatments that have previously been tried and found to be ineffective.

**CONCLUDING REMARKS**

There are many competing topics vying for medical trainees’ attention throughout medical school. Training on how to care for patients with intellectual disabilities is typically underrepresented in the curriculum. There is currently a need for clinical skills training regarding this special population starting at the medical undergraduate level. It is unfortunate since all physicians will come across such a patient in their practice at one point in time. Furthermore it can be an enriching experience to work with individuals who can be exceptionally affectionate, emotionally expressive, and appreciative of your efforts to achieve mutual understanding. It is rewarding to be involved in the care of intellectually disabled patients, and they can provide lessons on communication which can be transferrable to one’s general practice.

**ACKNOWLEDGEMENTS**

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**REFERENCES**


**Author Biography**

Paul Benassi is a final-year student at the Michael G. DeGroote School of Medicine, McMaster University. He is interested in pursuing psychiatry and health policy. Paul has worked with individuals with intellectual disabilities in various settings and agencies such as Hamilton Community Living, Lawson Ministries, and McMaster’s Special Needs Services.