

Disability Informatics & Information

Instructor Information

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Office hours: Tuesdays/Thursdays 11:00am – noon

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Course Overview

This course introduces students to a range of issues related to disability, information, technology, and information systems as social infrastructure. The course will comprise three main components: reading and participation (25%), contribution to a CEDI digital/data defense project (30%), and a panel presentation in the Symposium on Information for Social Good (35%). Students in the course will read, watch, and discuss a mix of personal accounts, empirical research, commentary, and theory related to information, technology, place, communities, and disability. The course is designed to allow students to gain broad exposure, while choosing an area of focus that aligns with your interests and/or career goals.

Teaching Philosophy:

This class is a learning community made up of students with varying interests, and who will go on to work in a variety of settings. This course holds, as a foundational premise, the inherent value of all human beings, and takes a critical, intersectional approach to understanding disability. We also begin with the assumption that the perspectives and the experiences of people with disabilities hold as much validity and importance for our work as those of professionals who work in fields that serve disabled people. While I have done research in this area, I do not consider my own expertise equal to or more than people with disabilities.

As the professor, I will provide you with appropriate materials and supports. I will guide your exploration as you consider the implications of the work being considered. Much of your inquiry will be done in conjunction with your classmates. This class is a space in which I expect respectful, but brave exploration

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of issues – a space to ask big (and small) questions, to work through messy concepts, and to think about how they apply to your current understandings and future practice.

Course Materials:

Students will be expected to complete readings in preparation for each class meeting. The assigned readings are listed on the course schedule and will be made available electronically, through the UNC libraries, e-reserves, or the Sakai site for the course. No textbook is required.

Honor Code:

The Honor Code, which prohibits giving or receiving unauthorized aid in the completion of assignments and exams is in effect in this class. Whenever you use the words or ideas of others, they should be properly marked as a quotation (and referenced) or the source of the ideas should be cited. APA citation format is required for assignments in this class.

Please contact the instructor if you have any questions about the application of the Honor Code to your work in this class. You can learn more about the UNC Honor Code at <http://honor.unc.edu> and about the Instrument of Student Governance at <http://instrument.unc.edu>.

I also expect that students will give proper credit to other researchers through proper use of citation. APA citation style will be used for this course.

Disability and Accommodations

The University of North Carolina at Chapel Hill facilitates the implementation of reasonable accommodations, including resources and services, for students with disabilities, chronic medical conditions, a temporary disability or pregnancy complications resulting in difficulties with accessing learning opportunities.

All accommodations are coordinated through the Accessibility Resources and Service Office. See the ARS Website for contact information: <https://ars.unc.edu/>

Relevant policy documents as they relation to registration and accommodations determinations and the student registration form are available on the ARS website under the About ARS tab.

Additional Course Policies

Laptops. Laptops and mobile devices are welcome in class, but should be used only for legitimate purposes related to this course. There will be times when students will be asked to close all laptops and devices.

You will be using SILS [library](#) and [IT services](#) during the course of the semester. Please remember that many of your fellow students also need to use the same equipment and materials. Follow the proper checkout procedures and return materials promptly to be a good SILS citizen.

Email is the most efficient way to communicate with the instructor outside of class, for brief questions or notes. Normally, you should expect a response within 24 hours. I am also happy to schedule a meeting with you. If you come by the office and my door is open, then I'm available for a conversation.

Projects

Digital/Data Defense Project (30 points total)

The Digital/Data Defense project focuses on building an open resource for a local community. In order to successfully complete this project, students will select an issue of importance to a specific segment of the disability community in Durham, North Carolina and create a local resource guide that addresses issues related to information, data, and/or technology as it relates to that topic. After editing, students will be given the option to publish their work as part of the CEDI Lab's (<http://cedi.web.unc.edu/>) Digital Equity project (either under your own name or as a "Lab Author").

Topic

The guide should address issues of importance to, and protect the interests of, individuals and families in the community rather than focusing primarily on the interests of community organizations and institutions, and do the following:

1. Describe the group, their local/national history, and their needs (include any relevant datasets that describe the community on a broader scale – such as census data or Department of Education data).
2. Describe the issue or topic and give a concise background as it relates to individuals
3. Provide information, datasets, resources that would be most helpful for this group.
4. Consider issues such as privacy, control over personal data/information, difficulty accessing information, differences between the way local systems *should* work and the way the *do* work.
5. Others that we will create as a class

This project may require talking to some people in your selected group, or asking service providers specific questions about your topic/issue. Example issues might include:

1. How to successfully apply for Medicaid or SSDI benefits
2. The IEP process
3. Finding Employment for adults with intellectual disabilities

Format

Each submission should include the following:

1. Multimedia Toolkit (may be website/video with captions/interactive PowerPoint/other format with approval). Should include, at minimum, a description of the local community, a description of the issue, a resource list (including contact information for local organizations/individuals as appropriate, and list of relevant datasets/information related processes/maps or geographic data/financial data), a description of associated problems/risks, and descriptions of solutions. Should make appropriate use of visual/audio/interactive components.
2. 5-7 page Toolkit Summary: This document should be formatted as an accessible PDF booklet (not as a double spaced paper) and should include same information as multimedia presentation version. This document should include a full reference list as the final page.

Important Dates:

1. Proposal Due (5 points) - January 23

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2. Workshop Day (5 points) - February 27
3. Full Project Submission Due – March 12
4. Final Project Presentation – April 9

Symposium on Information for Social Good (<http://info4socialgood.web.unc.edu/> & <https://twitter.com/hashtag/SILSSG2019>) (35 points)

Students in INLS 690_230 (Disability Informatics and Information), INLS 384 (Information and Computer Ethics – undergraduate level), INLS 690-197 (Information Services in a Diverse Society), and INLS 732-001(Children's Literature and Related Materials) will collaborate to host the 4th annual SILS Symposium for Social Good on **Friday April 17, 2020 from 8 am – noon**. Each student will be expected to make a scholarly contribution to this event, either in the form of a panel or poster presentation about an ethical issue or social problem related to information science. Presentations should be of professional quality.

The symposium will be held on a Friday morning. This will take the place of a final exam for this course (please note that final exams do not take place during the regularly scheduled class time)

Any student who is unable to arrange to be available for the symposium should consult the instructor for specific instructions to arrange a regularly scheduled final exam. Please make these arrangements prior to February 20 so we can plan appropriately for the symposium. Grade adjustments/make-up assignments will not be made based on failure to communicate and plan appropriately.

Content

Proposals should be related to this year's symposium topic and should address a topic related to Disability, information, data, and/or technology. Initial symposium topic proposals (and group selections) are due **February 20, 2020**. I will work with you to refine topics over the following 2-week period.

Panels should include a presentation component and a question-answer/interactive audience component.

While there are many ways to present your work (and we will discuss some of them during class), panel presentations should do the following, at a minimum:

- Describe/address a specific, applied topic, issue or current event
- Outline relevant professional/moral/ethical issues
- Identify the stakeholders involved
- Outline and suggest possible courses of action and/or suggested practice

Group participation/selection

Panels will comprise 3 group members each and will be 45 minutes long (total). There are only enough students in this section to make 2 groups, so it is not expected that panels will be completely “cohesive” in topic selection. You are responsible for ensuring that your collaboration is fruitful, and that your presentation fulfills the assignment as given in this course.

Time

Students are expected to attend the entire symposium session. Approximately one hour should be spent presenting, and the other two hours should be spent attending other students' presentations. The final

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portion of this project – an end of semester reflection on the symposium – should address your own presentation experience as well as your experiences interacting with other students' work.

Deliverables

1. Symposium Panel Proposals (February 20, 2020)

Proposals should be related to this year's symposium topic and should address a topic related to Disability, information, data, and/or technology. Topics that relate your chosen topic to current or recent events are preferred.

Format: Proposals should take the form of a single group panel abstract (300-500 words) describing the issues to be addressed by the symposium presentation. Submissions should include the following metadata:

1. Full names for each group member.
2. Title of presentation.
3. Full abstract for the panel presentation (300-500 words).
4. Short abstract (50-100 words) for use on the symposium website.

Each group member must submit a copy of the proposal document by the due date.

Presentation slots will be filled on a first come, first serve basis. Course instructors reserve the right to reject or modify proposals in consultation with students.

2. Symposium outline/preliminary research (Due March 26, 2020)(5 points):

Students must submit an outline of the presentation content (not just a plan for what you will talk about, but the actual information you will use to construct your presentation). While this does not have to be polished, it should be well-organized into topic areas, or headings that are indicative of the conceptual organization of your presentation. This should include a 15-20 item bibliography, and should cover the content areas described in "Content" above.

Students should also submit a short bio and photo for the symposium website by this date.

3. Symposium Practice Presentation (April 2, 2020)(5 points)

4. Symposium Participation (April 17, 2020, 8 am-12 noon) (20 points)

Students will participate in the symposium, and attend at least two other student presentations.

5. Symposium Reflection (5 points)(due at finals)

Students will write a 250-500 word reflection on your participation in the symposium. The reflection should include an evaluation of their own work and presentation experience, and a very brief summary/evaluation of two peer groups' presentations.

Course Schedule

January 9 (Week 1): Course Overview

Before this session...

Skim:

1. Our Data Bodies: Digital Defense Playbook [In Course Reserves]
2. Appleyard, R. (2005). Disability informatics. In *Consumer health informatics* (pp. 129-142). Springer, New York, NY.
3. Lazar, J., Langdon, P., & Heylighen, A. (2013). Special issue of the journal of usability studies: designing inclusive systems. *Journal of Usability Studies*, 8(4), 90-92.
http://uxpajournal.org/wp-content/uploads/sites/8/pdf/JUS_LazarIntro_August_2013.pdf
4. American Library Association. (2018, July 02). Services to People with Disabilities.
<http://www.ala.org/advocacy/intfreedom/librarybill/interpretations/servicespeoplesabilities>

Read:

5. Imani Barbarin (2018). <https://crutchesandspice.com/2018/05/15/disabled-people-have-an-ally-problem-they-need-to-stop-talking-for-us/>

January 16 (Week 2): Disability Frameworks

Before this session...

Read:

1. Berghs, M. J., Atkin, K. M., Graham, H. M., Hatton, C., & Thomas, C. (2016). Implications for public health research of models and theories of disability: a scoping study and evidence synthesis.
2. Whitaker et al., 2019. Disability, Bias, and AI. <https://ainowinstitute.org/disabilitybiasai-2019.pdf> (pp. 2-7).
3. Forlano, L. (2017). Maintaining, Repairing and Caring for the Multiple Subject. *continent.*, 6(1), 30-35. <http://continentcontinent.cc/index.php/continent/article/view/277>
4. Williams, R. M., (2019). “Metaeugenics and Metaresistance: from manufacturing the ‘includable body’ to walking away from the broom closet,” *Canadian Journal of Children’s Rights / Revue canadienne des droits des enfants*, vol. 6, no. 1, pp. 60-77.

Watch:

1. Stella Young. (2014). I’m not your inspiration, Thank you very much. TED Talk. [9 minutes]
https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much
2. Sitting Pretty Lolo. (2016). THINGS NOT TO SAY TO SOMEONE IN A WHEELCHAIR - TOP 3 [CC] || Sitting Pretty. YouTube. <https://www.youtube.com/watch?v=Z9enfss75XU> [9 minutes]

January 23 (Week 3): Community Information, Public Data, and Prefigurative Politics

Before this session...

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Read:

1. Giangreco, M. F. (2010). ‘The stairs didn’t go anywhere!’: a self-advocate’s reflections on specialised services and their impact on people with disabilities. In *Equality, Participation and Inclusion 1* (pp. 37-49). Routledge.
2. Lakshmi Piepzna-Samarasinha, L. (2018). Care Webs. In *Care Work: Dreaming Disability Justice* (pp. 32-68). [In Sakai Digital Course Reserves]
3. Our Data Bodies: Digital Defense Playbook [In Sakai Digital Course Reserves]

Watch:

1. Imani Barbarin. (2019) “Getting a Word In: Prioritizing Disabled People’s Narratives”
<http://cedi.web.unc.edu/2019-cedi-lecture-series/#prioritizing> [50 minutes]

Digital/Data Defense Project Proposal Due (5 points)

January 30 (Week 5): Disability Legislation & Pivotal Cases

GUEST LECTURER: Crystal Grant (<https://law.duke.edu/fac/grant/>)

Before this session...

Read:

1. Facts about the Americans with Disabilities Act: <https://www.eeoc.gov/eeoc/publications/fs-ada.cfm>
2. Section 508: IT Accessibility Laws and Policies
<https://www.section508.gov/manage/laws-and-policies>
3. 20 U.S. Code Chapter 33 – EDUCATION OF INDIVIDUALS WITH DISABILITIES
<https://sites.ed.gov/idea/statute-chapter-33>

Skim:

1. Disability Rights, NC website: <https://disabilityrightsn.org/>
Identify an issue of interest among the basic issue categories for discussion:
<https://disabilityrightsn.org/our-work/>

Watch:

Facundo Element. (2014). [The D: Detroit Deaf Education](#). [40 minutes]

February 6 (Week 6): Assistive Technology and Human Centered Computing

Before this session...

Read:

1. Faucett, H., Ringland, K., Cullen, A., & Hayes, G. (2017). (in)visibility in disability and assistive technology. *ACM Transactions on Accessible Computing (TACCESS)*, 10(4), 1-17.
doi:10.1145/3132040

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2. Hendren, S. (2017, June 16). All Technology is Assistive. Retrieved October 16, 2018, from <https://www.wired.com/2014/10/all-technology-is-assistive/>
3. Foley, A. and Ferri, B. A. (2012), Technology for people, not disabilities: ensuring access and inclusion. *Journal of Research in Special Educational Needs*, 12: 192-200. doi:[10.1111/j.1471-3802.2011.01230.x](https://doi.org/10.1111/j.1471-3802.2011.01230.x)

February 13 (Week 7): Guest Lecture: Autism

GUEST LECTURER: Kim Tizzard

February 20 (Week 8): Disability workplace issues

GUEST LECTURER: JJ Pionke

Symposium Panel Proposal Due (check)

February 27 (Week 9): Workshop Day

Be prepared to discuss your progress on data projects in progress.

March 5 (Week 10): Public Space and Civic Life

Before this session...

Read:

1. Kumbier, A., & Starkey, J. (2016). Access is not problem solving: Disability justice and libraries. *Library Trends*, 64(3), 468-491. doi:10.1353/lib.2016.0004
2. Stephanie Rosen, "Accessibility for Justice: Accessibility as a Tool for Promoting Justice in Librarianship," *In the Library with the Lead Pipe*, November 29, 2017, www.inthelibrarywiththeleadpipe.org/2017/accessibility-for-justice/.
3. Doucette, L. (2017). [If You're in a Wheelchair, Segregation Lives](https://www.inthelibrarywiththeleadpipe.org/2017/accessibility-for-justice/).
4. Vallas, R., & Fremstad, S. (2014). Disability is a cause and consequence of poverty. *Talk Poverty*. <https://talkpoverty.org/2014/09/19/disability-cause-consequence-poverty/>

March 6-16th Spring Break (Week 11): No Class

March 19 (Week 12): Library services for people with disabilities

Before this session...

Read:

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1. Bonnici, L. J., Maatta, S. L., Brodsky, J., & Steele, J. E. (2015). Second national accessibility survey: Librarians, patrons, and disabilities. *New Library World*, 116(9/10), 503-516. doi:10.1108/NLW-03-2015-0021
2. Brannen, M. H., Milewski, S., & Mack, T. (2017). Providing staff training and programming to support people with disabilities: An academic library case study. *Public Services Quarterly*, 13(2), 61-77. doi:10.1080/15228959.2017.1298491
3. Jaeger, P. T., Gorham, U., & Taylor, N. G. (2015). *Libraries, human rights, and social justice: enabling access and promoting inclusion. Chapters 4-6*. Lanham, Maryland: Rowman & Littlefield.

Full Data Defense Project submissions due

March 26 (Week 13): Universal Design for Learning

1. Wilson, J. D. (2017). Reimagining disability and inclusive education through universal design for learning. *Disability Studies Quarterly*, 37(2) doi:10.18061/dsq.v37i2.5417
2. Christensen, L. L., Shyyan, V., & Johnstone, C. (2014). Universal design considerations for technology-based, large-scale, next-generation assessments. *Perspectives on Language and Literacy*, 40(1), 23-31. Retrieved from <http://libproxy.lib.unc.edu/login?url=https://search-proquest-com.libproxy.lib.unc.edu/docview/1514905016?accountid=14244>
3. CAST (2018). Universal Design for Learning Guidelines version 2.2. Retrieved from <http://udlguidelines.cast.org>

Symposium Slides and Preliminary Presentation Data Due (5 points)

April 2 (Week 14): Symposium Presentation Practice Day

Come prepared to give your complete Symposium (5 points), and to give in-class feedback to your peers.

April 9 (Week 15): Data Defense Project Presentation Day

Come prepared to present your data project and to give in-class feedback to your peers.

April 17 - FRIDAY (Week 16): Symposium Day!

It's the big day! Join us for breakfast and our first session at 8 (time subject to change)!

April 23 (Week 17): Wrap Up and Symposium Feedback