CANVAS Meeting Minutes, 3-10-23

Participants in Attendance

- Alison Wessel (University of Dleaware)
- Andrea Haas (University of Massachusetts, Boston)
- Ariana Riccio (Education Development Center)
- Brad Cox (College Autism Network | Florida State University)
- Brett Ranon Nachman (College Autism Network | University of Arkansas)
- Bridget McElroy (Neurodiversity in the Workplace)
- Cam Fowler (University of South Carolina)
- Carolyn O'Laughlin (Saint Louis University)
- Christopher Clark
- Dakota Morales (Loyola University Chicago)
- Elinor Lim (University of Portsmouth)
- Helen Rottier (University of Illinois Chicago)
- Jenna Lamm (City University of New York)
- Jess Monahan (University of Delaware)
- Jonathan Vincent (Lancaster University)
- Kathy Szechy (Wayne State University)
- Ken Gobbo (Landmark College)
- Kristen Gillespie-Lynch (CUNY)
- Lars Veerhoff (Fontys University of Applied Science)
- Lauren Collier (Northeastern University)
- Lauren Allen (SUNY Empire State College)
- Lauren Baczewski (UCLA)
- Lee Williams (College Autism Network)
- Lisa Pennisi (University of Nebraska-Lincoln)
- Lori Henehan (Illinois State University)
- Marie-Eve Lefebvre (University of Montréal)
- Marla Draper (Colorado School of Mines)
- Mary Baker-Ericzen (San Diego State University)
- Matthew S. Joffe (LaGuardia Community College/CUNY)
- Meaghan Krazinski (Syracuse University)
- Megan Ames (University of Victoria)
- Sara Sanders Gardner (Bellevue College)
- Shannon LaPoint (University of North Carolina at Chapel Hill)
- Spenser Norris (Georgia State University)
- Summer West (Universität Kassel)
- Theo Bakker (Hague University of Applied Science | Vrije Universiteit)
- Vanessa Bal (Rutgers University)
- Zolinda Stoneman

CANVAS Updates

- Join our CANVAS list-serv Our primary means of connecting, sharing info
 - o Click here to join
 - Send email to the list <u>https://groups.google.com/a/collegeautismnetwork.org/forum/#!forum/can-canvas/join by emailing can-canvas@collegeautismnetwork.org</u>
 - o <u>CAN Membership Details</u> We appreciate the support your membership provides to help us offer CANVAS and other opportunities.
 - College Autism Summit 2023: Oct 18-20 at Vanderbilt University in Nashville, TN
 - Share a Resource! Are you conducting any research studies that you'd like the community to know about? Read an interesting article recently? Discovered a cool resource? This is your chance to briefly share that news with the CANVAS group! List your name and any relevant links below so others may access it at their convenience!
 - 1. CUNY Neurodiversity Conference 2023 Registration, April 14, Virtual: https://cunysps.swoogo.com/CUNYND
 - 2. PEACES Project Thanks to your help, we got 430 participants. More info later.
 - 3. Carolyn O'Laughlin successfully defended her dissertation on 2/28: Acts of Resistence and Resilience: Autistic College Student Persistence

Research Panel

- **Presentation Title:** CANVAS 5th Anniversary Panel: The State of Research on Autism in Higher Education
- **Presenters:** Helen Rottier (Doctoral Student, University of Chicago at Illinois); Dr. Kristen Gillespie-Lynch (Associate Professor, College of Staten Island), Dr. Jonathan Vincent (Lecturer, Lancaster University), and Dr. Theo Bakker (Professor, The Hague University of Applied Science; Researcher, Vrije Universiteit)

• Questions to Guide Conversation:

- What led you to study issues around autism/higher education?
 - Jonathan was an instructor for many years and establishing specialist provisions for autistic students. He was a disability practitioner who started provisions for autistic students at the University of York. He loved working on a participatory paper with students that debuted in 2017.
 - Kristen started out as a caregiver for nonspeaking autistic individuals and has many autistic relatives. While doing her doctoral work, she worked in Pathway, a higher education program at UCLA that aims to help autistic people get jobs. During her first year at CUNY, Kristen received funding to develop supports at CUNY for autistic college students.
 - Theo had been studying student success for many years. Through collaborations he began to research differences and similarities among autistic people and their peers.

- Helen was diagnosed with autism during her undergraduate journey. She
 was interested in studying socioemotional learning and gender in autistic
 children, and ultimately she started studying higher education.
- What was your understanding of the landscape of autism/higher education scholarship when you first started engaging in research?
 - Theo was intrigued by the lack of data on autism in higher education, which served as a good reason to engage in this space.
 - Kristen mentioned how, until recent years, much of the work was very siloed. There were only inklings of strengths-based approaches. The field was confused and only happening at a small scale, contributing to limited samples.
 - Jonathan was looking at his USB file from a decade ago. There was little, disparate info. What was significant was reading Aquamarine Blue 5:
 Personal Stories of College Students with Autism.
 - Helen is seeing to connect strategies across different spaces, and to see commonalities among peer mentoring models.
- What's it like to be a self-advocate engaging in this line of work?
 - Helen described it as thrilling, frustrating, and rewarding. Helen feels grateful to engage in this community. Dealing with misconceptions about autism over the past years have been hard, though the elevation of autistic perspectives as experts on their lived experiences, plus seeing more participatory research, is helpful.
- What is the current state of work on autism and employment?
 - Jonathan noted how outcomes tend to be very poor for autistic adults. There tend to be gaps in thinking that once autistic students go through college, they instantly attain jobs. Jonathan has been gathering evidence of the gaps that exist. He is working on a paper related to UK data (over six years) related to graduate outcomes and trends, comparing them among fellow disabled and non-disabled individuals. He has a dataset of 1.3 million individuals. There's 5X higher rates of unemployment among autistic vs. nondisabled individuals. We still don't know much. He hopes other people to contribute to research on this front.
- What possibilities exist in conducting longitudinal work amongst autistic participants?
 - Theo followed more than 20,000 students in Amsterdam over many years. It's helpful to compare data among groups of students with autism. Hopefully they can explore students' pathways after graduation.
- o In what ways can researchers work more closely with autistic communities in the design process, per participatory work?
 - Kristen said these projects require a lot of time, particularly for students to imagine and take on leadership roles.
 - There are often challenges about power dynamics and tokenism.
 - Sharing the AASPIRE guidelines have been very helpful. Decision-making to achieve consensus is super important.
 - Strengths and challenges must both be recognized to view autistic individuals holistically.

- What are the most important considerations when developing a new research project?
 - Helen: "ask yourself what you hope comes out of this research." Keep focusing on how to support students. Have stakeholder buy-in.
 - Jonathan says to remind yourself of who this work is for. Think of who it benefits.
 - Kristen said to ask for folks' input from the beginning. Is this relevant? Does it matter?
 - Theo said to think beforehand of what you plan to do. Pre-register thoughts.
- Where have been your favorite places to publish your work?
 - Kristen, Jonathan, and Theo love Autism and Autism in Adulthood, primarily based on the editorial ethos
- Where should the research be headed over the next five years
 - Theo is excited about bigger datasets, as well as labor market success and differences across regions.
 - Jonathan echoes Theo's points, especially more research on what comes next
 - Helen hopes for more diversity and elevation of autistic voices. Asking students what they want is essential.
 - Kristen was disappointed to hear via a CANVAS Employment panel that many employers do not consider higher education very relevant for employment. Building autistic community is also key.

• **Ouestions from Audience**

- Lee: "The term "neurodiverse" has become increasingly broad in definition, with autism as just one group within that definition. Other groups are decidedly different in many ways. How do researchers design research that is narrow enough to be statistically meaningful while still being inclusive?"
 - **Response:** Helen said it's worth thinking about how these terms are focused on being inclusive. There is often tension in research regarding how broad or narrow the work should be. Often people have multiple diagnoses under the neurodiversity umbrella, and it's hard to disentangle them. Helen said it can be difficult to identify how some traits are related to other autism versus other experiences.
- Jenna: "What do you think about pipeline to employment programs for autistic students that teach specific skills, and do you have recommendations of specific researchers doing work in this area?"
 - Kristen said it's important to consider in how people are hired. Developing those career skills are essential, but accessibility in hiring initiatives must be prioritized. Involving many people in the autistic individuals' process can help. Jonathan shares those sentiments; everyone can develop new skills. We just do not want to force autistic people into specific skills and spaces.

- Jess: Often grant proposals want heavy-hitter researchers listed, but those
 individuals may not identify as neurodivergent. How do you navigate that? Jess is
 wanting to engage in meaningful participatory work, though she wants them to be
 compensated, which can be a struggle.
 - Kristen said funding agencies have been much more open to participatory work than in the past. A study that Kristen orchestrated (through NSF) was not framed as explicitly participatory in the proposal, because they were not sure if they would be receptive; however, once funded, they engaged in participatory approaches. This branch of NSF was quite supportive of participatory efforts. IES is more open, too.
- o **Brett** concluded by asking each of the panelists to use one or multiple words to sum up the state of autism/higher education research:

Kristen: blossoming

• Theo: destigmatizing

Jonathan: gaining momentum

Helen: room to grow

Upcoming CANVAS Meetings

Fri, April 7 at 2pm EST

- **Presentation Title:** Autism, Adulthood and Employment Challenges: The Double Empathy Problem and Perceptions of an Autistic Employee in the Workplace.
- Presenter: Kathy Szechy (LMSW, PhD, Wayne State University School of Social Work)

Fri, May 5 at 11am EST

- **Presentation Title:** "Looking at the Whole Student:" Identities and the Higher Education Accommodation Process
- **Presenters:** Dr. Morgan Strimel (Doctoral Candidate, George Mason University), Dr. Grace Francis (Associate Professor, George Mason University), Dr. Jodi Duke (Associate Professor & Academic Program Coordinator, George Mason University)