(Re)imagining Leadership and Supports to Promote Enhanced Outcomes for Autism Spectrum Disorder Students in Universities: Exploring the Perspectives of Canadian Leaders, Accessibility Services Personnel, Teaching Faculty, and Autistic Students

Teresia T.C. Waisman
Doctoral Candidate, Werklund School of Education
University of Calgary
teresia.waisman@ucalgary.ca

Shelleyann Scott (PhD)
Professor, Leadership, Policy & Governance
Werklund School of Education
University of Calgary
sscott@ucalgary.ca

Donald E. Scott (PhD)
Associate Professor, Leadership, Policy & Governance
Werklund School of Education
University of Calgary
descott@ucalgary.ca

Autism Spectrum Disorder (ASD), or what is more respectfully known in the autism community as Autism Spectrum *Condition* (ASC), occurs in about one in 59 children and crosses all socio-economic, cultural, and racial barriers (Centers for Disease Control and Prevention, 2019). Forty-four percent of autistic children have average-to-above-average intellectual capability (Baio et al., 2018) and given that autism related strengths can include reasoning skills, reading skills, technological skills, and exceptional memory (Autism Canada, 2018), it is reasonable to consider that autistic individuals have sought, and will continue to seek, higher education learning and qualifications with the view to enhancing their employability, quality of life, and social mobility (Nazimuddin, 2015).

This manuscript, written by an autistic author, an author with a disability, and an author living and working with those of us with exceptionalities, is written in identity-first language. Informed by the autistic author and the preference of many in the autistic community, identity-first language is given privilege in this publication (Kapp et al., 2013; Kenny et al., 2016). This means we perceive autism as an inherent and normal part of our identity and so we prefer to be called an autistic individual rather than an individual with autism which indicates we are suffering some abnormality rather than simply being exceptional.

Currently in Canada, and indeed in many parts of the western world, those diagnosed with autism in their pre-adult years are afforded an Individual Education Plan (IEP) to support their learning in school. An IEP, a working document that grows and changes with the individual needs of the autistic child, is a framework generally overseen by the parent and the educational staff. Although some input by older children may take place – dependent on their abilities, age, interest, and relationship with the educator and parent – input by the autistic student is not mandatory. It is not surprising then that many autistic students reported their exclusion from the IEP development, monitoring, and reporting processes, and were not always aware of the goals and outcomes of the IEP, which reduced the positive impact of the IEP (Wei et al., 2016). Relevant to IEP collaborations, decisions such as planning for higher education are often made by well-meaning parents and teachers who may inadvertently act as gatekeepers for the student's future by deciding early-on that the student may not 'fit' the higher education mould. However, many autistic students are intellectually able for post-secondary education, desire higher education qualifications, and can be successful provided the 'right' supports are in place to advocate for their aspirations **and** to accommodate their learning needs.

As a result of better diagnostics, more inclusive policies, and better education about autism, more autistic students are moving into Canadian higher education than ever before (Surrey Place Centre & Toronto Catholic District School Board, 2015). In the UK it was estimated that 77% of students with special needs (e.g., ASC) actively sought higher education and training (Ambitious about Autism, 2017). For those students who are fortunate enough to qualify for higher education, a number of barriers exist that affect their ability to achieve their educational outcomes. Beginning with cost, some university and college students who suspect they may be autistic, may not be able to obtain a diagnosis due to long wait-times or excessive cost. Obtaining a diagnosis can cost between $2000-$4000, depending on the availability of services, thereby imposing a significant economic constraint. Without a formal diagnosis, autistic students cannot access accommodations that would promote enhanced educational outcomes. Additionally, many autistic students are reluctant to self-disclose their autism until an incident precipitates a crisis that forces them into self-declaring (Cox et al., 2017). Autistic students who do not self-disclose early in their educational process, may potentially be deprived of valuable resources, accommodations, supports, and a collaborative relationship with their higher education institution. Many reasons for non-disclosure are cited as: stigma, fear of being bullied by peers, discrimination by instructors, and more positively, a student simply wants a fresh start (Hong, 2015; Rochester Institute of Technology, 2014; Stronach, Wiegand, & Mentz, 2019).

Another significant barrier to autistic students' educational outcomes is the lack of effective accommodations and services available to them in higher education. Even though most universities have accessibility services departments, 'packaged' academic accommodations meant for various disabilities (i.e., not autism-specific) are often developed without input from autistic students or the autism community, which frequently lead to accommodations that are not useful or ideal for autistic students (Sarrett, 2018). As part of their access to accommodation policies, some universities require students with special needs to engage with mentors, social group gatherings, and/or one-on-one discussions with instructors, and for many autistic students these mandates require them to overcome significant aspects of their disability in order to access

learning-related accommodations. Hence, with the best intentions, these mentoring and social inclusion requisites can present additional barriers to autistic students' access to accommodations and may be detrimental to nurturing student comfort within the university setting. Indeed, this enforcement of social inclusion (e.g., mentoring, group discussions, etc.) can cause severe distress for some autistic students and worsen some of the co-occurring conditions of autism which can include: anxiety, communication difficulties, sudden behavioural changes, difficulty sleeping, and autoimmune conditions (Autism Canada, 2019). This highlights the importance of seeking input from the autistic community as well as individuals when establishing policies and expectations related to accessing accommodations and support services. As autism is a spectrum condition – where there is considerable variability in expression, symptoms, and needs – it is also crucial that collaboration occurs between staff and individual students to establish appropriate and useful accommodations specific to the individual's needs. This means that a one-size-fits-all policy and/or approach to accommodations for **all** autistic students would not only be inappropriate, but in some cases, deleterious.

Autistic students have other needs that require accommodation and support, and though they are not directly related to academic dimensions of learning, their effect on academic outcomes are significant (Gelbar, Smith, & Reichow, 2014). Some of these challenges include: living independently; socializing; instructors' collaboration expectations; group assignments; time management; and self-advocacy; all of which require skills training and accommodations that go beyond most higher education's current disability policies and mandates. Addressing these needs can mean the difference between success or failure in higher education for autistic students.

We posit that the assumption that autistic individuals should fit into general disability policies rather than applying the principles of accommodation to meet the specific needs of individuals is discriminatory and can cause unnecessary stress, anxiety, and worsening of negative symptoms to those who already represent some of the most vulnerable sectors of society. In the same way that it would not be acceptable for a higher education institution to force those with physical disabilities to overcome their disability and accept accommodations that do not address their *physical* needs, it is unacceptable to ask those with *neurological* disabilities to overcome their needs and accept accommodations that do not address their specific neurological needs. Therefore, we advocate that a 'person-centred approach' to faculty and staff attitudes, policies, accommodations, services, and supports is necessary to ensure autistic students on the spectrum can enjoy enhanced outcomes in higher education. This requires visionary leadership to move beyond simply meeting the Canadian human rights legislative requirements at a basic or fundamental level to an advocacy-oriented inclusive leadership stance. This move to an advocacy-oriented inclusive leadership stance would demonstrate an understanding of the variability across the autism spectrum and a deep ethic of care, and would celebrate and embrace the strengths that diversity represents within the higher education community – namely, the inclusion, enhanced support, and the success of **all** students including those on the autistic spectrum.

What is needed is an exploration of leadership that can optimally operationalize the provisions in the *Canadian Human Rights Act* and the *Canadian Charter of Human Rights and Freedoms* as

it pertains specifically to autistic university students . In particular, what leadership skills and characteristics does a Canadian university leader need to be able to effectively support enhanced outcomes for autistic students through action; for example, autism-informed policies, ongoing campus-wide education about autism, training and accountability for policy adherence, autism-informed curriculum design, and human rights compliance?

With a focus on advocacy-oriented inclusive leadership, a doctoral research study has been established which aims to identify how university leaders, professional staff, and instructors can support enhanced outcomes for autistic university students. In particular, the study will investigate:

1. What policies and practices currently exist that are designed to support autistic students and how effective are these?
2. What changes would be necessary to create policies and practices that facilitate enhanced outcomes for autistic students?
3. What teaching and assessment strategies effectively support autistic students in higher education in Canada to have enhanced outcomes?
4. How can/do higher education institutions benefit from the inclusion of autistic students in their communities?

This mixed methods study (i.e., questionnaires and interviews) will invite input from university leaders (provosts and deans), instructors, accessibility services personnel, and autistic students, and will encompass universities across Canada. This research is currently in the data collection stage and is due for completion at the end of 2020. We anticipate that research outcomes will provide clear direction to university leaders about the effectiveness of current policy and practices which are designed to serve students with special needs, specifically those with ASC. We also hope to be able to formulate recommendations regarding curriculum design, learning experiences, and assessment strategies which can provide pragmatic advice and guidance to professors in their pursuit of quality teaching and learning for all, including their autistic students.

References

Ambitious about Autism. (2017). *Stats and Facts*. Retrieved January 21, 2020 from
https://www.ambitiousaboutautism.org.uk/stats-and-facts

Autism Canada. (2018, August 4). *Characteristics: We are all unique*. Retrieved January 21, 2020
from https://autismcanada.org/about-autism/characteristics/

Autism Canada. (2019). *Co-Occurring/ CoMorbid Conditions*. Retrieved January 21, 2020 from
https://autismcanada.org/about-autism/comorbid-conditions/

Baio, J., Wiggins, L., Christensen, D., Maenner, M., Daniels, J., Warren, Z., ... & Dowling, N. (2018).
Prevalence of Autism Spectrum Disorder among children aged 8 years — Autism and
Developmental Disabilities Monitoring Network, U.S. *MMWR Surveillance Summaries, 67*(6),
1-23.

Centers for Disease Control and Prevention. (2019). *Autism Spectrum Disorder: Data and
statistics on Autism Spectrum Disorder*. Retrieved f January 21, 2020 rom
https://www.cdc.gov/ncbddd/autism/data.html

Cox, B. E., Thompson, K., Anderson, A., Mintz, A., Locks, T., Morgan, L., Edlestein, J., & Wolz, A.
(2017). College experiences for students with autism spectrum disorder: Personal
identity, public disclosure and institutional support. *Journal of College Student
Development*, *58*(1), 71-87.

Gelbar, N., Smith, W., & Reichow, I. (2014). Systematic review of articles describing experience
and supports of individuals with Autism enrolled in college and university
programs. *Journal of Autism and Developmental Disorders, 44*(10), 2593-2601.

Hong, B. S. S. (2015). Qualitative analysis of the barriers college students with disabilities
experience in higher education. *Journal of College Student Development*, *56*(3), 209-226.

McBride, S. R. (2013). Special education legislation and policy in Canada. *The Journal of the
International Association of Special Education*, *14*(1), 4-8.

Nazimuddin, S. K. (2015). Social mobility and role of education in promoting social mobility.
International Journal of Scientific Engineering and Research (IJSER), 3(7), 176-179.

Rochester Institute of Technology. (2014). *Emerging practices for supporting students on the
autism spectrum in higher education: A guide for higher education professionals*.
Retrieved January 21, 2020 from https://aspennj.org/wp-
content/uploads/2015/03/ASDinHigherEdGuide.pdf

Sarrett, J. (2018). Autism and accommodations in higher education: Insights from the Autism
community. *Journal of Autism and Developmental Disorders, 48*(3), 679-693.

Stronach, S., Wiegand, S., & Mentz, E. (2019). Brief report: Autism knowledge and stigma in university and community samples. *Journal of Autism Developmental Disorders, 49*(3), 1298-1302. doi:10.1007/s10803-018-3825-1

Surrey Place Centre & Toronto Catholic District School Board. (2015). *Transition to postsecondary pathways for students with Autism Spectrum Disorder (ASD): Translating research into practice*. (pp. 1-42). Toronto, ON: Toronto Catholic District School Board.

Waisman, T. C., & Simmons, M. (2018). Autism Spectrum Disorder and the implications for higher education: A literature review. *Journal of Educational Thought*, *51*(3), 317-338.

Wei, X., Wagner, M., Hudson, L., Yu, J., & Javitz, H. (2016). The effect of transition planning participation and goal-setting on college enrollment among youth with Autism Spectrum Disorders. *Remedial and Special Education, 37*(1), 3-14.

Ms. Teresia T.C. Waisman is a doctoral candidate in the Leadership, Policy, & Governance specialization, Werklund School of Education, University of Calgary, Alberta, Canada. She is a member of the editorial board of the *Autism in Adulthood* journal. She can be contacted at teresia.waisman@ucalgary.ca.

Dr. Shelleyann Scott is a Professor, Leadership, Policy, and Governance, Werklund School of Education, University of Calgary, Alberta, Canada. Her research interests include: leadership development of university leaders and school leaders, professional development in education and business, promoting instructional capacity that encompasses teaching strategies, learning experiences, and assessment approaches and practices. She can be reached at sscott@ucalgary.ca.

Dr. Donald E. Scott is an Associate Professor, Leadership, Policy & Governance, Werklund School of Education, University of Calgary. His research interests include: leadership development in higher education; enhancing the quality of university teaching and learning; professional development and capacity building; supporting at-risk students; and information and communication technologies. He can be reached at descott@ucalgary.ca.