

CANVAS Meeting Minutes, 11-12-20

Participants in Attendance

- Amy Radochonski (College Living Experience)
- Anita Rehberg (Harper College)
- Auston Stamm (Saint Mary's College)
- Ben Schwartzman (Vanderbilt University)
- Beth Felsen (Spectrum Transition Coaching)
- Brett Ranon Nachman (UW-Madison | College Autism Network)
- Carrie Shockley (City University of New York)
- Cheryl Paarlberg
- Cheryl Widman (University of Illinois at Chicago)
- Courtney Butler (Rutgers University)
- Denise Davidson (Loyola University Chicago)
- Emily Raclaw (Marquette University)
- Eric Endlich (Top College Consultants)
- Florencia Ardon
- Jamie Niman (Iowa State University)
- Jaya Sawhney (Itneris, Inc.)
- Jenna Lamm (City University of New York)
- Jess Monahan (University of Delaware)
- Jennifer Williamson (University of Calgary)
- Katelyn Lowe (Sinneave)
- Kathy Szechy (Wayne State University)
- Katie McDermott
- Ken Gobbo (Landmark College)
- Kim Jameson (STARS at Christian Brothers University)
- Lee Williams (College Autism Network)
- Mary Baker-Ericzen (San Diego State University)
- Megan Fok (Virginia Tech)
- Natalie Boice-Pardee (RIT)
- Norma Lopez-Reyna (University of Illinois at Chicago)
- Patrick Dwyer (UC-Davis)
- Sasha Zeedyk (Cal State Fullerton)
- Stephen Shore (Adelphi University)
- Suzanne Calgi (Ramapo College of New Jersey)
- Tom Beeson (Clemson University)
- Wes Garton (University of Delaware)

Meeting Plan

1. CANVAS Updates

- Join our CANVAS list-serv - Our primary means of connecting, sharing info
 - 1. Click [here to join](#)

2. Send email to the list by emailing can-canvas@collegeautismnetwork.org
 3. [Updated college autism programs list](#)
- [College Autism Summit](#) Recap
 1. Our event boasted more than 300 attendees and featured dozens of pre-recorded presentations, plus live sessions
 - Share a roughly 30-second elevator pitch of a recent article (magazine, news, journal) you have read or resource you would recommend people check out! List your name and a link to the article below so others may access it at their convenience!
 1. [ABC News article on autistic individual winning seat in PA House; references ASAN's Autism Campus Inclusion project](#) (Nachman)
 2. Lee mentioned a project involving creating autism-friendly campus designations and seeking input on what this might look like. Feel free to email her at lee@collegeautismnetwork.org if you would like more info or be involved.
 3. Mary: there is a new executive functioning and social cognition skill development evidence-based intervention for college students called College SUCCESS. www.interwork.sdsu.edu/main/achieve

2. Research Presentation

Dr. Cheryl Widman (University of Illinois at Chicago) discusses "Understanding Parent Participation in the Postsecondary Education of Students with Autism Spectrum Disorder"

Presentation Notes

- What positions Cheryl as unique in this space is serving as an educator in special education, parent, and researcher. She conducted this study because she recognized the influx of research on parental partners prior to college, and sees the value of their engagement in students' lives.
- Parents invest financially and emotionally in students' lives, and often serve as experts in their children's lives. Prior literature shows their necessity as a best practice with a participation mandate through IDEA.
- The purpose of Cheryl's mixed-methods research was to examine characteristics of parental participation in response to the needs of their autistic students in order to improve, retention, graduation rates, and outcomes.
- Cheryl conducted a systematic literature review, [utilizing the PRISMA method] through a synthesis of an established protocol of quality indicators for special education research (Magginet al.; Talbott et al.) and the methodology for PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses). She found eight main themes.
- Cheryl considers herself a constructivist and pragmatist, which is why she utilized grounded theory with quantitative methods.
- Cheryl reflected back on how she supported her son in preparing for college, and wondered what other parents do within the idea of three means of support. Her hypothesis was that parents were filling in the individualized (IEP) support gap.

- The mixed-methods design encompassed 45 dichotomous questions across three domains (social integration, autonomy, and emotional/stress relief), 13 open-ended questions embedded within each set of questions, and one final probe about supporting their student (child) in ways not already mentioned. Data were concurrently collected.
- Four research questions encompassed this study, three of which related to parental support and participation for their autistic children and one that related to the instrument itself.
- RQ1: “How do parents support social integration, autonomy, and emotional/stress relief?”
- RQ2: “In what other ways do parents support their postsecondary students with ASD?”
- RQ3: “Is the PPSASDS a reliable measure for assessing parent involvement with postsecondary students with ASD?”
- RQ4: “Through merging results, generally what does parent participation look like?”
- She engaged in snowball recruitment, aiming to have 10 participants per variable; Cheryl ended up having 45 participants
- Cheryl found that having an instrument with “yes/no” questions considered the needs of BAP/autistic parents (black and white/yes or no thinking) and would be transferable across cultures, languages, level of education, and functioning.
- Since data are non-parametric (don't distribute normally, so there are no measures of central tendency), Item averages were collected for each item, in an effort to figure out to what extent parents agreed with one another; the closer the average to 1, the stronger the positive characteristics associated with the item.
- Cheryl employed the Kuder-Richardson Formula (KR-20), which relates to internal consistency reliability. for dichotomous data.
- Mokken Scale Analysis was used to measure latent variable construct validity, a tool used in instrument development for dichotomous data to determine the scalability of an item, between two items, and among a group. This helped Cheryl see how she can continue to hone the dichotomous instrument for further development.
- Qualitative analysis entailed using grounded theory (making sense of the voices of parents in an inductive manner). Conceptual labels emerged as words repeated across texts. ATLAS.ti generated reports that included label counts and frequency of co-occurring labels which revealed latent relationships between labels (and domains).
- Participants encompassed 41 mothers and 4 fathers. Most had at least a Bachelor's degree. 84% of participants identified as White.
- Across the Social Integration Domain, Autonomy Domain, and Emotional/Stress Relief Domains, all had strong reliability. according to the KR-20 measurement. Social Integration and Emotional/Stress Relief yielded positive Item Average scores (>.60 to <.81) while Autonomy yielded a strongly positive Item Average score (>.81).
- Qualitative questions similarly covered the three major domains. in which they were embedded.
- Regarding external validity, both the social integration and autonomy were considered the most significant challenges and needs, according to parents of postsecondary students with autism, as other literature notes.
- Parents illustrated their commitment in helping their children. Cheryl aligned this with how Tinto's 1975 model accounted for the importance of family in shaping students'

experiences. And they fostered social integration according to Tinto's model as well as nurtured Autonomy consistent with Wehmeyer's (1999) model.

- RQ1: “How do parents support social integration, autonomy, and emotional/stress relief?” They fostered social integration, nurtured autonomy, etc.
- RQ2: “In what other ways do parents support their postsecondary students with ASD?” Parents offered assistance with organization, communication, financial aid, and other tasks. There is an important relationship between autonomy and executive function.
- RQ3: “Is the PPSASDS a reliable measure for assessing parent involvement with postsecondary students with ASD?” YES
- RQ4: “Through merging results, generally what does parent participation look like?” A general theme is that there was much in the way of fostering skills associated with self-determination.
- Cheryl called attention to Wehmeyer (2014) who underscored that self-determination is a family affair, and the role of parents has been underexamined in terms of how they promote self-determination among their disabled children. She thinks she has partially filled in the gap here through learning how parents of autistic postsecondary students are coaching skills associated with self-determination. She found evidence in neuroscience to explain why Executive Function (EF) skills, critical to self-determination, were not acquired prior to college and why parents continue to coach this through college. For some individuals with autism, neuromaturation comes late in life – through the fourth decade of life – and for some autistic adults, EF may never be achieved. Parents are more or less providing an EF intervention for their autistic students at a time they may need it the most: late adolescence.
- Moving forward, Cheryl sees development with the PPSASDS with more diversity, a more representative sample, a more robust sample size as guided through the findings of Mokken Scale Analysis.
- Cheryl views many opportunities for future research, including skills taught through high school transition, curricula, improvement on employment outcomes among those with college degrees, etc.
- This content has been understudied.
- Parents can foster a wide variety of self-determination skills for their children.
- The hypothesis for the study proved correct, as parents are filling in gaps of individualized services.

Questions:

- Flor: “Are you planning to study the effect of parents involvement (e.g., engagement of the student in their courses, GPA, persistence and graduation rate/time to graduation?)”
Response: This is good to study. I am on an autism transition task force, and sees there are many opportunities for improvement. I think many executive function skills deserve more attention prior to college. My response to Flor now would be to assert that we can see outcomes of parent involvement through graduation rates. 8 parents reported students with BA/BS degrees while 1 reported completion of a Master's degree. Still 1 was enrolled in a doctorate program, another was in a Master's program and yet 21 working on a BA/BS. Plus there were 12 in 2 year programs plus 2 in technical programs. (Slide 21)

- Beth: “Cheryl, did parents indicate how much of the support they provided themselves vs. how much they paid others to provide?^[FERP] Also wondering if you only included respondents with children who had IEPs in place through high school (through 12th grade).”
 - Response: I did not specify that respondents only needed to have children with an IEP in place through 12th grade. My thinking on this was because my son did not have an IEP through 12th grade. In fact, he didn't have an IEP after 5th grade, because I insisted on his inclusion in general education classrooms, and back then, if he had an IEP, they required him to be segregated in a Special Education classroom. This was before the Least Restrictive Environment mandate of 2004. But as long as my son had an IEP, I attended every IEP meeting, and I had provided support from Pre-K to graduate school. And parents here, too, were active participants in IEP meetings. Additionally, I may have mentioned that some parents provided a therapist for their students or they suggest that their students get services on campus.
- One question was about parental participation in IEP meetings. The overwhelming proportion had. The latter question wasn't asked specifically. Some parents paid for programs.
- Natalie: “I may have missed this but was whether they lived at home vs. away at college considered?”
 - Response: Yes, this was asked. I mentioned that some parents reported that they didn't want their children to experience social stress, so they lived at home and provided transportation to and from schools.
- Patrick: “I'm curious about what parents said about barriers to their involvement? I'm thinking of some recent instances where parents and students I know have been having trouble getting supports and institutions to loop in parents into the conversation, even if the student wants the parent looped in.”
 - Response: FERPA can be a barrier. It started being instituted in the 1974, one year before the EAHCA of 1975, the forerunner of IDEA. Disabled children didn't have a right to public education prior to 1975, so there were never any expectations of students with disabilities in college. I noted a report of nearly 20% (19.4%) of undergrads report a disability and nearly 12% of graduate students report a disability. Those are the ones we know about because a significant number do not report disability. College students with disabilities. FERPA can limit parental participation, but students can sign off for students to participate.
- Patrick also asked about future opportunities to bring in the student perspective. He mentioned being an advocate for a peer recently. Patrick thinks that could be very useful.
- Cheryl sees much value in involving their perspectives, and has seen a massive rise in the research. She talked about being interested in transitions out of postsecondary education, in terms of parental roles. The very first research I did involved autistic students, but it was very hard to get participants back in 2008 - 2010. There was no real research on postsecondary students, mainly because the population of students was so small. My son was the first autistic student to graduate from Purdue in 2002, and he was recognized for his achievement. Because he had participated in a transition program at Purdue, his

outcome was tracked, which is why we know about this status about being the first. It is only since the Least Restrictive Environment mandate through IDEA (2004) that students are being educated in the general education, resulting in matriculation to postsecondary schools. 10 years makes a huge difference.

- Kim: “I may have missed this- how did you find the parents that took your research study?”
 - Response: I distributed scripts through social media, CANVAS, and created a website. This was a self-selected process.
- Jess: Jess mentioned not anticipating from students in their program the disconnect between what they think and what their parents think. She thinks this would be fascinating to discover, as there have been strong feelings emerge in their focus groups.
 - Response: Some students did not want their parents’ involvement whatsoever. - and the parents participated anyway. I think all students are different. It is important to note that my son was an child who did not speak before the age of 4. I think it very important to remember that the heterogeneity is such that no two autistic individuals are the same, and he was diagnosed at a time when late speech was a diagnostic criteria for autism. I would argue that those with classic autism and who develop speech late might have different needs from those who may be extremely verbal. One of the things that happens in college - according to the literature - is that students think they no longer need help or need to file for services with the disability resource center (until they run into trouble) and this behavior of not wanting help from parents is in my mind consistent with that behavior. So in regard to the focus group, I might interview students individually about whether or not parents were buying tickets to college sporting events (this is how I supported my son's social integration), had financed therapy in college. These would be indicators of how parents were supporting in a way that the student might not perceive as parent help. Students may not even realize that by asking "Did you talk to your professor about your grade?" is a way of coaching autonomy (in his case self-advocacy perhaps). So parent involvement may "look" different to the student than to someone like me.

Upcoming CANVAS Meetings

- Early 2021 Schedule TBD