A Collaborative Framework for Supporting College Student on the Autism Spectrum:

Jody Goldstein Director of Disability Services Wellness Center at UMass Lowell

Transition Seminar

- Early Move in Program two days prior to move in.
- Focus on skills required to access accommodations and support in Higher Education for freshman transitioning form High School
- Mentors participate and assist in navigating campus, communication skills with faculty and visiting classrooms.
- Freshman meet and learn how to access additional support systems on campus.

Mentoring Program

A Collaboration with Ashleigh Hillier PH.D, Associate Professor Of Psychology and Coordinator of University of Massachusetts Lowell Disability Minor and Student Disability Services

Background

- Increasing number of students with disabilities attending university
- Many excel academically but may find the transition to university challenging
- Issues with time management, organization skills, social integration, anxiety etc. may jeopardize success
- Specially Designed for students with ASD
 - but have allowed others to participate.

Mentoring

- Mentoring has improved outcomes for lots of different groups including youth, foster children, and those in training within a business.
- Mentoring in university settings is receiving more attention, and has shown success.
- Could be a cost-effective way to provide supports to our students that improve their retention and success.
- One-on-one, individualized, personcentered, peer-to-peer.

Implemention of Program

- Collaboration between Student Disability Services (SDS) and Department of Psychology
- Mentees are recruited by SDS
- Mentors are recruited by Prof Hillier Department of Psychology and Disability Minor Coordinator
- Meet one hour each week for one semester
- Biweekly guidance sessions for mentors

Examples of Curriculum Topics

- Organization & constructing weekly schedules
- Accessing websites: WIKI, SIS, Library
- Getting to know the campuses: activities, recenter, library, dining halls
- Balance between academics and social life
- Socializing, connecting with other students
- Planning for the future: advising, picking classes, registering
- Working in groups
- Talking to professors
- Preparing for the end of the semester: moving back home, transitioning to vacation time, finals week, study tips

Demographics

- Mentees: n= 46 (36 male, 10 female)
 - Autism Spectrum Disorder: 15
 - ADHD/ADD: 16
 - Anxiety: 3
 - Dyslexia: 3
 - Medical: 6
 - "Other": 2
- Mentors: n=35, 3 male, 32 female. Junior and senior undergraduate students.

Evaluation: Mentees

- Mentees complete weekly feedback questionnaire
- Program Questionnaire (designed by us)
- Focus group

Evaluation: Mentors

- Mentors complete weekly fieldnotes
- Questionnaires: Expected Costs and Benefits to Being a Mentor Instrument (Ragins & Sandura, 1999); and one designed by us: Mentor Experiences Questionnaire
- Focus group

Findings: Mentee Questionnaire

Program Questionnaire showed some positive outcomes for mentees.

Program Questionnaire	Pre	Post	t(40)	p
I am worried about my success	6.4	5.5	2.06	.046
I understand what the academic expectations will be at the university	6.3	7.6	3.04	.004
I know how things work at the univ.	5.9	7.2	3.24	.002
I know how to access support services	6.9	7.8	2.39	.02
I know how and where I can find opportunities to meet people	5.9	6.8	2.66	.01
I know how to manage my time and organize myself	5.8	6.3	1.16	.25
I am able to advocate for myself and my needs	6.7	7.1	1.0	.32
I know how to successfully study	6.0	6.7	1.92	.06
I am worried about making friends	5.3	6.2	2.18	.04

How much is due to the mentor?

Rating	%
Very much so	13
Quite a lot	38
A little	37
Not at all	12

88% attributed improvements to mentor to some degree.

Findings: Mentee Focus Groups

- Two coders reviewed the transcriptions from the five focus groups and identified five themes:
- Supportive Relationship
- Social Skills
- University Knowledge
- Academics
- Program Feedback

Supportive Relationship

"It's been helpful to just have someone, just like I said to have someone to go to and ask little questions to and sort of know and be able to go to someone to talk to because there's sort of, like they're friendly kind of thing, it's not like a professor where its sort of almost a professional relationship. But at the same time, it's not like you're just hanging out. So when you want to talk about things, it's not like the friend where you'll get off on all these random topics. I mean talking to a friend and talking to a mentor, they both have their separate benefits, but you sort of get a different kind of more focused help with the mentor."

Social Skills

"Because I think at the beginning of this semester, I was kind of lonely...she sort of encouraged me. So she would ask like are you meeting people, how is dorm life, is your roommate okay? And just sort of little things like that, sort of promoting me trying to, and then it also made me, like when she asked me those questions, like oh I actually am starting to feel more comfortable. I am meeting new people, so just like sort of recognize that I made some progress with that."

University Knowledge

- "...And like guides you, as a freshman you're kind of lost and you don't know much about the university. And since your mentor is an upper classman, they can tell you about the university."
- "I was pretty much oblivious to south campus at first, but because my mentor has a south campus major and almost all of her classes are there, she was able to introduce me to the area."

Academics

- "Well, I've gotten some studying tips, like studying for finals. I used to have, like I'm trying to break a habit of mine for waiting until the last minute... We worked out a plan for finals."
- "I mean academically, she definitely helped me with understanding, because I had been studying before but not enough. But she had me understand like what I can do to help improve my studying and stuff and socially, she helped me with the balance between both academics and social."

Program Feedback

- "Maybe make it longer because my mentor and I were really getting along well."
- "To be honest, I was feeling really satisfied by the time it ended."
- "I feel like it could be better if you were able to be a little more friendly with your mentor. I don't know exactly how to accomplish that, but because I saw her once a week and that was really it. So it wasn't like someone who I was communicating with a lot, I mean I communicated with her a lot during that hour, but it's only an hour..."

Findings: Mentor Questionnaires

Mentor Experiences Questionnaire shows positive outcomes for mentors.

Findings: Mentor Focus Groups

- Personal Growth and Skill Development
- Knowledge of Disability
- Challenges of Mentoring
- Career Goals and Future Plans
- Program Model

Personal Growth and Skill Development

"Sometimes people get too caught up in life and just listen to have some type of response to say. I had to listen to detail and fully understand the situation before I could really input my opinion, advice or questions. I can use this in the professional world and in my personal relationships."

Knowledge of Disability

"I had done some work like in a classroom with that but, it was definitely interesting because you kind of put yourself in their shoes. You know it's different to read from a textbook, or reading about a scenario, but when you're actually sitting down one on one and talk about the struggles that people with a disability may have and how sometimes it can be very difficult to access those things. It really makes you think about... just how easy sometimes other people have it...."

Challenges of Mentoring

"It terrified me being one on one. I don't want to say this person was depending on me, but you're there if they needed something. Like you know what about this class or this professor and I never expected to get so close to them. But like in a way what you're saying, they're not your kids, but you do build this protective relationship with them or you're always thinking about...I don't know. I just always ended up thinking about my mentees even when we weren't meeting, and I wonder how they are doing."

Career Goals and Future Plans

"I learned a lot about interacting with individuals with disabilities and even about myself. Actually, this program confirmed my idea to become a school psychologist as I really enjoyed working with students in a school setting."

Program Model

- And I think too, when we did the role playing in here, that definitely helped a lot, because I actually used one of my situations that came up, in terms of like the drinking and what you do, who do you talk to."
- *One thing that I recommend for next year doing the session, I don't know if people will like this, but we should meet every week instead of every other week, because I just felt like every other week was not enough. And especially at the beginning I was just thrown into the session without, I wish we had more of the role playing and discussing actually like potential situations."

Other

Being a mentor made me feel much more connected as a student at UMass Lowell. It made me feel as if I was actually a part of something. I think I also benefitted because it allowed me to be more willing to try new things that I would never have thought of doing and made me see that stepping out of my comfort zone could have more benefits than doing harm."

Connections Support Group

- A Collaboration between....
 Student Disability Services
- Ashleigh Hillier PH.D, Associate Professor Of Psychology
- Counseling Center
- University of Massachusetts Lowell

Our Program Model

- Began in Spring 2009
- Designed for students with ASD
- 52 participants, 9 cohorts
- One hour a week, 7-weeks, 4-7 in each group

Curriculum Topics

- Introductions
- Interpersonal communication
- Relationships
- Working in groups
- Time and stress management
- Future plans / careers
- Bringing it all together

Evaluation

- Rosenberg Self-Esteem Scale
- **UCLA Loneliness Scale**
- The Counseling Center Assessment of Psychological Symptoms-32
 - Depression
 - General anxiety
 - Social anxiety
 - Hostility
 - Academic distress
 - Focus group

Findings

- Significant increase in selfesteem
- Significant decrease in loneliness
- CCAP: significant decrease in general anxiety but not other subscales

Focus Groups

- 7 groups, 5 main themes:
- Stress and Anxiety
- Executive Functioning
- Academics and Resources
- Social
- Self-awareness

Stress and Anxiety

- "I feel a lot more relaxed as a student, I feel more confident. I feel that I got more close acquaintances in the group"
- More confidence, doing better in calc, I'm getting out more, and meeting more new people"
- "I've also learned some effective relaxation techniques which to my surprise, worked really well. Cool!"

Executive Functioning

Because, there's no one that I met at the right places at the right time. All the physical stuff, I'm here or here or here, like I said it all goes back to the time management. Making sure I'm at this place at this certain time. I'm at my classes at this certain time, make sure I have this, this, this, and this done at a certain time. All of this can be related to Connections because it actually helped me with my study habits. It also helped me with my habits in life in

Academics & Resources

- "I got some good tips about studying."
- "It's like, ask anyone here and they can guide me toward help. Really helpful."
- "Well, the internships and all that other stuff available. That was helpful."

Social

- "Well I figured out, I didn't know this before, but I figured out how to change my social skills a little bit, and pieces that I didn't know were actually very negative."
- "Sometimes it's hard for me to pick up cues and like the group made suggestions about how to be able to pick up something like that, like subtle cues."
- "I actually learned that I shouldn't express everything, because I'm very... a bit passionate."

Self-Awareness

- "I understand who I am now and don't question myself or my thoughts as much as before"
- "I made new friends, learned more about myself, and gained more confidence in myself"
- "I got a greater understanding of my disability and what I can do about it to help my problems. I also got valuable experience in meeting others like me which helped me understand myself better."

Self-Awareness

"I think it just makes me feel better, just knowing there's people out there just like me trying to just find myself. Even with the ASD, the spectrum disorder, knowing that I can pretty much do anything that anyone else can. I just have a back up system. I know I have people to talk to and people that I can ask for support. Or whatever, I take time, but I know I can do just as much as anybody, if not more."

Self-Awareness

- the spectrum is, and it showed me how others are on the spectrum in an open environment. Before this, I haven't talked with many people on the spectrum."
- "I am not as alone as I thought I was."

Conclusion

- There are cost effective ways to support students with disabilities which contribute to their success at university
- These programs also provide our students with important experiential learning opportunities
- Support from the administration makes these programs possible, and fosters the collaboration across faculty and

Thank-you

Questions?

Supporting College Students on the Autism Spectrum: Discussions on Academic, Social, and Behavioral Approaches

Todd Levine MD, FAAP
Instructor in Psychiatry and Human Behavior
Brown Center for the Study of Children at Risk
Warren Alpert Medical School of Brown
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Learning Objectives

- Understand how to identify specific areas of behavioral challenges (anxiety, social anxiety, attention difficulties, and disruptive behaviors) to allow staff to support colleges students with ASDs.
- Discuss the framework, implementation and learning objectives of the Peer to Peer Mentoring program, and Connections Group for students with ASD at the University of Massachusetts, Lowell.
- Case study

Diagnostic Considerations

Core deficits in language, communication, and socialization lead to difficulties with:

- Reliability of self-report
- Inability to self-report
- Interpretation of motivations behind behaviors

DSM-IV Considerations

Some diagnoses exclude/modify for Autism Spectrum Disorders:

- Social Phobia (Social Anxiety Disorder)
- Separation Anxiety Disorder
- Selective Mutism
- Generalized Anxiety Disorder
- ADHD
- Pica
- Rumination Disorder
- Schizophrenia (Delusions/Hallucinations present)
- Schizoid Personality Disorder
- Schizotypal Personality Disorder

With this in Mind...

Children and adults with ASD are at higher risk for anxiety¹, depression², and ADHD³

Psychiatric medications are likely to be prescribed to those with ASDs⁴

Psychotherapies have been adapted for children with ASDs and anxiety⁵

¹Gillot et al. Autism (2001), ²Ghaziuddin et al. J Autism Dev Disord. (2002),

³ Ghaziuddin et al. *J Intellect Disabil Res* (1998), ⁴Mandell et al. *Pediatrics. 2008*, ⁵Chalfant et al. *J Autism Dev Disord* (2007)

Psychotropic Prescribing in ASDs

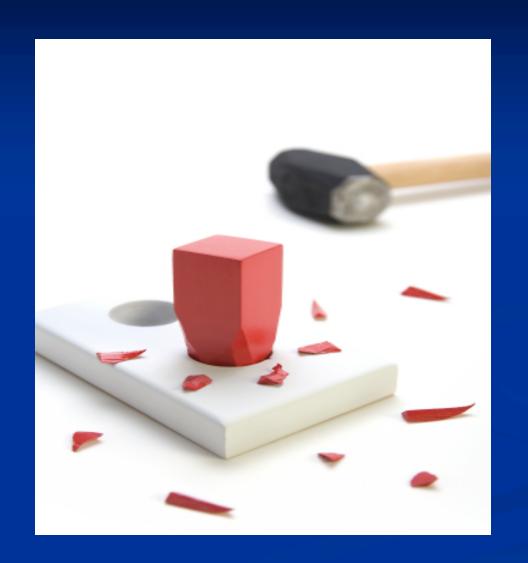
- In a sample of 60,641 children with ASDs, 56% used at least 1 psychotropic medication
- 20% were prescribed 3 medications concurrently
- Use was common even in children aged 0 to 2 years (18%) and 3 to 5 years (32%)
- Neuroleptic drugs were the most common psychotropic class (31%), followed by antidepressants (25%) and stimulants (22%)

Taking a Different Perspective



Obsessive Compulsive Disorder vs. Repetitive Interests in ASD

- Obsessions are "recurrent and persistent thoughts, impulses, or images that...cause marked anxiety or distress" (DSM-IV)
- Compulsions are acts designed to counteract those thoughts, impulses, or images
- Are either consistent with "restricted repetitive and stereotyped patterns of behavior, interests, and activities" in ASD?



Does Inattention=ADHD in ASD?

- Triad of ADHD symptoms is hyperactivity, impulsivity, and inattention
- Studies indicate stimulant medications are very good in acute treatment of ADHD symptoms
- Children with ADHD may not be as invested in activities (especially those that are social) and appear inattentive
- Inattention is the final common pathway for children with a variety of psychiatric issues

Disruptions and Oppositionality

- Tantrums and aggression are common problem areas for children with ASD
- Could language deficits and communication difficulties play a role?
- A potential role for "Theory of Mind"
 deficits
- Oppositional Defiant Disorder may not fit many children with ASDs

Can Someone with an ASD be Socially Anxious?

- Excluded from Social Anxiety Disorder diagnosis
- Socially anxious people are fearful of humiliation and opinions of others
 - Can someone with an ASD be aware of these factors?
- Many with ASDs appear dysphoric or anxious in groups of people, but is this anxiety?
- Cognitive behavior strategies have been applied

The Elusive "Inner State"

- Ohio How reliable/valid are self-reports in individuals with ASDs?
- Can parents tell us more about their kids with ASDs than the kids?
- Can we look at more concrete, biological markers of emotional response to help understand psychiatric reporting?
- There are few psychiatric measures for these children

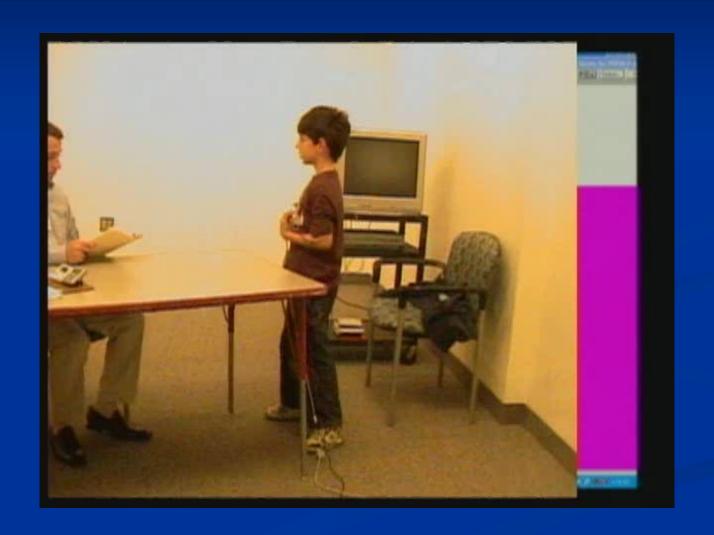
The Study of Social Anxiety in Asperger's Disorder

- ◆ Compares children ages 8-12 years old with Asperger's Disorder (AD, n=19) to those without (n=12) during a social stressor
- Protocol involves parent and child reports of anxiety (MASC and SPAI-C), child selfreport of anxiety during the events, and measurement of psychophysiology:
 - Electrodermal reactivity (EDR)
 - Heart rate variability, "vagal tone" (VT)
 - Salivary cortisol reactivity

Participant Example #1



Participant Example #2



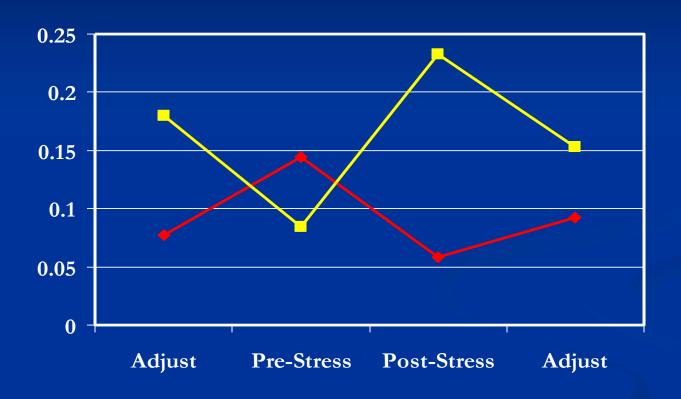
Who Has an ASD?

#1 #2





A Look at Cortisol Responses

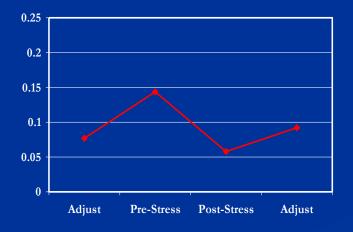


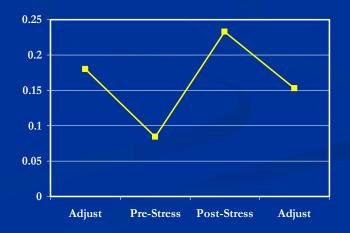
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What's Next?



Trends in Medication Treatment Studies in ASDs

- Most studies focus on specific behaviors vs. diagnostic criteria
- Specific behavioral measures have been created or modified for ASD patients
- Successful strategies in neurotypical children have been applied to children with ASD and similar behaviors

Problem Behaviors Targeted by Psychotropic Medications

- Hyperactivity
- Lack of Attention
- Agitation
- Insomnia
- Aggression
- Self-injury
- Stereotypies

- Tantrums
- Repetitive Behavior
- Compulsive Behavior
- Anxiety
- Hyperarousal
- Irritability
- Impulsivity

Side Effects of Psychotropic Medications

- Hyperactivity
- Lack of Attention
- Agitation
- Insomnia
- Aggression
- Activation

- Agitation
- Repetitive Behavior
- Compulsive Behavior
- Hyperarousal
- Irritability
- Tics

Antipsychotics

- Used for aggression in multiple populations in multiple contexts
- Multiple products available, but Risperidone remains best evidence based treatment
- Increased evidence for use in children
- Targets aggression in children with ASD
- May decrease repetitive behaviors

The Case for Risperidone

 Effectively treated irritability, tantrums, aggression, self-injurious behavior, anxiety, and hyperactivity

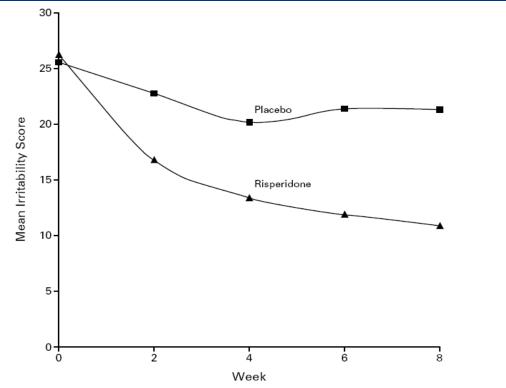


Figure 1. Mean Scores for Irritability in the Risperidone and Placebo Groups during the Eight-Week Trial. Data are for all 101 children (49 assigned to the risperidone group and 52 assigned to the placebo group). Higher scores indicate greater irritability.

Antidepressants

- Serotonin Specific Re-uptake Inhibitors
 (SSRIs) have evidence for use in children
 and adolescents with anxiety and depression
- U.S. FDA Black Box warning spurned controversy over use of SSRIs
- Applicability to ASD behaviors has been explored: repetitive behaviors and anxiety
- Recent research has changed previous conceptions about SSRI use in ASD

Stimulants and Others

- Methylphenidate (Ritalin) may help with ADHD symptoms in ASD, but there is a also a higher rate of adverse events*
- Amphetamines (Adderall) are poorly studied, but may be a treatment option
- Guanfacine (Tenex) may improve hyperactivity, inattention, insomnia, and tics

Meds...The Ultimate Solution??





What is RI-CART?

- The Rhode Island Consortium for Autism Research and Treatment (RI-CART) was established in 2009 by a group of researchers, clinicians, and community advocates.
- RI-CART's mission is to improve the lives of Rhode Islanders with autism spectrum disorders by promoting collaborative, cutting-edge research, improving health care and support services, and providing data-driven education and advocacy.



AutismRI.org

































My Home

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