

CANVAS Meeting Minutes, 8-13-20

Participants in Attendance:

- Alanna Carrasco Drummond (University of Texas at Dallas)
- Alexandra Jacobs (Loyola Marymount University)
- Amy Radochonski (College Living Experience)
- Anita Rehberg
- Ann-Marie Orlando (University of Florida)
- Annette Bade
- Ariana Riccio (CUNY)
- Auston
- Bella Kofner (College of Staten Island)
- Beth Felsen (Spectrum Transition Coaching)
- Brett Ranon Nachman (CAN/University of Wisconsin-Madison)
- Chandra Lebenhagen (University of Calgary)
- Cheryl Widman (University of Illinois at Chicago)
- Claire Barnett (Vanderbilt, Frist Center for Autism and Innovation)
- Courtney Butler (Rutgers University)
- Dan Burger (Vanderbilt, Frist Center for Autism and Innovation)
- Dana Kanhai (Michigan State University)
- Dave Caudel (Vanderbilt, Frist Center for Autism and Innovation)
- Dorothy Simister
- Eilidh Cage (University of Stirling)
- Emine Gurbuz (University of Portsmouth)
- Jack Howes
- Jennifer Wick (RIT)
- Jennifer Williamson (University of Calgary)
- Jill Underhill (Marshall University)
- John Sheehan (Purdue Fort Wayne)
- Katie McDermott (Shrub Oak International School)
- Kelsey Bohlke (Emory University)
- Ken Gobbo (Landmark College)
- Laura Dean (University of Sheffield)
- Lee Williams (CAN/NASPA)
- Monique N. Colclough (NC State)
- Patrick Dwyer (UC Davis)
- Shana Oates (Miami University)
- Steven Kapp (University of Portsmouth)
- Summer West (Universitat Kassel)
- TC Waisman (University of Calgary)

- (a few other folks joined in by phone or did not have names listed)

Meeting Plan

CANVAS Updates

- Join our CANVAS list-serv - Our primary means of connecting, sharing info
 - Click [here to join](#)
 - Send email to the list by emailing can-canvas@collegeautismnetwork.org
 - [Updated college autism programs list](#)
- [College Autism Summit](#) (virtually; Oct 27-30)
 - Keynote speakers include Robia Rashid (*Atypical* creator) and Anthony Pacilio (JP Morgan Chase)
 - Check out the website for registration rates
 - We are seeking organizational/institutional sponsors. See website for more details.
- CANVAS Cross-Institutional Collaborations Working Group
 - (TC Waisman): Autism &UD Training for Faculty. Faculty & TAs welcome: www.autismresearch.international for more information or if you have any questions. The team is planning to pilot the study soon and head into recruitment. Faculty and TAs who want to incorporate this training are welcome to do so.
- Share a roughly 30-second elevator pitch of a recent article (magazine, news, journal) you have read! List your name and a link to the article below so others may access it at their convenience!
 - [“SUNY Empire Launches Groundbreaking Program to Expand College Access by Becoming an Autism-Supportive College...”](#) (Eric Endlich)
 - [Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals](#) (Eric Endlich)
 - Frist Center webinar series (Claire Barnett)
<https://my.vanderbilt.edu/autismandinnovation/2020/08/06/upcoming-autistics-roundtable-webinar-entrepreneurship-as-an-option-for-autistic-adults>
 - New toolkit on autistic individuals establishing self-determined goals (Lee Williams)
<https://my.vanderbilt.edu/autismandinnovation/2020/08/06/new-toolkit-available-helping-young-autistic-people-set-self-determined-goals/>
<https://vkc.mc.vanderbilt.edu/assets/files/resources/selfdetermination-toolkit.pdf>
 - Article on marijuana use during pregnancy linked to autism in children (Bella Kofner)
<https://www.forbes.com/sites/tommybeer/2020/08/10/marijuana-use-during-pregnancy-linked-to-autism-in-children-study/#59a1561c195a>

Presentation Notes

- We welcomed guest speakers Dr. Eilidh Cage (University of Stirling) and Jack Howes (autistic writer and fundraiser) as they discussed "Dropping out: Understanding the university experiences of autistic students who could not complete their studies"
- Many autistic people seem to drop out of higher education. Eilidh found the lack of research on why autistic people might be more likely to drop out concerning.
- Their exploratory survey aimed to figure out why might there be a high risk of non-completion.

- Among the areas they examined included diagnosis and disclosure, academic experiences, social experiences (do they fit in and identify with the institution or feel lonely), mental well-being, sensory sensitivities, and transition to university.
- 230 autistic adults completed measures.
- 151 had graduated, 34 graduated after several attempts (this was a distinct group), 45 had not completed.
- Participants included 60% female, 30% male, 10% other. Mean age was 33.9. 64% studied in the UK.
- Key findings:
 - Transitioning to university (the did not complete group found this more challenging)
 - Academic experiences (did not complete had a poorer academic experience)
 - Social experience (did not complete had significantly lower social identification, had lower organizational identification)
 - In a matched sample, logistic regression indicated that difficulty with the transition to university was the only significant predictor of completion.
- After the survey, they conducted interviews with 14 individuals with people who attended university in the UK but dropped out; three diagnosed before university, one during, 10 after
- Students possessed diverse experiences, based on age and attempts at attending college.
- Common systemic issues were a lack of autism understanding, mental health strain, outsider status, and accessing diagnoses.
- There is high co-occurrence regarding anxiety and depression which impacted on the participants experiences.
- Jack talked about his own experiences in feeling like an outsider at university – not feeling like he belonged – as he had not yet been diagnosed at that time.
- When at university, many students experienced culture shock, such as handling academic skills and studying independently. Dealing with such expectations, sensory overstimulation, and desires for structure (which was lacking) are overwhelming.
- Students may become disengaged due to both culture shock and lack of proactive support (it's often unclear who can provide help and what such individuals could have done).
- Life after dropping out entails a wide variety of emotions. Many students exhibited resilience. Autistic students generally are remarkably resilient just to attend university – though this is a point not made in the research!) For some students, it's okay to drop out, and perhaps some may return to university later.
- Among interviewees diagnosed before starting university, even supports offered on campus were inadequate.
- Students' challenges in making friends and socializing amounted to not having the space to crowdsource knowledge while taking classes. (One of the things problems socialising amounted to)
- Autistic students may benefit from additional support when transitioning to university
- Supports need to be accessible and clear
- Many systemic issues exist, not just in the university context.
- Some students may find university experiences to be traumatic.

- Implications include the following: needing more evidence-based transition support; staff may benefit from training about autism, especially to highlight some of the systemic barriers affecting autistic people (referred to the faculty training led by CANVAS members); tutors need to be approachable and knowledgeable; and greater flexibility, structure, and clear expectations.
- Eilidh and Jack mentioned that incorporating Universal Design principles are vital; tools that help autistic people will help everyone.

Presentation Q&A

- **John:** When you say "lack of understanding" is that the understanding coming from others, or understanding of self-awareness of their own autism? Or maybe both?^[P]_[SEP]
Answer: From others. The self-awareness point is valuable to consider as well. Sometimes students don't always understand themselves if they're still making sense of their diagnoses.
- **Beth:** Have you examined survey results for neurotypicals and students with other disabilities to see if these results for autistic students drop out rates and experiences are different?
Answer: The authors not have a comparison with neurotypicals, though find this is very needed. Eilidh said there is already some existent literature on this front. Financial difficulties and feeling like courses they chose weren't right for them appear.
- **Emine:** I suppose disclosure and mid or late diagnosis did not predict the risk of non-completion based on survey data?
Answer: Eilidh said she would like to see more data on people diagnosed before university and compare.
- **Summer:** I am curious about your thoughts on why the percentage of females dropping out of HE was higher?
Answer: Not sure, Eilidh said. Jack supposed high rates of discrimination based on gender; he said that different rates
- **Cheryl:** Cheryl validated what Jack said. She found her son's diagnosis was very helpful in helping her understand her own experiences. Cheryl talked about autism often being masked by other disabilities.

Comments during Q&A (messages are copied and pasted from the chat):

- **Laura:** I'm in the UK too - my experience is that many personal tutors actively don't want the role and so do it badly so it is taken off them
- **Steven:** FYI for attendees Eilidh and Jack cited the 2008 Italian study in their brilliant paper: Di Pietro, G., Cutillo, A. (2008). Degree flexibility and university drop-out: The Italian experience. *Economics of Education Review*, 27(5), 546–555.^[P]_[SEP]
- **Cheryl:** Suggesting Tinto (1975) Dropout from Higher Education: A Theoretical Synthesis of Recent Research (still very relevant)
- **Bella:** Suggesting Cai, R. Y., & Richdale, A. L. (2016). Educational experiences and needs of higher education students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46(1), 31-41.
- **Laura:** I am quite a critical person but I don't feel the late diagnosis is accidental in the UK. My research found that diagnosis was happening at age 4-7 or not until age 17. This

isn't coincidental. At age 17 children no longer have to receive resource from schools. Diagnosing at age 17 saves the councils a lot of money

- **Steven:** Autistic women also tend to have more or sharper mental health problems.
- **Laura:** I have spoken with many many newly diagnosed HE students who have said that they have been trying to get a diagnosis for up to ten years and only got past the gatekeepers suddenly at age 17.
- **Alanna:** They may have more mental health problems due to the lack of support (from a psychologist perspective).
- **Laura:** Women in the UK are also misdiagnosed as depression and eating disorders
- **John:** It also explains a bit why the sources of support kids have in primary and secondary school suddenly evaporates when going to college. That falling off a cliff and the change between schools leading the advocacy for students to students being forced to self-advocate in college compounds the problem. It is the same here in the U.S.
- **Dave:** Women are better than men at masking the very markers they use to diagnose autism, as well.
- **Bella:** Women are assumed to be normal which is why they are successful in making their autism.
- **John:** Hands are held prior to college. Hands are cut off in college. It is a very different dynamic for all students, but particularly those with ASD.
- **Beth:** Transition plans (at least in Virginia) for students who want to go to college are terrible
- **Patrick:** Yes, entirely agree that there is more need to practice self-determination, time management, etc., in high school.

Upcoming CANVAS Meetings

- **Thurs, Sept 17** at 11am ET: **Dr. Jonathan Vincent** (York St. John University) discusses "Transitions from higher education for autistic students and graduates: qualitative insights from the UK context"
- **Thurs, Oct 15** at 2pm ET: **Dr. Julie Lounds Taylor** (Vanderbilt University) discusses serving as an editor of the *Autism* journal: "Pulling back the curtain: tips from the editorial desk"
- **Thurs, Nov 12** at 3pm ET: **Dr. Cheryl Widman** (University of Illinois at Chicago) discusses "Understanding Parent Participation in the Postsecondary Education of Students with Autism Spectrum Disorder"