

AUTISM IN ADULTHOOD
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Building Neurodiversity-Inclusive Postsecondary Campuses: Recommendations for Leaders in Higher Education

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Scope

- Autism (primarily), ADHD (secondarily)
- North America
- Students in for-credit programs, with a focus on undergraduate education

History of the recommendations

- Spring 2018 – foundation of UC Davis peer support group



Aggie Neurodiversity Community

History of the recommendations

- Spring 2018 – foundation of UC Davis peer support group
- November 2019 – group members decide to conduct neurodiversity trainings to address faculty/staff ignorance
- March 2020 – first neurodiversity training conducted

Many people to thank

- Mostly Aggie Neurodiversity Community members
 - Most are UC Davis students, some are students at other institutions
- One parent ally

History of the recommendations

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- March 2020 – first neurodiversity training conducted
- April 2021 – we conducted a neurodiversity training for the Math Department, and a math professor, Javier Arsuaga, went on to invite us to prepare neurodiversity recommendations for the UC Senate
- July 2021 – recommendations endorsed by the Senate; we begin preparing *Autism in Adulthood* submission

Implementation of the recommendations – TBD!

3 types of recommendations

- Diversity, Equity, and Inclusion
- Disability Supports and Accommodations
- Communication

Diversity, Equity, and Inclusion Recommendations

1. Recognize neurodiversity as a DEI issue

- DEI is often conceptualized in terms of race, culture, gender, and first-generation students; disability is often an afterthought
- This not only ignores a very marginalized population that experiences considerable discrimination and stigma, but also ignores intersectionality
 - In the USA, 44% of autistic people whose parents have postsecondary education go on to participate in postsecondary education themselves, compared to 14% of those whose parents did not (Roux et al., 2015)
 - 85% of American autistic postsecondary students are male, and female students have 5x lower odds ratio of persisting (Wei et al., 2015)
 - Non-White ADHD students show slower graduation progress (DuPaul et al., 2021)

1. Recognize neurodiversity as a DEI issue

- Making sure DEI personnel have neurodiversity/disability competence
- Making sure all DEI programs consider disability and neurodiversity
 - Even if a program is targeted towards a specific group, e.g., first-generation or indigenous students, must consider intersectionality
- Collecting data to document gaps and challenges – e.g., in USA, only 1% of NIH grants have disclosed disabled PIs (Swenor et al., 2020)
- Effectively addressing discriminatory behaviour, e.g., through remedial training or discipline

2. Campus-wide training

- Can increase autism knowledge, diminish stigma, promote more positive attitudes towards Universal Design (Waisman et al., 2022)



3. Disability Cultural Centres

- Totally distinct purpose from a disability accommodations office
- About community, culture, identity



4. Neurodivergent Leadership

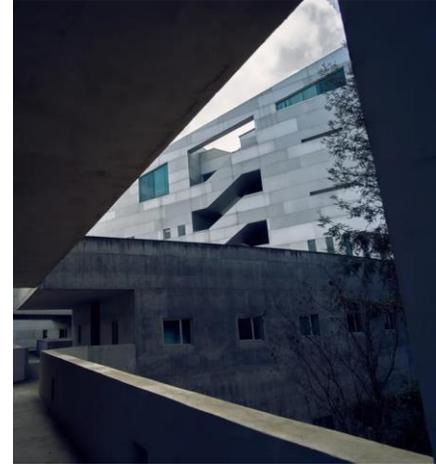
- Autism trainings are most effective when co-developed with autistic people (Gillespie-Lynch et al., 2021)
- Should be appropriate compensation
- Multiple pathways possible, e.g.:
 - Hiring neurodivergent employees to run initiatives
 - Forming groups of neurodivergent students/other personnel to oversee initiatives

**Nothing
About Us
Without Us**

Disability Supports and Accommodations

5. Integrate accommodations so that they are more accessible

- Many separate offices – for example, at UCD, might need to go to:
 - Student Disability Centre for most academic things
 - Dean's Office for some other academic things
 - Student Housing and Dining Services
 - Disability Management Services for student employee things



5. Integrate accommodations so that they are more accessible

- Ideally, there should be a single point of contact to coordinate everything
- At the very least, the system should be more transparent, have better communication between offices, and feature harmonized eligibility requirements

6. Increase flexibility of documentation requirements

- Documentation requirements seem variable in the United States
- In Canada, due to eligibility requirements for federal disability funding schemes, most institutions require rigorous and expensive assessments (e.g., neuropsychological testing) from within 3-5 years
 - Quality and utility of such reports are highly variable (Baum et al., 2018)

6. Increase flexibility of documentation requirements

- Accept IEPs and similar documents
- Do not require up-to-date documentation
- Determine eligibility for accommodations in a collaborative, person-centred manner

6½. Allow people to take reduced course loads without losing eligibility for financial aid

(I didn't realize this wasn't available everywhere when we prepared the recommendations. Oops.)



7. Recognize and accommodate sensory discomfort, distress, and overload

- Sensory issues may be more salient to autistic people than to neurotypical college staff, based on focus groups (Knott & Taylor, 2014)
 - Often not accepted as legitimate grounds for accommodations
- Can be serious barriers in multiple contexts
 - Housing
 - Meals
 - Sensory overload during lectures
 - Distraction in exams, libraries, other work areas

7. Recognize and accommodate sensory discomfort, distress, and overload

Through things such as:

- Sensory escape areas
- Single dorm rooms, quiet dormitories
- Flexibility re: type of food, where it is eaten
- Design of physical spaces – lighting, etc.
- Flexibility re: where exams taken – room in department, official disability testing centre, regular classroom should all be options

8. Supporting the transition in

- Summer transition programs (e.g., Lei et al., 2018; Gillespie-Lynch et al., 2017)
- Regular check-ins, to identify students who might be struggling but not coming forward to seek supports
- Mentorship programs (e.g., Lucas et al., 2017; Thompson et al., 2020; Zwart et al., 2002)
 - Choice of mentor should be intentional – and we think neurodivergent people make great mentors (Capozzi et al., 2019; Cifuentes, 2019; Crompton et al., 2022)

In North America, these programs often have extra costs, which violates principles of equity and inclusion

9. Supporting the transition out

- May require partnerships with external agencies
- Should not be based on stereotypes (e.g., autism & tech fields)
- Should be based on students' goals; should not aim too low



9. Supporting the transition out

- **Actual employment placements!!!**
- Education about the “hidden curriculum”
 - Information sessions about hidden curriculum of employment
 - Faculty/grad student mentor for those heading to graduate school



10. Better mental health supports

- Exacerbation of ongoing mental health struggles is a key part of the experience of autistic students who drop out (Cage & Howes, 2020)
- We know mental health supports are seldom geared towards autistic people's needs (Maddox et al., 2020) and ADHD people can also have poor experiences (Schrevel et al., 2016)
 - Therefore, counsellors with neurodiversity expertise needed
 - Also, people should be able to stick with one preferred counsellor
- Autistic students need more counselling appointments to derive best outcome, compared to neurotypicals (Anderberg et al., 2017)
 - Thus, we should not limit the number of appointments
- Furthermore, formal mental health support groups for neurodivergent people

11. Mechanisms if accommodations are denied

- This is one of a number of ideas we lifted straight from TC Waisman's doctoral thesis
- Needs to be simple, accessible, without undue advocacy burdens
- Various possibilities (not mutually exclusive):
 - Mediation panel
 - Easy way to switch case workers
 - Offices to ensure compliance with relevant disability laws/policies

Communication Recommendations

12. Follow individual's preferences re: advocates and support people

- Something we particularly struggled with
- On the one hand, neurodivergent students often lean on parental support (C. Anderson & Butt, 2017; A.H. Anderson et al., 2020; Lei & Russell, 2021; Morgan, 2009; Van Hees et al., 2018)
- Multiple parents have complained to me that they are made to feel unwelcome, or prevented from being present/involved at all
- On the other hand, parents' involvement can also be unwanted and resented by neurodivergent students (C. Anderson & Butt, 2017; A.H. Anderson et al., 2020; Sibley & Yeguez, 2018; Van Hees et al., 2018)
 - Career choice conflicts
 - LGBTQIA2S+ students

12. Follow individual's preferences re: advocates and support people

- Our recommendation is that there should be a simple, transparent process for a neurodivergent person to either:
 - request an support person be present/involved, or
 - reverse/change that request.
- In line with recommendation (5), this should not need to be repeated with any new person/office – the student should be able to select what they want the person to be involved in
- Once the decision has been made, university personnel should respect it

13. Communication flexibility

- As we know, autistic people vary in communication modality needs and preferences
 - Nonspeaking spellers (Capozzi et al., 2019; Jaswal et al., 2020)
 - Some of us like Zoom video cameras; others don't
 - Some of us like in-person classes; others prefer learning remotely (Pellicano et al., 2020)
 - Most of us hate phones (Doherty et al., 2022; Howard & Sedgewick, 2021)

13. Communication flexibility

- The neurotypical world is often inflexible, imposing just one modality
 - For classes, for booking appointments, for attending appointments
- We believe greater flexibility is needed, consistent with UD principles



Discussion?

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