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**Developmental Disabilities Clinical and Research Rounds**

The Developmental Disabilities Program will again be running our monthly series of Clinical and Research Rounds during the 2017/2018 academic year.

These rounds are held on the second Wednesday of each month, at the Child and Parent Resource Institute. The first session will be held on Wednesday, October 11, 2017 at 4pm. These rounds are accredited by the Canadian Psychological Association, and the Royal College of Physicians and Surgeons.

There is no fee associated with attending these talks, and if you cannot attend in person, each session is live-streamed using zoom software.

For more information, or to add your name to the distribution list for these rounds, please email Sarah O’Flanagan at [sarah.oflanagan@lhsc.on.ca](mailto:sarah.oflanagan@lhsc.on.ca)

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**Research in the Developmental Disabilities Program**

The Developmental Disabilities Program offers two Research Grants every year. The C. Kingsley Allison Research Grant Competition is now accepting submissions for the Fall 2017 competition.

This grant is intended to provide seed money in grants of up to $9,000 to members of the Western University Community and the Developmental Disabilities Sector, in order to conduct research of relevance to the field of intellectual and developmental disabilities, thereby helping to improve the lives of individuals living with DD and ID.

This competition is open to any student (undergraduate or graduate), faculty member, or employee of the Western University Community (with the stipulation that the Supervisor listed, or a Co-Investigator listed on your application, is a faculty member at Western University who is eligible to hold research funds).

Applications are also invited from non-Western University persons working with agencies in the London region providing services to people with intellectual and developmental disabilities and their families. In this latter case, a member of the Western University faculty (who is eligible to hold research funds) must be listed as an Investigator. Applications from all departments of the University will be accepted, without preference to any department, school, or faculty. Value of an award may range up to $9,000, with the actual value of each award being determined by the number of funded proposals and the quality of each proposal. The awards are not limited in scope – rather they are for any and all research projects which are of relevance to the understanding of the causes, diagnosis, and treatment of intellectual and developmental disabilities.

**Interested candidates should complete the application package.**

The application package is available on our website; <http://www.schulich.uwo.ca/ddp/research/research_grants.html>

Or by emailing Sarah O’Flanagan, at [sarah.oflanagan@lhsc.on.ca](mailto:sarah.oflanagan@lhsc.on.ca)

Research grant recipients will be required to submit a summary of their research for publication in this publication.

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**Student Awards**

*The Annual Dr. Greta T. Swart Essay Competition*

An annual essay award is available to both undergraduate medical students and postgraduate medical residents at the Schulich School of Medicine & Dentistry, Western University. The essay should describe an experience managing a patient at any stage in the lifespan with a developmental disability. This includes management of physical health, mental health or both, either in the hospital system or in the community, including family medicine.

This year we had 5 applicants. Each essay will be published in an upcoming issue of our clinical bulletin. The essay by Dr. Bethany Oeming, a resident in the department of Anesthesia & Perioperative Medicine at the Schulich School of Medicine & Dentistry at Western University was featured in our Summer 2017 issue. Dr. Oeming’s essay was the winner in the Postgraduate Medical Resident category of this competition for 2017.

In this issue, we are featuring the entry by Joshua Friedland, MD Candidate, 2019 – Schulich School of Medicine & Dentistry, Western University. Joshua’s essay was the winner in the Undergraduate Medical Student category of this competition for 2017.

As a second-year medical student I often feel out of place in a hospital setting. At this point in our careers, my colleagues and I have yet to start clerkship, and our learning is primarily confined to lecture halls. However, in our free time, we have the opportunity to shadow specialists from the various areas of medicine. These opportunities, commonly referred to as observerships, provide us with the chance for career exploration by gaining insight into the day to day work associated with different specialties. Recently, I took such an opportunity to observe a gastroenterologist for a morning in the endoscopy clinic.

There, as a passive observer, you are unlike any other person in the room. Having no real role nor responsibility, you predominantly try to stay out of the way. Although you remain mostly useless to the medical team and patient’s care, this fly-on-the-wall like perspective can result in unique insights into what is going on around you. Actions routine to the particular care setting tend to standout to you in ways they do not to the clinic’s regulars. This leads you to ask a lot of obvious questions:

“Why did we use midazolam and fentanyl this morning for sedation, but are using Propofol now?”

“Because the anesthesiologists weren’t available then”

“Why are you using the pediatric colonoscope on an adult?”

“Because it is easier to pass strictures with”

Akin to a child unfamiliar with the world incessantly asking their parents why things are the way they are, so too can be the dialogue between the naïve medical student and their supervisor. So, when the gastroenterologist told me:

“I don’t expect we’ll find anything with the next case”

Naturally I had to ask:

“Why not?”

“The patient has cerebral palsy and sever developmental delay. It’s probably *behavioural.”*

We hurried to meet the patient. Lying on their side on a hospital gurney I noted their small stature and the way their body was locked in tonic contraction. Their spasticity manifested itself in uncoordinated movements, thrashing against the nurses as they wrestled to record the vitals. We were introduced to two family members, and through our patient’s grunting and grimacing, they recounted to us the history. We were told that the caretakers at the patient’s care facility had been having trouble getting them to eat and that the patient had lost a significant amount of weight. My supervisor then explained the procedure we would perform and went through the process of consent.   
 Here, I noticed the first deviation from the routine of the endoscopy clinic I was finally beginning to familiarize – we did not talk to the patient directly about the procedure, just the family. Next, I realized tasks usually done prior to sedating the patient were done after sedation such as the insertion of the bite guard and endoscopy mouth port. In retrospect, every modification to the routine seemed to be an attempt to make the patient as uninvolved as possible.

During the procedure, no behavioural problems were found in the patient’s esophagus. Instead a peptic stricture and esophagitis were discovered. My supervisor reiterated his disbelief that we found something pathological and proceeded to dilate the esophagus. A proton pump inhibitor was prescribed to decrease the acidity of the patient’s stomach and allow the esophagus to heal. After, my supervisor explained to me that the peptic stricture and irritation was caused by the acidic contents of the stomach being regurgitated into the patient’s esophagus. He went on to speculate that perhaps the patient was spending a lot of time supine at their care home which could have contributed to the development of their condition. I recounted how we first met the patient, lying on their side, curled up like a question mark waiting for a diagnosis. Though we had provided an answer and treated the medical cause of the patient’s difficulty eating, I felt uneasy. I wondered, how much time was this individual relegated to this position? And, while the rest of the endoscopy team was ready to move on to the next case, I found myself stuck. Prior to this exposure, I had no experience with those with developmental and intellectual disabilities. It forced me to consider what factors contributed to everything that had happened. Moreover, it led me to realize and investigate the barriers and challenges this patient population faces when interacting with the healthcare system.

Firstly, I have come to learn that patients with developmental and intellectual disabilities face biases and stigmatization that can directly affect the care they receive. Specifically, in this case, the physician was quick to attribute the patient’s avoidance of food and weight loss to be due to behavioural problems rather than the understandable and natural reaction to the pain and discomfort associated with their medical condition. This way of thinking is a form of fundamental attribution error. Fundamental attribution error takes place when people give more weight to dispositional factors over situational ones. Dispositional factors are factors that are internal characteristics of an individual. The most common example cited is observing another driver pass through a light just after it has turned red. In this situation, we are likely to attribute their action to their disposition and assume them to be a reckless driver. On the other hand, situational factors are those associated with the context, environment, and circumstances – so called external factors in a given situation. Perhaps the aforementioned driver went through the red light because there was a medical emergency and they were rushing someone to the hospital. People, including caregivers, often give undue weight to dispositional factors over situational factors when making decisions and passing judgments. In this case, as an uninvolved observer, I was not surprised with the end diagnosis. Based on the environment we were in – an endoscopy clinic, the patients’ symptomatology, and positioning – a peptic stricture with esophagitis seemed like a logical result. Yet, by fixating on the developmental disability it becomes clear how one might misattribute the symptoms as behavioural in nature. Was the grimacing, grunting, and resistance our patient demonstrated due to their inherent irritability, or was it an appropriate response to us forcing actions upon them that they did not understand or want done? Did they not understand the actions because of their inherent intellectual disability, or was an inadequate effort to explain what was being done performed? Both are possibilities, but fundamental attribution error explains that we often use the intrinsic factors or disability to rationalize an individuals’ response rather than the extrinsic or contextual factors. Low-context independent deduction, based solely on one characteristic of a patient, is dangerous and leads to the formation of negative stereotypes resulting in subpar care and stigmatization. Therefore, as clinicians treating those with developmental and intellectual disabilities, it is essential for us to think in high-context interdependent ways by acknowledging the relation of individuals to their environment and how it may account for their behaviour.

While making the case for acknowledging the context in addition to the disability, so too must a case be made for acknowledging the patient. In this case, there was a stark contrast between the level of involvement the other patients had in their care versus the exclusion of the patient with the developmental and intellectual disability from their care decisions. Perhaps the rationale behind this exclusion is that the latter was deemed incompetent, and was thought to not have the capacity to decide whether to undergo the procedure or not. While this may be partially true, that is not to say that they did not have the capacity to understand some of what they were being subjected towards. One important lesson I have learned in my training as a medical student is that there are varying degrees of capacity. In my past, as an electrical engineer, many of the problems I worked with dealt with binary 1’s and 0’s of the digital world. Clinical medicine and all its intricacies differ in that they cannot be reduced to something so discrete. All too often, capacity is viewed as an all or nothing phenomenon. Developmental and intellectual disabilities may limit independence, but why should we as clinicians impair it further? In class, we are taught models that describe the different forms the physician-patient relationship can take. One such approach, the paternalistic model, describes a physician-patient relationship where the physician alone decides what is best for the patient. In recent years, efforts have been made to move away from paternalistic approaches, with strives towards approaches that prioritize patient values. While these advances have been made in the treatment of the general public, the physician-patient relationship involving individuals with developmental and intellectual disabilities have lagged behind. In order to practice effective and ethical clinical medicine, we must seek to remove this inequity when treating this patient population. This can be accomplished by recognizing the spectrum of capacity and making a concerted effort to involve patients with developmental and intellectual disabilities in their own care to the best of their ability.

In addition to bias, stigmatization, and reduced autonomy another barrier patients with developmental and intellectual disabilities face is a lack of physician knowledge about their condition and their unique healthcare needs. This became evident to me when I recounted this story to a family friend, a pediatric neurologist, who specializes in cerebral palsy and runs a multidisciplinary spasticity clinic in Hamilton. I expected them to find this narrative interesting, unique, and insightful. Instead, they informed me that it is well established that individuals with cerebral palsy are prone to gastric reflux and they were shocked that neither myself nor the healthcare professionals I worked with that day were aware of this association. While anecdotal, this interaction reflects on the lack of focus the management of individuals with developmental and intellectual disabilities takes in medical curricula. Individuals with developmental and intellectual disabilities experience significantly higher rates of morbidity and mortality compared with the general population, and they should not have to face this increased challenge with suboptimal support. Like I said, prior to this case I had no experience with those with developmental nor intellectual disabilities. Not just in a healthcare setting, I mean not at all. How can someone as a future care provider adequately care for a patient population you know nothing about? As healthcare professionals, it is our duty to educate ourselves in order to meet the needs of this underserved and often marginalized patient population. This experience has been the impetus that has driven me to actively seek further information and expertise in the management of these patients. Nevertheless, I cannot help but wonder how many of my classmate and colleagues are still in my initial potion of ignorance. Overall, I believe more needs to be done at the level of undergraduate medical education to properly arm us with the knowledge and tools needed to effectively care for patients with developmental and intellectual disabilities.

In closing, in order to provide equitable care to individuals with developmental and intellectual disabilities we must remain cognizant of the potential for negative bias and stigmatization to cloud our clinical judgement, strive to the best of their ability to involve patients in their own care, and aim to educate ourselves on the unique needs of these patients. Personally, as I approach the end of pre-clerkship and get ready to leave lecture hall based medicine behind, I am becoming acutely aware of how much learning I still need to do. In sharing this reflection, I hope to encourage my peers and colleagues to seek knowledge, raise awareness, and ultimately address the inequities and challenges this patient population faces. To paraphrase American writer Peral Buck: society is best judged by how it treats its most vulnerable members. For the medical community, this sentiment holds true, just the same.

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**Upcoming Conferences on Developmental Disabilities.**

*Health and Wellbeing in Developmental Disabilities*

The University of Toronto and the Community Networks of Specialized Care are hosting the Health and Wellbeing in Developmental Disabilities Conference in Toronto from November 29 – November 30, 2017, in Toronto Ontario.

This conference aims to engage health care professionals to improve the health and wellbeing across the lifespan for persons with a developmental disability.

Submissions for poster presentations are open until June 9, 2017. More information can be found on their website; <https://www.healthandwellbeingindd.ca/>

*Regional Support Associates Annual Conference*

Regional Support Associates will hold their annual conference from September 21-September 22, 2017 in London Ontario.

The theme of this year’s event is; Walking the Line; Minimizing Risk and Maximizing Resiliency, and will feature a keynote address by Mandy Wintink from the Centre for Applied Neuroscience.

More information can be found by contacting Karen Araujo at [karaujo@wgh.on.ca](mailto:karaujo@wgh.on.ca) or 519-421-4248

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*Submissions welcome. Articles published or abstracted in this Bulletin do not necessarily reflect the opinions of Western University or the Developmental Disabilities Program.*