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Annual C. Kingsley Allison Research Grant

Competition History

During the 2009-2010 academic year, the Developmental Disabilities of the Department of Psychiatry established an annual research award to encourage and fund new research specific to Developmental Disabilities (DD). It is named the "C. Kingsley Allison Award", named after the donor of the endowment, who was an executive of the "O Pee Chee Corporation" of London.

In 1951 there was a small gathering of parents who called themselves the "London Parents Council for Retarded Children". They established a school at St. Paul's Anglican Church, and Kingsley Allison's daughter Mary Beth was one of the six original pupils.

Under the new name: the "Association for the Help of Retarded Children", Mr. Allison became the president in 1953, and his wife was a volunteer at the school. He brought his business experience to the group, and the AHRC in London became one of the first associations in the province to focus on the needs, educational and otherwise of children with DD. Under his direction the small school moved from the church to a vacant school on Gore Road.

The "Association for the Help of Retarded Children" grew into the "London and District Association for the Mentally Retarded" and then into "Community Living London". Given his leadership, it is appropriate that Kingsley Allison's name is still associated with the work to improve the lives of people with developmental disabilities.

Competition Description

The C. Kingsley Allison Research Grant is meant to facilitate research specific to **Intellectual Disabilities** (as defined by DSM 5). Proposals may involve investigations of causes, diagnosis, and/or treatment of Intellectual Disabilities. Proposals may also involve conditions that are comorbid with Intellectual Disability (such as Autism Spectrum Disorder or Epilepsy), but the project must ultimately be directly about Intellectual Disability. That is, for example, a proposal

about Autism Spectrum Disorder will only be accepted if it is about Autism Spectrum Disorder in people with Intellectual Disability. Relevance statements and project descriptions **must** clearly outline how the proposed research relates to this population. Relevance to the field of Intellectual Disabilities is one of the most important criteria in reviewing proposals. The review committee looks to applicants to help us understand why their particular project warrants support when resources are limited. Although the relevance may seem obvious to the applicant, the review committee still looks for an explicit statement about relevance – it is up to the candidate to convince the reviewers of the project’s relevance.

Eligibility requirements

This competition is open to any student (undergraduate or graduate), faculty member, or employee of the Western University Community. 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 all cases, a member of the Western University faculty (who is eligible to hold research funds) must be listed as an Investigator or Supervisor. 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 \$5,000, 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 disabilities.

*Projects will only be funded once.

*Applicants will only be funded once in a 3 year period.

The following rating criteria will be used to evaluate each submission:

1. Applicant (marked out of 5, includes experience, ability to complete the project, resources, supervision, etc.)
2. Project and Methodology (marked out of 5 points)
3. Relevance to Intellectual Developmental Disabilities (marked out of 5 points)

Proposals must be received by October 31 of each year. Applicants who meet the eligibility criteria and whose work is judged to be relevant to the mission of the DDP will be considered for funding support. Recipients will be notified after the review process, and projects will be funded in the same academic year, beginning in January, or sooner if possible. Project completion dates will depend on the project description.

Research grant recipients will be required to provide proof of publication of their findings in a peer-reviewed journal, OR to submit a summary of their research for publication in the *Clinical Bulletin of the Developmental Disabilities Program*. They will also be encouraged to present their research at the annual Developmental Disabilities Research Day.

Interested applicants can fill out the application form here: https://uwo.eu.qualtrics.com/jfe/form/SV_0PnTOFCt9xosT2Z

If you have any questions about the application process, please contact Sarah O'Flanagan at ddp@uwo.ca.

Further, if you have any attachments you would like to submit along with your application, please email them to Sarah O'Flanagan at ddp@uwo.ca, and include your name in the subject line.

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.

In 2019, we had 4 applicants. In this issue, we are featuring the essay by Michael Wodzinski, *meds 2019*.

February 2019.

In February of 2019 I arrived at Ontario Shores Centre for Mental Health Sciences to complete a two-week elective at the Dual Diagnosis Service (DDS), a 10-bed inpatient unit designed for patients with neurodevelopmental disabilities in addition to other psychiatric comorbidities. The program aims to assess patients with intellectual disability, autism, and other developmental conditions, identify mental health issues and behaviors that are impairing the quality of life of patients and caregivers, and create a supportive, personalized plan for patients to live and succeed outside of hospital. Due to the varying nature of their conditions, patients come in with a wide range of difficulties, such as aggressive outbursts towards themselves or others, complex health issues compounded by difficulties with communication, and needing significant support that their stressed caregivers cannot always provide. As a fourth year medical student with a passion for both psychiatry and brain development, I was eager to learn all I could about the cellular and molecular mechanisms of development, the unique challenges in genetics and medication use, and how to combine this biological approach with equally important psychosocial management strategies. Although I did read up on these topics on my own time, what made this experience so much more interesting and enriching was learning all I could from the amazing healthcare team at DDS, re-framing developmental disability into a person-centered model, and simply spending time with the patients to learn, laugh, and grow together.

Although I was involved in the care of all the patients on DDS, my first day was also the first day of a new patient. YM was a 20 year old male with severe intellectual disability and autism who was admitted because of recurrent outbursts of violent behavior towards himself and his parents. Despite many attempts at managing his behavior and getting other services involved, including combinations of high dose antipsychotics, his caregivers were at their wits end and admission was arranged. The first few days were fairly unremarkable; as expected, YM seemed confused about his circumstances but not comfortable enough to fall into his regular patterns. Eventually, however, the outbursts started. It was difficult at times to engage with YM as his episodes appeared to come without warning, and his communication was severely impaired. As I read about his past difficulties from his chart, saw first-hand the occasionally dangerous outcomes of his distress, and tried to help YM manage his emotions, it was hard to not feel overwhelmed by all the care he required yet deserved. As with most complicated problems in life, the answer was in a group of dedicated, passionate people coming together.

The healthcare team on DDS is by necessity multidisciplinary, collaborative, and cohesive. During my elective I not only worked with the psychiatrist (who acted as the team lead) but also with nursing staff, occupational therapists, behavioral therapists, and social workers in order to learn what each profession could bring to patient care. Working both individually with patients and coming together for regular meetings, each

team member was able to provide a unique perspective on the biological, psychological, and social determinants of a patient's health and wellbeing. Unlike my other psychiatry electives, on DDS I was able to spend full days with allied health professionals to see first-hand what their work entails beyond simply reading about them or seeing their reports. In YM's care I participated in nursing rounds and helped during meals; joined a behavioral therapist on several recreational outings with him and other patients; accompanied an occupational therapist as they learned about his preferences and sensitivities in a sensory room; and took part in case conferences between social workers, his parents, and his group home. All of the things that physicians hear about and know are vital in-patient care, yet don't do themselves. I am incredibly grateful to not only the team that allowed me to learn about their professions but also to my preceptor who stressed the importance of doing so. I believe this will inform my expectations, interactions, and desire to collaborate with these and other professionals in my future practice, with the acknowledgement that medical care is just one piece of a patient's life.

In fact, this was probably the elective that I least utilized biomedical knowledge acquired in medical school. As my preceptor repeatedly reinforced to me, there is no evidence that antipsychotics, benzodiazepines, or other medications are useful in treatment of behavioral issues in neurodevelopmental disorders. Indeed, we often worked in the opposite direction and de-prescribed unnecessary medications for patients, which was the case for YM. The real treatment was in understanding the behavior and the person behind it, not in sedating medications with significant side effects. This requires listening well to caregivers and patients, taking time to understand the world from their viewpoint and seeing what motivates, entertains, or scares them. For example, over time we learned that YM was mistrusting of male providers due to past traumatic experiences with security guards, that he had strong auditory sensitivities, and that he became very distressed when new information was provided too quickly. Working with the allied health professionals above, we tried as best we could to have female providers when possible, utilized noise cancelling headphones, and wrote out new information step-by-step for him to understand. We slowly saw an improvement in his outbursts and were able to gradually introduce male providers as well. As much as these concepts of patient-centered care are espoused in our classrooms, the constraining realities of time and resources make this a difficult thing to do in clinic and on the wards; and yet, it is undoubtedly the patient that eventually suffers when we choose the quick fix instead of taking our time. Remembering how freely antipsychotics are used in this population on my other rotations, it is definitely something I hope to apply in my practice going forward.

My love for mental health is born out of a love for people's stories- that is, the narrative of one's life goals, successes and hardships, and how uniquely each person experiences the world. Although I would probably say that spending time with patients was my favorite part of all of my psychiatry rotations, my two weeks at Ontario Shores actually involved getting to know patients beyond their health conditions and spending

time with them outside of an interview room. As part of their daily routines we walked them through household chores and graded responsibilities, reinforcing good habits and activities of daily living. Some patients even had part time jobs in different parts of the hospital to promote self-reliance and self-esteem, and I believe YM will eventually be able to work up to this task. On other days I joined certain patients in learning how to make meals and clean the kitchen afterwards, which allowed me to both see the extent of their capabilities and learning styles as well as learn their preferences and humor. There was even an outing arranged at a local aquarium where we enjoyed seeing various fish, reptiles, and other creatures, and getting used to being out of the controlled environment of the hospital. Despite their disabilities, each patient had a story to tell- a memory of the past, an experience of the present, and hope for the future- and it was in those small moments that their personalities shone through. The time spent learning how people think, behave, interact, and enjoy life, and the laughs shared along the way, was invaluable because it improved trust and communication between us, and reinforced the human experiences we all have no matter what our medical or mental health conditions may be.

As I reflect on this experience and look ahead to starting my psychiatry residency in just a few months, a few lessons stand out to me. First, by the nature of medicine and psychiatry in particular, we often work with people who are disadvantaged, marginalized, or otherwise facing life in much more trying conditions than ourselves. I can only begin to imagine what the world looks like from YM's perspective- people who don't understand your emotions and actions, who bring to you to strange new places, and where communication is a continuous struggle. At times we strive to break down inequalities through medical care or social initiatives; at other times we inadvertently perpetuate these hardships. Working with perhaps the most disadvantaged individuals in our society as taught me that those who need the most support as just as deserving of our care as those that are more independent. Caring for patients with developmental disabilities often requires intensive management, many resources, and a team of people; while some may find the cost too great, I learned first-hand that the benefits of easing caregiver burden, promoting self-care and autonomy, and improving the patient's quality of life is just as important and rewarding. The amount of thanks received from exhausted parents and workers who were finally granted a break and new strategies was so incredibly gratifying. Seeing the growth of YM in terms of communication and independence, even from just the first two weeks, was encouraging despite knowing the long road ahead. Lastly, perhaps more than anywhere else in medicine, working with patients with developmental disabilities brings to light the ever important discussion about goals of care- that is, what their goals are in life, and how we as physicians can help facilitate them. I never once heard the terms "cure", "remission", or "symptom-free" during my time on DDS; instead, phrases like "helping around the home", "taking care of self", and "enjoying free time" were commonplace. As difficult as it is to go so against our solution-oriented medical model, the value in learning how to help someone live with their condition and live a fulfilling, enjoyable life is perhaps the greatest contribution any physician can provide to their patients.

As someone who is training to become a psychiatrist and hopefully continue working with patients with neurodevelopmental disabilities, this experience has motivated me to seek out similar opportunities apply what I've learned to any patient I see. I am grateful to the staff, caregivers, and patients that made my experience at the Dual Diagnosis Service so humbling and motivating. I would definitely encourage any medical student with an interest in psychiatry, a sense of duty to marginalized populations, and a love for people's stories to participate in a developmental psychiatry elective.

Upcoming Conferences Specific to Developmental Disabilities

The NADD (North American Association on Developmental Disabilities) annual conference will be held from October 23-25 in New Orleans Louisiana. More information and registration information can be found here: <http://thenadd.org/conferences/36th-annual-conference-and-exhibit-show/>

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