



**The Clinical Bulletin  
of the  
Developmental Disabilities Program**

[www.ddp.uwo.ca](http://www.ddp.uwo.ca)

ISSN; 2369-9604

Vol 27 – No. 3

Fall 2016

**Annual Developmental Disabilities Spring CPD**

On April 13, 2016, the Developmental Disabilities Program in the Department of Psychiatry at the Schulich School of Medicine & Dentistry, Western University, held their 14th Annual Developmental Disabilities Spring Continuing Professional Development day. The event featured three invited speakers; Joan Gardiner, Speech Language Pathologist, who spoke about Communication Disorders in people with Developmental Disabilities.

Heather Bailey, Occupational Therapist, who spoke about Sensory Impairments in people with Developmental Disabilities.

Stephanie Gratton, from Developmental Services Ontario (DSO), who spoke about the role of the DSO, and how to navigate the DSO system.

In our last issue, Vol 27, issue 2, we featured a summary of the presentation given by Joan Gardiner, M.C.I. Sc., S-LP ©, Reg. CASLPO, about communication disorders.

In this issue, we summarize the presentation by Stephanie Gratton from DOS, and in our next issue, we will feature a summary of the presentation given by Heather Bailey, OT.

Below, find a summary of the “Navigating the Development Services Ontario System, for families, and their HealthCare Providers” by Stephanie Gratton, from Developmental Services Ontario.

---

## Navigating the Developmental Services Ontario System

Presented by Stephanie Gratton, DSO

The DSO, or Developmental Services Ontario, is the starting point for Adults with Developmental Disabilities who are seeking supports in Ontario. Developmental Services Ontario determines eligibility for services, assesses support needs, and facilitates the process of connecting people with services

The DSO confirms eligibility for Ministry funded adult developmental services and supports according to Policy Directive 2.0. The DSO confirms that the person has a Developmental Disability with a required psychological assessment or report signed by a psychologist or a psychological associate. Adults who access services and supports through Developmental Services Ontario must have a developmental disability as defined within the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2008)*, and the psychological assessment helps to determine eligibility.

The report assesses cognitive functioning, adaptive functioning, and age.

Additional Eligibility Requirements for Developmental Services Ontario includes age (an applicant must be 18 years of age or older), and applicants must produce a birth or baptismal certificate, a passport, a driver's license, or other government document to prove age. They also include proof that the applicant is a resident of Ontario, and applicants must produce a document to prove residency, like a rental or lease agreement, statement of direct deposit for Ontario Disability Support Program, employer record, mailed bank account statement, or a utility bill.

Once eligibility is confirmed, the DSO completes an assessment of the person seeking support's specific support needs. They do so by using an "application package". This package consists of the Application for Developmental Services and Supports (ADSS), and the Supports Intensity Scale (SIS). This Application process is facilitated by a trained DSO staff member, called an "Assessor".

The ADSS is a questionnaire that consists of seven sections;

- a) General intake information
- b) Information about the individual
- c) Getting to know you
- d) Current services and supports
- e) Additional medical and behavioural supports
- f) Care concerns
- g) Unpaid caregiver concerns

The SIS measures the level of support a person with a developmental disability requires to live successfully in their community. It determines the intensity of supports required in the following areas;

- a) Home living
- b) Community living
- c) Life-long learning
- d) Health and Safety
- e) Social Activities
- f) Employment
- g) Protection and Advocacy

After the assessment process is complete, the matching process begins. Direct Service Agencies identify their available resources to the DSO, and they then use the assessment to match support seekers to appropriate direct supports. Developmental Services Ontario does not determine prioritization for service access that is determined by legislation and the Ministry of Community and Social Services.

Developmental Services Ontario has offices across the province. For more information, or to locate your nearest office, visit their website at [www.dsontario.ca](http://www.dsontario.ca)

---

### **Developmental Disabilities Clinical and Research Rounds**

The Inaugural session of the Developmental Disabilities Clinical and Research Rounds was on Wednesday September 14, 2016, at the Child and Parent Resource Institute in London Ontario.

Dr. Julio Martinez-Trujillo, Associate Professor in the Department of Physiology and Pharmacology, Roberts Researcher, and Provincial Endowed Academic Chair in Autism, Schulich School of Medicine & Dentistry, Western University, gave a talk entitled “The Effect of Methylphenidate in Prefrontal Neuronal Activity During Shifts of Attention”.

These rounds will continue to be held at CPRI, on the Second Wednesday of each month during the academic year, with the next session occurring on Wednesday October 12, 2016. The rounds will alternate between a research presentation one month, and a clinical case presentation the next. For our October session, we welcome Dr. Rob Nicolson, Chair of the Developmental Disabilities Program in the Department of Psychiatry at the Schulich School of Medicine & Dentistry at Western University, who will give a case presentation.

All are welcome at this event, no registration is required.

If you cannot attend in person, but would like to watch the event as a live-streamed webinar, please contact Sarah O’Flanagan, Program Coordinator for the Developmental Disabilities Program for details on how to do so.

These talks are also available for viewing after the fact on our website at;

[http://www.schulich.uwo.ca/ddp/education/continuing\\_professional\\_development.html](http://www.schulich.uwo.ca/ddp/education/continuing_professional_development.html)

This is an accredited learning series through the Royal College of Physicians and Surgeons and the Canadian Psychological Association.

We are currently waiting for final approval for accreditation from the College of Family Physicians of Canada.

---

### **Grand Rounds in the Department of Psychiatry**

The Developmental Disabilities Program in the Department of Psychiatry at the Schulich School of Medicine & Dentistry at Western University hosted the first Grand Rounds session in the Department of Psychiatry for the 2016/2017 academic year on Thursday September 8, 2016.

The program welcomed Dr. Jessica Jones, D.Clin.Psy., C.Psych., Clinical and Forensic Psychologist, Associate Professor of Psychiatry & Psychology at Queens University to speak at the event.

Dr. Jones gave a presentation entitled "Offenders with Intellectual Disabilities and/or Autism Spectrum Disorders".

Dr. Jones has kindly made her slides from this presentation available for viewing on our website here;

<http://www.schulich.uwo.ca/ddp/docs/WesternOffendersID%20ASD%20Sept%208%2016%20-%20handouts.pdf>

For more information on Grand Rounds in the Department of Psychiatry at the Schulich School of Medicine & Dentistry at Western University, please visit their website here;

<http://www.schulich.uwo.ca/psychiatry/education/cpd/index.html>

---

## **Research in the Developmental Disabilities Program.**

The Developmental Disabilities Program offers 3 research grants and awards throughout the calendar year.

We offer 2 seed grants (the Annual Dr. Benjamin Goldberg Research Award, and the C. Kingsley Allison Research Award), as well as an essay award (the Dr. Greta T. Swart Essay Award).

The C. Kingsley Allison Award's submission deadline is October 30. The award is open to any student (undergraduate or graduate), faculty member or employee of the Western University Community. Applications are also invited from non-Western persons working with agencies in the London region providing services to people with intellectual and developmental disabilities and their families\*.

Eligibility Criteria, submission deadlines and further descriptions of each award is available on our website;

[http://www.schulich.uwo.ca/ddp/research/our\\_research.html](http://www.schulich.uwo.ca/ddp/research/our_research.html)

\*details available on our website.

---

### **Dr. Benjamin Goldberg Research Award.**

The Annual Dr. Benjamin Goldberg Research Grant is intended to provide seed money to students who seek to gain a better understanding of the health and mental health conditions of people living with intellectual and developmental disabilities, and/or conducting research of relevance in the field of ID/DD, thereby helping to improve the lives of individuals living with ID or DD. The award is open to anyone registered as a student at a community college or university in southwestern Ontario. In 2014, the Annual Dr. Benjamin Goldberg Research Award was awarded to Kelly Carr, a Ph.D. candidate at the University of Windsor, to fund her Study "Changing perceptions of disability: Perspectives of fitness trainers for adults with autism and an intellectual disability". Below, find a summary report of the study, and its findings.

---

## **Changing Perceptions of Disability: Perspectives of Fitness Trainers for Adults with Autism and an Intellectual Disability**

**Authors:** Kelly Carr, Chad A. Sutherland, Sean Horton, Nadia R. Azar

**Affiliation:** Adapted Physical Exercise (APEX) Research Group,  
Department of Kinesiology, University of Windsor

Subscribing to a social model of disability assumes a distinction between ‘impairment’ and ‘disability’. Impairment, acknowledged as a biological phenomenon, is the functional limitation residing within the individual as a result of a physical, mental, or sensory deficit. It is the social implications imposed upon these impairments that create disability, which is the unequal opportunity for community engagement due to constraints that are physical (e.g., inaccessible entrance to a building) or social (e.g., exclusionary attitudes) in nature.<sup>1,2</sup> Thus, it is not the individual’s impairment that is disabling; rather, it is the society in which the individual dwells.<sup>1</sup> Constructed this way, disability can be eliminated through social change and the alteration of societal structures, such as assumptions and beliefs that drive exclusionary and discriminatory human action.<sup>3</sup> Social theory suggests that such prevailing assumptions of disability can be altered when exposed to individuals with disability acting in ways that challenge common perceptions.<sup>3</sup> Given the lower levels of physical activity<sup>4,5</sup> and fitness,<sup>6</sup> and higher levels of obesity and co-morbid conditions<sup>7</sup> among people with autism spectrum disorder (ASD), participation in physical exercise by these individuals may exemplify one such behaviour that challenges dominant beliefs regarding abilities of people with ASD. In order to explore this avenue for social change, we qualitatively examined the impact of volunteering as a fitness trainer for an adapted physical exercise (APEX) program designed for adults with ASD and an intellectual disability (ID).

To gather such information, 9 volunteers (undergraduate students from the Department of Kinesiology) from the APEX program completed one-on-one semi-structured interviews related to their experience as a personal fitness trainer for an adult with ASD-ID. Personal fitness trainers attended the APEX program two times per week, for a total of 12 weeks, with each session being 90 minutes in duration. During this time, fitness trainers were responsible for guiding APEX participants in a traditional exercise regimen, which involved cardiovascular training on a stationary bike, strength training using weight machines and free weights, as well as coordinating sports and games participation. To prepare data for analysis, semi-structured interviews were audio-recorded and transcribed verbatim. Inductive content analysis using a constant comparison method was then employed to organize common themes between participant quotes.<sup>8</sup>

Results indicated that the impact of volunteering as a personal fitness trainer for an APEX program could be depicted through two broad categories: (1) challenging personal perceptions, and (2) shaping an inclusive future. Subcategories within ‘challenging personal perceptions’ included knowing the individual and emphasizing the capacity for growth. Volunteers recognized that individuals with ASD-ID have unique personalities that are not defined by their diagnoses, a realization that challenged previous misconceptions. An APEX fitness trainer who indicated, “I expected a general personality, I expected everyone to be similar, and then they all had their own personalities, so it was a better experience because you got to know everyone”, illustrates this altered assumption. Additionally, through time spent with the APEX program, volunteers recognized the capacity of these individuals to

learn new skills and complete activities that are typically set outside imaginable possibilities for people with disabilities. For example, a volunteer explains, “we started on weight machines and that was cool to see that they could do that, another surprise too, that they could do free weights... they can do most things that people without autism can do.”

The second broad category entitled ‘shaping an inclusive future’ included building skills and creating a ripple effect. Volunteers recognized that skills (e.g., patience, humbleness) learnt through supporting participants in the APEX program would benefit their future careers and volunteer positions pursued within the field of disability studies, aiding the development of an inclusive community. An APEX fitness trainer identifies the development of such skills when stating, “one thing I have gained from this program would be the confidence in that I can work one-on-one with an adult [with ASD-ID] and effectively communicate”. Moreover, APEX volunteers saw themselves as ambassadors of social change as they exposed other gym members to the abilities of individuals with ASD-ID, as one volunteer explained, “I liked being the trainer... showing other people that this is possible”. Through this exposure, volunteers noted reduced stigma toward individuals with ASD-ID within the gym setting, creating a ripple effect regarding the impact the APEX program has on shaping an inclusive community.

Taken together, quality time spent engaging with individuals diagnosed with ASD-ID in an exercise setting had a positive effect on perceptions of disability by emphasizing the uniqueness and potential of the whole person with ASD-ID. It is through the development of personal qualities and skills suitable for interacting with individuals with a disability, and positive exposure to people with ASD-ID, that we can foster social change, eliminate disabling constraints, and create inclusive communities.

### **Acknowledgements**

Community Living Essex County, especially Nancy Wallace-Gero, Lori Huson, and Lynne Shepley

Schulich School of Medicine and Dentistry – Developmental Disabilities Program

Rebecca-Jane McAllister, for her contribution to the collection of data and coordination of transcriptions

### **References**

<sup>1</sup>Union of the Physical Impaired Against Segregation [UPIAS]. (1976). *Fundamental principles of disability*. Retrieved from <http://disability-studies.leeds.ac.uk/files/library/UPIAS-fundamental-principles.pdf>

<sup>2</sup>Barnes, C. (1991). *Disabled people in Britain and discrimination*. London: Hurst and Co.

<sup>3</sup>Giddens, A. (1984). *The constitution of society: Outline of the theory of structuration*. Berkeley, CA: University of California Press.

<sup>4</sup>Pan, C., Tsai, C., & Hsieh, K. (2011). Physical activity correlates for children with autism spectrum disorders in middle school physical education. *Research Quarterly for Exercise and Sport*, 82(3), 491-498.

- <sup>5</sup>Pan, C., Tsai, C., Chu, C., & Hsieh, K. (2011). Physical activity and self-determined motivation of adolescents with and without autism spectrum disorders in inclusive physical education. *Research in Autism Spectrum Disorders, 5*(2), 733-741.
- <sup>6</sup>Pan, C. (2014). Motor proficiency and physical fitness in adolescent males with and without autism spectrum disorders. *Autism, 18*(2), 156-165.
- <sup>7</sup>Rimmer, J. H., Yamaki, K., Lowry, B. D., Wang, E., & Vogel, L. C. (2010). Obesity and obesity-related secondary conditions in adolescents with intellectual/developmental disabilities. *Journal of Intellectual Disability Research, 54*, 787–794.
- <sup>8</sup>Ryan, G.W., & Bernard, H.R. (2003). Techniques to identify themes. *Field Methods, 15*(1), 85-109.

---

### **Dr. Greta T. Swart Essay Award.**

Each year the Developmental Disabilities Program offers the Dr. Greta T. Swart Essay award to Undergraduate Medical Students and Postgraduate Medical Residents at the Schulich School of Medicine & Dentistry at Western. Applicants are asked to submit an essay describing the care of a patient with a developmental and/or intellectual disability at any stage in the lifespan.

This year we had 3 applicants. The winning essay was by Abdullah Nasser, and was titled; “Why are These Demons Chasing Me”.

We have chosen to publish not only Abdullah’s winning essay, but also the essays of the other two applicants (with their permission), because all three submissions were exceptional.



---

## Why Are These Demons Chasing Me?

*With the first rays of sun they came  
And took my brother and sister away  
I swear I hear them yelling, screaming  
And I see them in my dreams everyday*

By Abdullah Nasser

It was the end of a busy day on the psychiatric ward. I had interviewed three new patients and followed up on another three. I was finally done. I headed to the nursing station to document those encounters. As I was about to finish my last note, I heard the charge nurse announce a new admission coming in.

“Acute psychosis,” she declares.

The patient is assigned to Kathy, a fifty-something nurse with a no-nonsense reputation. She hurries to take the handover report over the phone. I sit there in anticipation, unsure if my attending will ask me to see him.

He does.

I start by looking this patient up in our computer system. I find nothing. I give Kathy a bit of time to arrange for the patient transfer before speaking to her. She tells me this patient is a Middle Eastern male in his third decade of life. He came to the hospital because he had “bizarre behavior;” acting out and conversing with himself. Apparently, he was also aggressive in the emergency department. It seemed like a run-of-mill case of acute psychosis, maybe drug-induced or potentially an evolving organic disease in this young man. I go to the exam room with this mental image.

My preconceived notions were put to the test when I first interviewed Ali<sup>1</sup>. He was a pleasant, cooperative man. He was especially ecstatic to find out I could communicate with him in Arabic; his command of the English language was limited to four simple words. He began by asking me when he would be allowed to leave. I tell him we need to sort out how we could help him before discharging. He does not hide his frustration, but agrees to go on with the interview.

My standard interview does not yield much by way of information. When I confront Ali with the circumstances of his arrival to the hospital, he appeared to shrug it away. He denied having hallucinations and being aggressive. I noted that whenever I asked him about a date of an event: when he moved to Canada, when he began to learn English, last completed year in school, etc. he would always respond with the same three words: six years ago. When I inquired about this, he was not able to

---

<sup>1</sup>Name and minor biographical details changed to protect patient confidentiality

provide a coherent answer. I also noted that he punctuated the interview with repeated questions of when he would be discharged. I answered each question as if he were asking for the first time.

The psychiatric review of systems was mostly insignificant. Ali only endorsed occasional nightmares where he is “chased by demons,” and appeared to mostly answer my questions with one- or two-word answers.

I was not successful in gaining much insight into the case from the interviewing. I decided to call his family for collateral history. His mother picks up and substantiates much of what was in the record: the patient was acting aggressively at home, and she felt unsafe. She also said he would wander around the house asking himself: “why are those demons chasing me?”

“Oh, and he is slow; probably the mental age of an eight year-old.” She nonchalantly footnotes the conversation. I quickly flip through the chart, and find no documentation of his mental disability.

Recalling how Ali kept referencing “six years ago,” I ask her if anything had happened then. Her voice breaks and she starts crying. She tells me it was the year Ali’s siblings were murdered back in the Middle East. The siblings’ only crime was working as translators for the international forces in the country. Ali had witnessed the whole episode; they were shot in the head multiple times. “Ali had not been the same since then,” she tells me. As the conversation ends, I hang up the phone in awe of what this young man had been through.

I go back to my attending to summarize the case. He listens attentively, then asks me what I think is happening.

“Mental disability, with some psychotic features?” I answer hesitatingly.

He shakes his head and reminds me Ali’s mental age is only eight. “If an eight-year-old child comes after experiencing a traumatic event, how would they cope with it?” He asks me rhetorically. I nod my head in agreement as I jolt down post-traumatic stress disorder (PTSD) on the chart.

In retrospect, this case has taught me four important lessons. The first is how immigrant communities perceive mental disabilities can impact the services they receive. Unfortunately, the stigma attached to mental health makes frank discussions of disabilities a difficult task within many of those communities. As a result, those with developmental disabilities who happen to be of immigrant backgrounds are less likely to receive the services they need than are non-immigrants. Throughout Ali’s whole ordeal and up to the point I spoke with his mother on the phone, not once did his family disclose to first-responders or healthcare providers that he had a developmental disability.

Second, the case highlights how mental disability can be easily mislabeled in hospitals as various psychiatric illnesses. This gentleman was described as psychotic, and was admitted as such. He was noted to have auditory hallucinations. In reality, these “hallucinations” were simply Ali’s way of dealing of the trauma he had experienced back in his homeland. In that sense, it is no different than coping mechanisms children, who share Ali’s mental age, exhibit after being exposed to a stressor. Those children are not labeled as psychotic. Neither should Ali.

Third, the importance of communicating in the patient's native language is even more crucial when the patient is developmentally disabled. Ali was noted to be aggressive when he was initially brought in. As it turns out, his aggression was the result of fear; he was surrounded by security officers and healthcare providers in a strange setting. He did not speak the language, and did not understand what was happening. He was scared and trying to protect himself. It is perfectly reasonable to be agitated in that setting.

Finally, and most importantly, the presentation of mental illness combined with disability can be markedly different than that of mental illness alone. In Ali's case, it was PTSD combined with mental disability. The disability hindered his ability to articulate the distress he was experiencing, but it did not mean he was not experiencing the same emotional trauma any of us would experience if we were in his shoes. The "demons" that chase Ali in his dreams are his way of experiencing intrusive memories of his siblings' murder.

With a better understanding of Ali's history, we adjust our management. We begin by taking him off the antipsychotics and addressing his PTSD. We start him on some medications to help with the hyper vigilance and the nightmares.

I saw Ali the second day on the floor. Pleasant as ever, he asks me when can leave. I tell him to sit down so we can talk about what his mother had told me. He agrees, so I ask him what happened six years ago. He pauses, and then recounts the events he witnessed. It was a matter-of-fact description, but between the lines, hints of emotional distress would come out. It was the first time I heard him talk for more than one sentence continuously. I was surprised by the level of detail he was able to recall; it was clear this was a very traumatic event. I thank him for his honesty, and explain to him the diagnosis at which we had arrived. I cannot be certain he fully understood what I explained, but he seemed to agree with the overall picture I painted for him.

On the third day of Ali's stay in the hospital, we began to notice some changes. I go to see him on the floor and find out he is still in his room. I go there and wake him up. Excited as ever, he tells me he had a great night's sleep. He says he saw less demons yesterday. "You killed my demons!" he tells me excitedly.

A few days later, Ali was significantly more communicative. He had been sleeping better and the demons were slowly retreating from his life. I call his mother to tell her the news, and she starts weeping, telling me he had not slept well in six years. I ask her to come see him so we can arrange for the discharge. She agrees enthusiastically.

Ali was finally discharged seven days after he was admitted. He left the hospital with a diagnosis and a management plan. His mother was educated on his condition and what can be done to support him through PTSD and his developmental disability.

Me? I left the experience with a much better understanding of the interaction of psychiatric illness with developmental disability. But more importantly, I left the experience deeply thankful I had the chance to help with the care of someone as brave, and special as Ali.

---

**By Peter Cordell**

Developmental disabilities are a group of conditions due to an impairment in physical, learning, language or behavior areas (CDC definition)<sup>1</sup>. Most people have some understanding of what a Developmental disability looks like through personal experience, often from their time in the public education system. However, Developmental disabilities are not always self-evident, and even when we understand someone to possess such a disability, empathy is more challenging with the learning, language, and behavior areas of Developmental disabilities compared with the physical limitations. Specifically, physical disabilities are often visually clear and people can more easily identify the skill that is limited in the person with the disability and apply it to themselves and form a concept of this limitation. In contrast, this is not so easy with learning disabilities, language difficulties, or behavior issues stemming from brain Developmental disorders. As a result, it can be challenging for the general public to form a good understanding of Developmental disabilities and places the emphasis on public education mostly in the education system.

In order to accurately empathize with people who have any disability we must first understand the difference between able and unable, as well as the spectrum in between. For example, a person with Cerebral Palsy that has a physical disability that limits their ability to walk inspires empathy because we can immediately assume certain limitations and challenges that people without a disability take for granted. However, this becomes very challenging when we are focusing on the language, learning and behaviour aspects of Developmental disabilities – especially Intellectual Disabilities and Autism Spectrum Disorders. When we think of social skills, we usually think of the opposite in defining what social skills are, in that we really are quite challenged to describe these skills but can certainly point to situations where they are absent. The same lack of transparency applies to intellectual abilities. Although Psychologists are excellent at psychometric testing and forming clear definitions of specific intellectual skills, the general public is not especially skilled at identifying and quantifying such abilities. As a result, it can be very challenging for people to understand the background limitations that are encompassed by the term intellectual disability or learning disability. Instead, we learn to identify the outward and often termed behavioural manifestations of these limitations. People generally can understand the reason for a behavioural outburst when someone with Cerebral Palsy becomes upset because of how their disability limits them from performing a desired activity. However, behavioural outbursts in people with Autism and other Developmental disabilities do not trigger the same empathic response as a result of the limited understanding the general public has of these disabilities.

As a result of the complexity of Developmental disorders, personal experience with someone who is diagnosed with a Developmental disorder is very important to help the general public learn from this group about where we need to adapt to their needs. We do not diagnose the general public with a specific learning disorder with regard to Developmental disabilities, but in many ways this accurately reflects the challenge that families and persons affected by Developmental disabilities experience. As a result, the onus is really on public education because these disabilities are not self-evident.

My first personal experience with Developmental disabilities came in elementary school when bonding with a classmate who had an Intellectual disability and then later with a close family friend who had a son diagnosed with an intellectual disability. The first understanding I came to as a child was that there was a difference of some sort, but that this difference implied both limitations as well as strengths such as the ability to enjoy life in the moment as we always had so much fun together. Perhaps my

understanding hasn't really changed all that much over the years, as I have really just learned more about the specific limitations and strengths as they are explicitly defined in the Developmental disabilities literature.

Direct experience is certainly the best educator as it diverts you from the over-simplified black-and-white thinking of able and disabled – instead, you humble yourself to learn there is a spectrum. My first formal training in Developmental disabilities came in the form of working as a Child and Youth worker where I had the privilege of working with youth and adolescents with Developmental disabilities living in a Toronto group home. As part of an excellent team, I learned to plan programming for the youth, cook meals with them and for them, and we always tried our best to make the group home truly feel like home for each of youth that lived there. After spending a year working there full-time, I was surprised by how much it came to feel like home for me. It was hard to leave the wonderful group of adolescents and staff when I decided to pursue medical school to become a physician.

Medical school has provided me with a variety of valuable experience and taught me a great deal about Developmental disabilities. One such lesson is that in Autism spectrum disorders there is a reduced capacity for theory of mind – which in simple terms, is the ability to figure out what someone else is thinking. However, people diagnosed with autism spectrum disorders may argue that ironically, people have horrendous theory of mind in trying to understand what they are thinking about, as illustrated by many of the episodes of misunderstanding that occur regularly for the families of those with Autism. Even in medicine, as much as we pursue greater understanding through research and clinical experience, our list of criteria for diagnosing Autism does not imply we have a better understanding of what is going on in the mind of a child with autism at any given moment. This mystery is both challenging as well as beautiful and fascinating.

One anecdote that I often tell comes from my experience working in the aforementioned group home. One of the adolescents there stood a modest six foot six inches and could likely lift up a truck if he ever felt inclined to do so. He had shortly trimmed hair with brown eyes and a stern expression for the most part, brightened by moments of intense laughter, the source of which we usually did not understand. He had no outward signs of a disability to the casual observer. As we say in medicine, there were no dysmorphic features. As everyone else would say, he was a handsome young man who did not appear to have any disability. He always insisted on holding hands when walking together around Toronto and kept a stern expression while doing so. I feel confident in saying that while walking around the city, people certainly assumed we were a proudly gay couple. Other staff often joked that people who saw us ironically would be completely wrong in their own theory of mind assumptions as this adolescent was probably intensely focused on the types of sticks on the ground and not the advocacy he was inadvertently doing for the LGBTQ community by dragging me around Toronto with a sternly defiant look and a gait indicative of clear purpose.

This wonderful adolescent was most interested playing with twigs and smelling scented markers. He disliked sports, especially basketball which had undoubtedly been evident when I passed him a basketball and he looked at me and said “Nope” and dropped the ball, instead electing to choose a particular stick from the ground to play with. He had very limited language and only words in an effort to communicate something he wanted. He was essentially nonverbal in most aspects of his life, that is until the thought of chocolate milk came to mind, at which time he would grab your hand and bring you to the fridge and say “Milk”. He would burst into laughter and skip around the room when you correctly understood him, which at six foot six was quite a sight. He was diagnosed with Autism and lived with six similarly diagnosed peers in the group home. They collectively brightened my days and taught me what it means to be human in addition to endless lessons on Autism and Intellectual disabilities. Although labeled with a disability, they performed many activities and roles with skill. Depending on ability, they learned to do their own laundry, cook meals independently, plan outings, and so much more. They attended school during the day and we would meet them at the bus each evening and they would come

inside and perform their after-school chores, have snack, and then we would go on an outing to park or a variety of locations that Toronto offers. Living each day with this group for a year was my best educator and inspired me to pursue a career working with and giving back to this community.

On the other hand, my first clinical exposure to Developmental disabilities was with Dr. Rob Nicolson, a Child and Adolescent Psychiatrist with the Child and Parent Resource Institute (CPRI) in London Ontario. Aside from teaching me about the history of CPRI as a Tuberculosis Sanatorium, Doctor Nicolson captured my tangential learning style with his passion for everything Developmental Disabilities. As I saw his relationships unfold with the families he treats, I realized my career path and potential for impact. I thank him, the staff of CPRI, and the families of the many patients I met for allowing me the privilege of being involved in their care and for the inspiration that gives my career purpose.

My hope by sharing some of my experience is to indicate the beautiful and rewarding experience of working with people with Developmental disabilities. This population teaches you about life and what we take for granted in terms of brain skills that are valued by our work sector in contemporary society. This brings me to an area that needs to be highlighted and certainly needs future advocacy – Adults with Developmental disabilities. Simply put – Where do Adults with Developmental disabilities fit in our workforce and how can this be a respectful and beneficial relationship?

Research has demonstrated significant health benefits from working and as this body of understanding continues to grow, the need for creative solutions will be vast. Although there is an excellent focus in the education system on integration and inclusion, this is a lesson that has not translated adequately to the adult world with respect to developmental disabilities. This is a very important area to apply creative integration strategies to involve people with Developmental disabilities in a way that values their skills and respects their limitations. There are already creative ideas out there that adequately integrate adults with Development disabilities and I am excited to see the development of this area in the future.

I will end with a quote from 'A Mind Apart – Understanding Children with Autism and Asperger Syndrome' by Dr. Peter Szatmari: "it's all in the way you see things"<sup>2</sup>.

## References

- 1) World Health Organization. Developmental Disability. Accessed May 30, 2016:  
<http://www.cdc.gov/ncbddd/developmentaldisabilities/index.html>
- 2) Szatmari, P. A Mind Apart: Understanding Children with Autism and Asperger Syndrome. 2004. The Guilford Press.

---

By Travis Barron

Developmental disability is something that most people have been aware of for much of their lives; personally, I remember the students in my elementary school who would need extra supports, or who had their own classroom. Developmental disability has also found the way to the big screen, being featured in movies like *Radio*, *Forest Gump*, and *I Am Sam*. Going through medical school, I gained even more exposure through my experience in not only family medicine and psychiatry, but paediatrics, internal medicine, and virtually every discipline. It's fair to say developmental disability is pervasive in our society, and especially the world of medicine. In fact, it would be quite difficult to practice any type of medicine *without* encountering developmental disability. That being said, it wasn't until my child psychiatry rotation that I realized while most of medical students are aware of developmental disability, very few of us have actually been touched by the disorder, and even less of us can truly appreciate the impact it can have on a family's life.

It started with a scream. I was towards the end of my child psychiatry rotation, and I had just arrived at Maryvale, the pediatric psychiatry inpatient unit in Windsor. As I walked through the front doors, I could tell something was wrong. The staff were gathered in the hallway and there was shouting coming from somewhere in the crowd. It was patient Q – Q was a girl I had met earlier in my rotation who had been admitted for aggressive behavior/medication optimization. She had a history of developmental disability, and the psychiatry team had compared her mental age to that of a six year old. In truth she was twelve, and had the size to match. This made her particularly difficult to deal with, because she could hurt you when she was angry. On this morning in particular, one of the nursing staff had tried to give her insulin injection (she was being treated with risperidone and had subsequently developed metabolic syndrome) when Q snatched it out of her hand and had tried to stab the nurse with it.

My first thought was wow; Sam Dawson (*I Am Sam*) wouldn't have done that. Certainly not *Forest Gump*. But when I thought about it a bit harder, I did have vague memories of some incidents with the developmentally disabled children at my high school when I was younger. One particular conflict from Grade 7 came to my mind, when I can remember one student throwing his desk across the classroom. This was when I first began to truly appreciate the concept of developmental disability. It's obvious to most that many of these students face huge challenges in terms of academics and employment, but this only scratches the surface. Many people with developmental disability are delayed not only in critical thinking and academia, but in reasoning, in social aptitude, in self-awareness and self-control, all functions which are essential for us to operate smoothly in society. Without these tools, how could Q appreciate the repercussions of trying to stab someone with a needle? The answer was simple; she couldn't.

It's easy to lay blame in these kind of situations. Q should have known better. The nurse should have approached her in a different way. The psychiatrist should have done a better job with her medications. At the end of the day however, most health care professionals that work with these populations have enough experience that they know that there was likely nothing anyone could have done to mitigate the situation; these anger outbursts are often unprovoked, are usually nonsensical, and are always upsetting for all those involved. This makes it easier for health care professionals to appreciate while each and every single one of these incidents is tragic, it isn't *anyone's* fault, and certainly not Q's. Mom and dad however were a different story.

Enter the parents. Dad was a business person and spent some time away from home as part of his job. Mom was a teacher, but she recently had to quit her job to care for Q, who was now at home full-time. Prior to her admission to Maryvale, Q had acted out at school and tried to strike a teacher. School boards in Ontario have a policy for such an incident, where students with developmental disability are removed from school when aggressive with teachers and are only allowed back after they have been treated. Ideally, these students leave school, have their medications and behavior optimized, and return to school without incident. Mom tried. She instituted a rewards system, she tried stricter punishments and she tried lighter punishments. She took her to the grocery store to expose her to being out, she tried to get Q's siblings involved and she tried teaching Q the curriculum herself. Nothing worked. Q was still aggressive and mom was still tired, and then it happened. The stress, the anger, the exhaustion had all culminated and Q had finally swung at mom.

Dad was the one who brought Q to Maryvale. He was in Windsor when the incident had happened, and he was appalled. Here was his wife, the love of his life, who was trying so hard to do something for their daughter, and Q just couldn't get it. At a later date than the needle incident, I spoke with dad, and he told a very sad story. This was far from the first time something like this happened. Q had acted out on the plane when the family had flown to Australia a few months prior and the pilots had to consider diverting the flight back to Canada because Q was acting out on the plane; dad ended up having to bear hug Q for the entire flight so she wouldn't cause an incident. She regularly swung at dad, and she regularly visited Maryvale. This had been her fifth or sixth admission. I could sense the frustration in his voice but I thought I sensed something else – was it blame?

The parents wanted a solution. Mom wanted to go back to work and dad wanted to be able to enjoy their family vacations, so they turned to Maryvale. On previous admissions, Maryvale had kept Q as an inpatient for a few weeks, even months. They had a school program on campus that children who were admitted would attend, but it was also opened to parents raising children with developmental disabilities as a form of relief. The school at Maryvale was specifically designed to work with these populations, whereas regular public schools had obvious difficulties - maybe, just maybe, an environment more conducive to Q's needs could turn things around for this family. It sounded like a great idea. Unfortunately, those programs had all been discontinued at Maryvale by the time this admission rolled around due to government-facilitated budget cuts. All the program could offer was two hours relief a week for mom - one hour every Wednesday, and one hour every Friday. Maybe she could get some grocery shopping done?

It was my turn to be appalled. I really felt like the government had failed not only Q, but her entire family. Q wouldn't get the help she needed, and wouldn't be given the opportunity to achieve her full potential. Mom wouldn't get the chance to return to work. Furthermore, the amount of discord these incidents had caused the family was palpable – I wouldn't have been surprised to see Q being the issue the family broke up. It was at this point that I understood dad's blame; he wasn't mad at Q, or mom, or even himself. He knew that they were all doing their absolute best. He blamed the system, the system that time and time again had failed to provide the necessary supports for a hard working family that just wanted to love their children and have them succeed. He saw the course that had been set for his family, and for his daughter, and it wasn't a good one. We had met with Q's principal, and he disclosed it was unlikely she'd be allowed to return to school due to safety concerns. There were programs in Toronto, but the waiting lists were months and the city is 400km away. I can only begin to imagine the sense of helplessness the parents felt, the realization that there was very limited help and they would ultimately be left to deal with this on their own. I truly believe that this realization is what drove the parents to take the step they took next – they wanted to abandon Q at Maryvale.

I know what you are thinking. How could any parent who loves their child possibly consider such an idea. A fair thought, but it's easy to forget just where this family is coming from. This is a family whose lives have become conflict. Every moment of every day had become a calculated move to



compensate for Q's illness. Furthermore, Q *could* do better – in a different environment. There were programs, such as the Ontario Special Services at Home (SSAH) which for over thirty years offered support to children and parents dealing with developmental delay, the government just seemed unwilling to provide them at this point – except in one circumstance. If Q were made a ward of the government, the government would be obligated to provide the best possible care. She would immediately get into whatever program she needed to help her succeed. She'd have more support than she ever had before, and maybe this could make all the difference. Q was given such a little chance to begin with, the parents just wanted to provide her with every morsel they could possibly manage, even if that meant leaving their daughter under the care of the government.

The decision between keeping their child and allowing their child to succeed is one no parent should ever have to make. I didn't know what to say. All of this had been discussed in a family meeting between family, principal, psychiatrist, psychologist, and social worker. We were all at a loss. It was so obvious to everyone how the system had failed this child and this family, and as much as we all yearned to do more, our hands were tied. I'm sure the staff at Maryvale had dealt with similar issues over the years; they had worked through the government funding cuts in 2015, and were in all likelihood the front line breaking the bad news to parents. For myself however, this was my first exposure to the financial aspect of medicine I have otherwise not been able to experience, and an aspect I'm not sure I'm entirely comfortable with. The Hippocratic Oath obliges us as physicians to do everything we possibly can for a patient, to help them to the best of our abilities. What then, when we know there are better care options out there, but we are unable to provide them? Caring for people with developmental disability is particularly vulnerable to this question, since interventions are often extremely time and cost intensive. I'm not sure I have an answer.

Developmental disability is a topic many medical students are introduced to and seldom explore. It is easy to take developmental disability at surface value and forget the real challenges these patients have in daily social interactions that are integral to function in society. I'm not sure what happened with Q after my rotation ended, but I do know one thing. More has to be done for her, and for her family. As medical students, I believe it is our duty to study these populations so that we may be able to provide better care for them in the future; after all, they are in need of help more than most. Above all, it is our responsibility as health professionals to advocate for these populations which are otherwise incapable of advocating for themselves.

---

**Upcoming Conferences on Developmental Disabilities.**

*National Association for the Dually Diagnosed*

*NADD 33<sup>rd</sup> Annual Conference and Exhibit Show.*

November 2-4, 2016. Niagara Falls Ontario.

“Weaving Solutions: Research/Policy/Practice in IDD/MI”

**Keynote Addresses;**

**Developmental Disabilities and Addictions: The “Other” Dual Diagnosis.**

Elspeth Slayter, PhD, Salem State University, Salem, MA.

**Autism: Innovative Approaches to Improve Mental Health Across the Borders**

Susan Havercamp, PhD, OSU, Nisonger Center Columbus, OH and Peter Szatmari, MD, The Hospital for Sick Children and Center for Addiction and Mental Health , Toronto, ON, CAN.

Information and registration information can be found on the NADD website – [thenadd.org](http://thenadd.org)

---

*Editor:* Sarah O’Flanagan, Program Coordinator, Developmental Disabilities Program, Department of Psychiatry, Schulich School of Medicine & Dentistry, Western University. Parkwood Institute, Mental Health Care Building.  
550 Wellington Road, London ON, N6C 0A7  
P: (519) 646-6100. X47694  
[ddp@uwo.ca](mailto:ddp@uwo.ca)  
[www.ddp.uwo.ca](http://www.ddp.uwo.ca)

*Submissions welcome. Articles published or referenced in this Bulletin do not necessarily reflect the opinions of Western University, the Schulich School of Medicine & Dentistry, The Department of Psychiatry, or the Developmental Disabilities Program.*