

CANVAS Meeting Minutes 2025-11-21

People in Attendance:

- Brett Ranon Nachman (University of Pittsburgh | College Autism Network)
- Elinor Lim (University of Portsmouth)
- Lee Williams (College Autism Network)
- Brett Binkowski (Michigan State University)
- Colleen Grillo (University of Central Florida)
- Elena King (University of Washington Bothell)
- Emine Gurbuz (University of Portsmouth)
- Eric Trezell (University of Washington)
- Florencia Ardon (Cornell)
- Gina Hoagland (University of Maryland, Baltimore County)
- Gretchen LaBonte
- Hunter Mackenzie Mattern (Penn State University)
- Iliana Magiati (University of Western Australia, Perth)
- Jackie Brousseau-Pereira
- Kate Lukasavage (SUNY Ulster Community College)
- Katie McDermott
- Ken Gobbo (Landmark College)
- Kiley Sturgeon (Marquette University)
- Maria Keller
- Maria Montenegro (University of Texas, Rio Grande Valley)
- Mario Crown (Boston University)
- Mark Tapia
- Mindy Thornton (Marshall University)
- Ney Alliey (University of Texas, Rio Grande Valley)
- Samantha Solis (University of Texas, Rio Grande Valley)
- Steven Kapp (University of Portsmouth)
- Tom Beeson (Clemson University)
- Vanessa Blais

Presentation Details

Presenters: Elinor Lim, PhD Candidate, University of Portsmouth

Presentation Title: The Role and Impact of Family in Autistic Students' University Journeys

Presentation Notes

- The past week Elinor submitted her PhD thesis. This work reflects this work on how families impact autistic university students' journeys.
- Researchers have noted how college represents a period of both greater interdependence and continued interdependence. This exists among many individuals including families, communities, and friends.

- This work follows a participatory approach. Although it was not full community-based participatory research, this study still had many applicable elements. For one, there was a steering group with five autistic university students and graduates, three family members of autistic university student, and two specialist autism mentors (those with particular training). In this group they discussed a variety of research topics and they helped guide the focus of the inquiry.
- The overall research question focused on the role and impact of family in autistic students' university journeys.
- Elinor's PhD involved a scoping review of the literature, qualitative study, and quantitative study.
- The scoping review found many gaps in the literature. For one, there had only been one literature review (US-based) that centered on six studies over a decade. The results were inconclusive due to insufficient data. Between 2008-2024 they identified 23 papers, most of which were qualitative. Most focused on family involvement and/or support in their autistic children's lives. Nine studies centered on the roles of family members.
- In reviewing these articles, Elinor found how family is key to providing non-academic support, but this must be balanced with students' independence.
- One major gap is the absence of work in the UK. The studies also focus only support provided to students, but not by students.
- The qualitative study featured questions about family dynamics.
- Elinor interviewed 26 autistic students and 11 family members; all were in the UK context. Most were white, female, and formally diagnosed.
- This study employed reflexive thematic analysis.
- Elinor showcased a concept map illustrating various patterns with family relationships and family involvement/support at the center. Today she focuses on two of the five themes.
- One theme centers on how those family relationships and involvement/support are intertwined. Positive relationships contribute to support; negative mean the lack thereof. For instance, one anecdote centered on how the student tried to have two-way relationships with their family members, demonstrating interdependence.
- Another theme focused on the parents advocating for the student, connecting the student with university support. It stems from the student asking for help and consenting to the process, of course. This study demonstrated the complexities of these dynamics. In times of emergency (e.g., health issues, meltdowns, distressful situations), family support also surfaced.
- Finally, the third study – quantitative in focus – aimed to quantify links between support and outcomes. Here the research questions asked about how family support impacted autistic students' subjective wellbeing, academic performance, university completion, and post-university engagement.
- The online survey featured 52 autistic students, graduates, and ex-students. Students' demographic info mirrored what was found in the qualitative study.
- They were interested in five types of family support: emotional, informational, practical, emergency, and financial. Items drew mainly from AASPIRE, co-developed with autistic people. The participants shared how much support they received from their family members when requested.

- Four student outcomes: well-being, academic performance, university completion, and post-university engagement (the latter two shown to graduates and ex-students).
- Albeit the plan was to engage in a regression analysis, the participant numbers did not quite lend itself to that (9 who completed university and 9 in post-university engagement).
- They found that family support lacked a statistically significant impact on autistic students' subjective well-being or academic performance.
- In asking 45 students what was most helpful in enabling them to get through university, the most common responses were university factors (e.g., support staff, accommodations), with half of participants noting that.
- Elinor offered that the findings indicate family support is indeed beneficial, but it's difficult to discern quantitative impact due to complex links with other factors.
- One implication entails the need to leverage student-family-university partnerships. Clear and proactive communication from institutions would be helpful. Having info readily available to students and families (including recruitment events and open days) would be useful.
- There is also a strong need to strengthen support for students, such as in the mental health and crisis space, plus in elevating financial aid.
- This study appears to be the first to specifically focus on the links between family and student outcomes for autistic students.
- Further work should explore families in understudied sociocultural contexts.

Q&A

- Mark: "Was there a finding that surprised you or a finding you didn't expect to find?"
 - Did not go in with any expectations, though hoped to find statistical significance and more participants. Perhaps the biggest surprise was in having students open up to her during interviews.
- Katie: "In the qualitative, did students talk about support they received from family members that was not wanted?"
 - Some research has focused on overbearing parents. That said, it did not seem to manifest quite apparently. If anything there was a mismatch in desired supports. For instance, a student may have wanted more emotional support but that wasn't reciprocated.
- Jackie: "Did students talk about whether their faculty were sources of support and/or whether they disclosed their diagnosis to their faculty?"
 - Yes, particularly in the quantitative study faculty were viewed as helpful. In the qualitative study, there were a few. Some individuals also serve as personal tutors. Disclosure varied depending on the vibes they received from their faculty.
- Mario: "Even though this sample was largely white, how do you think cultural differences and familiarity with the college process would influence family support and students' perceptions towards this "support"?"
 - They looked into parents' backgrounds with the higher education setting. That could have been a mitigating factor. Quantitatively there was no difference in support between first-gen and continuing-gen students. On the cultural front, we may have specific ideas of how much emerging adults should rely on family. In

western cultures there are often beliefs behind the student leaving from the house to start their lives.

- Gina: “Was there any difference in results between students who reside on campus and those who lived at home?”
 - Analysis was not split based on living situation, but they asked about it. Everyday living was often easier for those who lived at home and received support from their parent with meals, chores, and other tasks. For one student, the living at home situation was meant to help the daughter focus on studying.
- Flor: “I'm assuming the neurotype of the family members is unknown?”
 - Elinor asked this as a demographic question, but no specific analysis split by this.
- Mario: “Have you thought about how differences in the college environment, itself, would impact family support? Like the type of institution, how close it is to their family, presence of disability-related clubs, etc.?”
 - It's very possible that institutional type could play a role; this looks different across different country contexts. In any case, Elinor asked about the nature of their living situation. As for disability-related clubs, she had considered that as a form of community, but that was not thoroughly explored. Nonetheless these clubs helped with recruiting for the study.
- Maria: “How do you suggest to involve parents in academic affairs when there are confidential issues to take into account. In USA certain things cannot be discussed with anybody but the student?”
 - Most countries have some version of this due to privacy issues. Some participants in the qualitative study referenced this. For most institutions there is a way for people to sign waivers that release info to family members. Institutions partnering with parents can help, but there are still policies to account for.
- Katie: “I'm sorry if I missed this, but did you interview sets of families/students? Or were your participants families and students unrelated?”
 - They recruited parents and students independently. However, there was one mother-daughter dyad; that was unintentional, though, and they were interviewed independently. From an ethical standpoint they chose to not interview pairs overall. (I didn't explain during the meeting but there was a concern about participants being pushed by their family members to participate if dyads were required).

Upcoming Meetings in 2026 To Be Announced!