

Disability Studies / Psychology M139
Current Perspectives on the Autism Spectrum and Neurodiversity

CLASS SYLLABUS

Instructors: Linda Demer, MD, PhD and Judy Mark, MA

Teaching Assistant: Shelby Kretz

Office Hours: Shelby Office Hours: Thursdays 3-4pm / Tuesdays 12:30-1:30pm

Class Description and Design

Current Perspectives on the Autism Spectrum and Neurodiversity is a class that focuses on the rapidly changing issues surrounding autism. History is rich in strongly opposing viewpoints with many earlier views on autism having to be retracted. The understanding of autism is undergoing rapid, radical evolution. As autism diagnosis, awareness, and research funding continue to increase dramatically, thinking about the cause and treatment of autism is continually shifting. Americans now are much more likely to know and interact with autistic people on a regular basis because individuals with autism have moved from isolation in institutions to more inclusion in schools and the community. Additionally, autistic self-advocates are demanding a seat at the leadership table and are starting to set the agenda for the autism community.

Current Perspectives on the Autism Spectrum and Neurodiversity will explore a wide range of points of view of the experience of the autism spectrum. This includes the perspectives of individuals with autism, their families, educators, medical professionals, therapists, neuroscientists, advocates and attorneys, policy makers, and the media.

The class has a theme each week featuring one perspective with readings, media, and expert guest speakers. The topics for class lectures, readings, and viewings include the latest revelations in the autism world including: the acceptance and accommodation of individuals with autism as part of neurodiversity, identity-first vs. person-first language, the limitations of using labels based on functional level, inclusion in the community, reductions in conservatorship, and other issues.

Because of the shifting views on autism, we will use primarily reading materials and media from the last few years from varied scientific and popular sources, with a comparison of a historical reference. A significant portion of the material is produced by autistic individuals themselves, called self-advocates. All of the class materials will be available online and on CCLE. No books will need to be purchased.

Special attention will be paid to disparities in the diagnosis, treatment, and support of individuals with autism based on race, ethnicity, and language spoken at home. While autism affects children equally, regardless of background, children coming from low-income, traditional minority, and immigrant backgrounds have significantly lower rates of diagnosis and effective treatment, as well as much lower use of effective special education and government-funded supports.

Class Requirements

1. Class Attendance – 10%

Students are expected to attend every online class. Classes may be shorter than the 4-6:50 pm time slot, but we want students to be available during that time. If a student knows in advance that they will miss a class, they must contact the T.A. at least one week prior to request an excused absence. If the student is sick, they must contact the T.A. at least one hour before class to receive an excused absence. Each unexcused absence will lower the student's grade by 2%. Every absence, regardless of whether it is excused, must be made up by submitting a one-page double-spaced summary of the recorded lecture from that week.

2. Class Participation - 15%

All readings should be completed before the start of each class and students should come prepared to engage in discussions and to ask questions of guest speakers. We will be asking students to keep their video/camera on during the synchronous classes. Each week, every student must come ready to present about the readings to classmates in a breakout session. Students will be randomly chosen to present about the readings, so they must be prepared each week.

3. Report on Interview with an Individual on the Autism Spectrum - 20%

Students are expected to carry out and report on an interview with an individual on the autism spectrum. Assistance will be provided in identifying and contacting interview candidates, if needed. Reports must also meaningfully analyze and incorporate ideas from at least three class reading assignments and two guest speakers comparing the interview with the course material on neurodiversity. A scoring rubric will be put on CCLE and discussed in class. 5-6 double-spaced pages. **Due by the end of Week 3 (11:59 pm, Sunday, October 25) to CCLE.** *NOTE: Late submissions will negatively affect your grade.*

4. Report on Interview with a Family Member of a Person on the Autism Spectrum or Professional in the Autism Field - 20%

Students are expected to carry out and report on an interview with a family member of an individual on the autism spectrum OR a professional in the autism field. Reports must also meaningfully analyze and incorporate ideas from at least three class reading assignments and two guest speakers comparing the interview with the course material on neurodiversity. A scoring rubric will be put on CCLE and discussed in class. Minimum 5 double-spaced pages. **Due Week 6 (11:59 pm, Friday, November 13) to CCLE.** *NOTE: Late submissions will negatively affect your grade.*

5. Final Research Paper - 25%

Each student is expected to write a final paper on an aspect of autism that interests them to demonstrate their knowledge and understanding gained from the class. The paper should take an issue discussed in class and compare and contrast that issue between the medical/historical/traditional model in the autism field versus the social/neurodiversity/inclusion model, including those forwarded by the neurodiversity movement. The paper must contain a thesis and arguments and critical analysis to defend the thesis. It should meaningfully analyze and incorporate readings and concepts from class lectures and guest speakers, which back up your thesis. It should also incorporate additional independent research from articles and writings from broader literature, which back up your thesis. A scoring rubric will be put on CCLE and discussed in class. Specifically, the paper must:

- Be minimum **seven** (7) double-spaced pages with a 12-point font and one-inch margins.
- Meaningfully incorporate at least **five** references from class materials, class lectures, or guest speakers.
- Meaningfully incorporate at least **three** references from outside source materials.
- Include a bibliography of source material using APA guidelines.

A one-paragraph abstract covering your topic choice plus at least two outside of class references is due on Week 7 (11:59 pm on Friday to CCLE). Feel free to arrange a meeting with the TA or professors. Professor Mark will approve each student’s topic and may ask for revisions or alternatives.

The research paper is due on week 10 (11:59 pm, Friday) to CCLE. *NOTE: Late submissions will negatively affect your grade.*

6. Group Final Presentations – 10%

Groups of 2, 3 or 4 students will give brief oral presentations based on their final research papers. The student groups will present for 8-10 minutes, depending on the size of the group. Groups will be assembled by the instructors based on similar subject matter. This is a very short amount of time so each student will only be able to present the most salient points of their research in about 2-3 minutes. **Final Presentations will take place on Finals Week** – *Note: If you are unable to attend the final class, please discuss your scheduling conflict with the instructors or TA to find an alternative time to present.*

CLASS ASSIGNMENTS AND ACTIVITY SCHEDULE

Assignment/Activity	
Report on Interview with Person on the Autism Spectrum	
Paper on Interview with Family Member or Professional	
One paragraph abstract and references on final paper topic	
Final Research Paper	
Final Group Oral Presentations and End of Class Celebration	

Class Readings and Other Media Assignments

All readings should be completed before each session. The readings and videos listed below have links and are posted on CCLE. If you are having trouble with a link for a reading, try using a different search engine or contact the T.A.

Course Schedule, Guest Lectures, and Weekly Reading Assignments

Class 1 – Overview of Current Perspectives on the Autism Spectrum and Neurodiversity

Required Readings:

Armendariz, R. (2019, September 18). The Autism Acceptance Hoax. National Council on Severe Autism. Retrieved from <https://www.ncsautism.org/blog//the-autism-acceptance-hoax>

Autistic Self-Advocacy Network. What is Autism? Retrieved on 2019, December 22) <https://autisticadvocacy.org/about-asan/about-autism/>

Bailin, A. (2019, June 6). Clearing Up Some Misconceptions about Neurodiversity. *Scientific American*. Retrieved from <https://blogs.scientificamerican.com/observations/clearing-up-some-misconceptions-about-neurodiversity/?redirect=1>

Centers for Disease Control and Prevention (2016, April 18). *Diagnostic criteria: Autism spectrum disorder*. Retrieved from <https://www.cdc.gov/ncbddd/autism/hcp-dsm.html>

Kapp, S. K. (2020). *Autistic Community and the Neurodiversity Movement: Stories from the Frontline*. Chapter 1. Introduction. Retrieved from <https://link.springer.com/content/pdf/10.1007%2F978-981-13-8437-0.pdf>

Summers, S. (2012, May 7). 10 tips on how to communicate with autistic people [Web log post]. Retrieved from <https://autismum.com/2012/05/07/10-tips-on-how-to-communicate-with-autistic-people/>

Walker, N. (2014, September 27). Neurodiversity: Some basic terms and definitions (Blog post). Retrieved from <http://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions/>

Class 2 – Perspectives of Individuals with Autism/Self-Advocates

Required readings:

Brown, Lydia (2011). Identity first language. Retrieved from

<http://autisticadvocacy.org/home/about-asan/identity-first-language/>

Centers for Disease Control and Prevention. Communicating with and about People with Disabilities.

Retrieved on December 22, 2019 from

https://www.cdc.gov/ncbddd/disabilityandhealth/pdf/disabilityposter_photos.pdf

Haelle, T. (2019, July 31). Identity-first vs. person-first language is an important distinction. *Covering*

Health. Retrieved from <https://healthjournalism.org/blog/2019/07/identity-first-vs-person-first-language-is-an-important-distinction/>

Neuroscience News. (2019, June 21) Researchers call for the term ‘high functioning autism’ to be

consigned to history. Retrieved from <https://neurosciencenews.com/high-functioning-autism-14290/>

Sequenzia, A. (2013, September 26). More problems with functioning labels [Web log post]. Retrieved

from <http://ollibean.com/problems-functioning-labels/>

Class 3 – Perspectives of Family Members

Required Readings:

- Deweerd, S. (2017, May 18). The joys and challenges of being a parent with autism. *The Atlantic*. Retrieved from <https://www.theatlantic.com/family/archive/2017/05/autism-parenting/526989/>
- Greenburg, C and Des Roches Rosa, S. (2020). "Two Winding Parent Paths to Neurodiversity Advocacy." *Autistic Community and the Neurodiversity Movement: Stories from the Frontline*. Retrieved from <https://link.springer.com/content/pdf/10.1007%2F978-981-13-8437-0.pdf>
- Mishori, R. (2012, September 3). Autism can have large effects, good and bad, on a disabled child's siblings. *The Washington Post*. Retrieved from https://www.washingtonpost.com/national/health-science/autism-can-have-large-effects-good-and-bad-on-a-disabled-childs-siblings/2012/08/31/e35a82e2-b956-11e1-abd4-aecc81b4466d_story.html?utm_term=.9ae0d662e0cc - <https://www.washingtonpost.com/nat>
- National Council on Severe Autism (2019, January 5). New advocacy group seeks realistic solutions for severely disabled autistics. Retrieved from <https://www.ncsautism.org/blog/2019/1/5/new-advocacy-group-seeks-realistic-solutions-for-severely-disabled-autisticsnbsp>
- Opar, A. (2019, February 4). New group faces backlash over goals for severe autism. *Spectrum*. Retrieved from <https://www.spectrumnews.org/news/new-group-faces-backlash-goals-severe-autism/>

Class 4 – Perspectives on Education and Therapies for People with Autism

Required Readings:

Haskins, C. (2020, September 17). "I barely have anything left to give": What it's like parenting kids with autism during the pandemic. *Buzzfeed News*
<https://www.buzzfeednews.com/article/carolinehaskins1/parenting-autism-pandemic>

Ito, J. (2018, September 6, 2018). The educational tyranny of the neurotypicals. *Wired*. Retrieved from <https://www.wired.com/story/tyranny-neurotypicals-unschooling-education/>

Prizant, B. (2015). We have autism all wrong: The radical new approach we need to understand and treat it. In B. Prizant & T. Fields-Meyer, *Uniquely human: A different way of seeing autism*. Retrieved from http://www.salon.com/2015/08/16/we_have_autism_all_wrong_the_radical_new_approach_we_need_to_understand_and_treat_it/

Siegel, B. (2018). The Illusions of Inclusion. Retrieved from <https://brynasiegel.com/blog.php#illusions>

Suskind, R. (2014, March 7). Reaching my autistic son through Disney. *The New York Times Magazine*. Retrieved from <https://www.nytimes.com/2014/03/09/magazine/reaching-my-autistic-son-through-disney.html>

Class 5 – Perspectives on Employment and Housing for People with Autism

Required Readings:

Autism Society San Francisco Bay Area. (Retrieved September 2020). Overview of Current Adult Autism Housing Options. Retrieved from <https://www.sfautismsociety.org/housing-options-for-adultswith-autism.html>

Autistic Self-Advocacy Network. (2018, October). *Real Work for Real Pay: A Self-Advocate's Guide to Employment Policy*. Retrieved from <https://autisticadvocacy.org/wp-content/uploads/2018/10/Real-Work-For-Real-Pay-A-Self-Advocates-Guide-to-Employment-Policy-Plain-Language.pdf>

Escher, J. (2019, November 14). NCSA Letter: We must retain non-competitive employment options for Americans with severe disabilities. Retrieved from <https://www.ncsautism.org/blog//ncsa-letter-we-must-retain-non-competitive-employment-options-for-americans-with-severe-disabilities>

Oliver, S., et al. (2019). The outcomes of individualized housing for people with disability and complex needs: a scoping review. *Disability and Rehabilitation*. Retrieved from <https://www.tandfonline.com/doi/full/10.1080/09638288.2020.1785023>

Raynor, O., et al. (2018). Community Conversations to Increase Employment Opportunities for Young Adults With Developmental Disabilities in California. *Journal of Disability Policy Studies*. Retrieved from <https://www.semel.ucla.edu/sites/default/files/publications/4.pdf>

CLASS 6 – Racial and Ethnic Disparities for People with Autism

Required Readings:

Harrington, C., & Kang, T. (2016). Disparities in service use and expenditures for people with intellectual and developmental disabilities in California in 2005 and 2013. *Intellectual and Developmental Disabilities, 54*(1), 1-18. doi: <http://dx.doi.org/10.1352/1934-9556-54.1.1>

* Report PDF will be uploaded onto CCLE

Heilker, P. (2012). Autism, rhetoric, and whiteness. *Disability Studies Quarterly, 32*(4). Retrieved from <http://dsq-sds.org/article/view/1756/3181>.

Senate Select Committee on Autism and Related Disorders, Task Force on the Equity and Diversity for Regional Center Autism Services (2014). *A preliminary report by the Taskforce on Equity and Diversity for Regional Center Autism Services*. Retrieved from <http://www.uscuedd.org/component/jdownloads/send/15-racial-disparities-equity-and-cultural-proficiency/83-report-by-the-taskforce-on-equity-and-diversity-for-regional-center-autism-services>

Westling, A. (2017, March 13). Letter to Senator Scott Wiener. Retrieved from <http://arcanet.org/wp-content/uploads/2018/01/equity-testimony.pdf>

CLASS 7 – Perspectives on Health Care and Research

Required Readings:

Autism Speaks. (2019, January 14). Autism Speaks names top 10 autism studies of 2018. Retrieved from <https://www.autismspeaks.org/news/autism-speaks-names-top-ten-autism-studies-2018>

Bishop-Fitzpatrick, L. and Kind, A. (2018, November). "A Scoping Review of Health Disparities in Autism Spectrum Disorder." *Journal of Autism and Developmental Disorders*. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5693721/>

Office of Developmental Primary Care, University of California, San Francisco. Supported Health Care Decision Making. Retrieved on December 26, 2019 from <https://odpc.ucsf.edu/supported-health-care-decision-making>

Opar, A. (2018). The healthcare system is failing autistic adults. *Spectrum*. Retrieved from <https://www.spectrumnews.org/features/deep-dive/healthcare-system-failing-autistic-adults/>

Robison, J. (2020). "My Time with Autism Speaks." *Autistic Community and the Neurodiversity Movement: Stories from the Frontline*. Retrieved from <https://link.springer.com/content/pdf/10.1007%2F978-981-13-8437-0.pdf>

Shapiro, J. (2020, June 9). COVID-19 infections and deaths are higher among those with intellectual disabilities. National Public Radio. Retrieved from <https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabili>

Class 8 – Perspectives on Supported Decision-Making and Conservatorship

Required Readings:

American Civil Liberties Union. FAQs about Supported Decision-Making. Retrieved on December 26, 2019 from <https://www.aclu.org/other/faqs-about-supported-decision-making>

Disability Voices United. (2020). With support and without the court. Link to come.

Dvorak, P. (2015, September 21). Why a man with intellectual disabilities has fewer rights than a convicted felon. *The Washington Post*. Retrieved from https://www.washingtonpost.com/local/why-a-man-with-intellectual-disabilities-has-fewer-rights-than-a-convicted-felon/2015/09/21/2281f5c0-605e-11e5-b38e-06883aacba64_story.html

Jager, E. (2019, November 5). Autism and Guardianship: When It's an Easy Decision. National Council on Severe Autism. Retrieved from <https://www.ncsautism.org/blog//autism-and-guardianship-when-its-an-easy-decision>

Class 9 – Perspective on Safety for People with Autism

Required Readings:

Autistic Self-Advocacy Network. (2020, June). What is Police Violence? A plain language booklet about anti-Black racism, police violence, and what you can do to stop it. Retrieved from <https://autisticadvocacy.org/wp-content/uploads/2020/06/PL-Police-Violence-Toolkit.pdf>

Baladerian, N. J., Coleman, T. F., & Stream, J. (2013). *Abuse of people with disabilities: Victims and their families speaks out: A report on the 2012 National Survey on Abuse of People with Disabilities*. Retrieved from Spectrum Institute, Disability and Abuse Project website: <http://www.disabilityandabuse.org/survey/survey-report.pdf>

Silberman, S. (2017, September 19). The police need to understand autism. *The New York Times*. Retrieved from <https://www.nytimes.com/2017/09/19/opinion/police-autism-understanding.html?action=click&contentCollection=Opinion&module=Trending&version=Full®ion=Marginalia&pgtype=article>

Class 10 – Perspectives on Autism in the Culture

Optional Readings and Viewings:

Duan, C., et al. (2018, April 2). Why 'The Good Doctor' Is Bad Medicine for Autism." *The Hollywood Reporter*. Retrieved from <https://www.hollywoodreporter.com/news/why-good-doctor-is-bad-medicine-autism-1098809>

Ferguson, S., Saines, E. G. (Producers), & Jackson, M. (Director). (2010). *Temple Grandin* [Motion picture]. United States: HBO.

Excerpts

* Highly recommended: Watch the entire movie of *Rain Man*

Johnson, M. (Producer), & Levinson, B. (Director). (1988). *Rain Man* [Motion picture]. United States: United Artists, Star Partner II, Ltd., Barris Industries, & Guber-Peters Company.

Excerpts

* Highly recommended: Watch the entire movie

Sanny Wendy (2013, January 21). *Sheldon Cooper Asperger's Syndrome*. Retrieved from <https://www.youtube.com/watch?v=SiQtKWkIt5o>