

NEURODIVERSITY, COMMUNICATION, AND HEALTH - Teaching/Learning Opportunity

Fall, 2019

This semester, the MSU Speech, Language, and Neurocognition Lab (PI: Dr. Laura Dilley) will be undertaking teaching-learning community activities focused on the *innovative, current topic of Neurodiversity* and how this topic intersects with topics in health communication and research/professional practice issues in communicative sciences and disorders. Topically-focused Working Groups (led primarily by undergraduate researchers, with input from the post-doc and PI) will be reading and discussing papers. Members of the ComArtSci community are **invited to attend open presentations/discussions on the dates below**. Further, interested members of the ComArtSci community (including MA students, Ph.D. students, undergraduates, staff, and/or faculty) who might be especially interested in contributing to any of the five topical Working Groups listed below are invited to contact PI Dilley (ldilley@msu.edu) ASAP with their interest in involvement. Further information about the structure of the teaching-learning activities can be found below:

DATES FOR PRESENTATIONS. Lab meetings will be on Fridays from 1-2 p.m. in Oyer 101 unless otherwise noted. Presentations to be approximately 1:10-1:30 (~20 minutes), with ~10 minutes additionally for discussion.)

Presentations will be relaxed and informal in nature, with an emphasis on questions and discussion.

September 27, 2019 – **Neurodiversity and Communicative/Cognitive Differences** (Working Group #1 Update)

October 4, 2019 – **Disability Studies, History, and Theory** (Working Group #2 Update) – RM. 107 Oyer

October 11, 2019 – **Social Status and Stigmas** (Working Group #3 Update)

October 18, 2019 – **Autism Spectrum Disorders and Autism Self-Advocacy** (Working Group #4 Update)

October 25, 2019 – **Personal Narratives and Empowerment** (Working Group #5 Update) (Lab-led meeting; LD at CSD Faculty Retreat)

November 1, 2019 – **Neurodiversity and Communicative/Cognitive Differences & Disability Studies, History, and Theory** (Working Groups #1 & #2 Update)

November 8, 2019 – **Social Status and Stigmas & Autism Spectrum Disorders and Autism Self-Advocacy** (Working Groups #3 & #4 Update) – RM. 107 Oyer

November 15, 2019 – **Personal Narratives and Empowerment** (Working Group #5 Update) & **Potpourri**

November 22, 2019 – **General Discussion; TBA** (post-doc led meeting; LD at ASHA)

November 29 – Thanksgiving Holiday

December 6, 2019 – **No presentations**; possible student-led meeting; LD and JW at ASA)

December 13, 2019 – Finals Week; No meeting/presentation

I. Goals: Understand and develop proficiency with conceptualizing and communicating current topics around Neurodiversity.

- a. Big picture goals. A major goal of this semester's lab activities is *to teach each other key concepts*, as well as *to develop enhanced proficiency with thinking and communicating about them*. The efforts will be directed toward developing teaching and learning materials which constitute background on topics for which our lab is embarking on research study and professional advocacy for best practices. Through full participation in these activities, you will be contributing to original research, since the topics that you communicate orally and in written format will form the basis of background literature reviews that will be disseminated in various writings and works to be produced by our lab in the coming months and years. Further, you will be accumulating professional knowledge relevant to hot topics in the field and broadening your educational perspective on communication sciences and disorders-related concepts and topics. Further detail on our goals can be found below:
- b. Key concepts. Through readings, presentations, written reflections, and discussion, we seek to answer questions such as: What are the most important concepts in this area? How do the important concepts in this area relate to those of other core groups? (You will develop written and oral summaries.)
- c. Holistic understanding. Through active presentation and discussion, a broad goal for all lab members and working groups - and participants in conversations - is to develop a holistic understanding of neurodiversity issues.
- d. Experts and resources. We seek to identify various stakeholders, experts, and resources that bear on these topics. Who are the experts on these topics - on campus, locally, and nationally/internationally? What additional resources or groups focus on these topics? What different perspectives or emphases do they offer?
- e. Historical development. Given the highly interdisciplinary nature of our current inquiry, we ask the following. Through what methods and historical events has knowledge, concepts, and applicable constructs accumulated and developed in areas which intersect on these topics?
- f. Readings. What are the key readings and resources in each area? How do the various assigned readings relate to the topic? What additional readings are relevant? Which are most important?
- g. Research methods. What are the research methods that have been used to study the topics or accumulate knowledge? How common are these methods in CSD? How do these ideas rank in terms of research knowledge/strength? What research methods does CSD have to offer?
- h. Terms. What professional terms/jargon have been used to describe different concepts? Are the terms different across related fields? What connotations do the terms carry for different groups? What are the conditions or situations when the terms are applicable? Are there cases when using certain terms could be misunderstood, and how can such misunderstandings be avoided? What are the advantages and disadvantages of terms currently in use?
- i. Further goals. Working Groups are encouraged to identify additional goals and resources for development. Working Groups are further assigned to consider how the specific topics in your group fit in with Dilley lab research activities - past, present, and future.

II. General Working Group activities and guidelines

- a. Approaching the scholarly evidence base. Don't be overwhelmed by the volume of papers you have been provided with! It's important to note that each scholarly paper which has been identified is *selectively relevant* to questions being posed to working groups. That is to say, *you do not need to read each paper word-for-word*. Instead, your approach should be to *understand the questions posed for each working group* and how the papers provide parts of answers to those questions.
 - i. Your approach should be to read the questions, then scan the papers for ways in which each is potentially relevant to the questions being asked.

- ii. You will need to compile arguments and evidence from a variety of papers, followed by organizing the information in a coherent, logical, thoughtful, articulate way.
 - iii. Think of it as being like a scavenger hunt where you're constructing a solid house out of the scavenged materials. Each paper contains some "treasures" - items for your scavenger hunt. You have to find all the "clues" and then piece together the puzzle – answering the group's questions (building your house) by drawing on the select pieces of evidence (the scavenged "treasures" in your hunt). Be sure to use so-called "in text citation format" where you name sources by the authors on the paper and the year, like this: Link and Phelan (2001); Mattan, Kubota, and Cloutier (2017).
 - iv. Groups are encouraged to ask for input about which papers are most relevant/pertinent, and whether there are additional resources beyond the short list at the end of this document.
- b. Group and individual activities: Lab presentations and working groups. Rather than assign individuals specific papers, I am instead going to be sharing both (a) a suggested reading list highlighting some key suggested papers, and (b) a Dropbox folder with those papers, as well as further resources. Your job is to work *both individually and together as a group* to understand how pieces of evidence, arguments, and definitions from the scholarly research literature can be brought together *to formulate coherent, well-supported answers to the questions posed to Working Groups*. Here are the steps you should undertake:
- i. Read through the Working Group key concepts and questions and email me with a rank-ordering of your interest in the Working Group topics by Monday, 9/16 at 5 p.m. You can copy-paste the form at the end of this document into an email to me and enter the numbers to indicate your working group ranking. Each individual will be assigned to at least two working groups and more at the discretion of PI Dilley. I will aim to circulate a list of lab members to Working Groups by Wednesday 9/18.
 - ii. Starting the week of Sept. 27, a portion of each lab meeting will focus on a specific set of questions assigned to a given Working Group. Lab members will have been provided with a set of readings will be assigned to lab members that bear on questions addressed to one or more working groups (usually more than one).
 - iii. A week or more in advance of a lab presentation date, read/skim through the papers, focusing on the big picture of questions posed to your working group(s). Next, work individually to develop some ideas about how papers you have been provided with – *and others that you are encouraged to try and find* – provide some answers to the questions your group was posed. Each lab member should make notes and entries in the Discussion forum for the respective working group. This will be a documentation of individual effort. A suggestion is that questions posed to working groups could be "threads" in the discussion.
 - iv. Come up with your own outline of general answers to questions asked for working groups. You're not expected to come up with answers to all questions – just focus on trying to answer some and figuring out what is within grasp to answer based on the material to be presented/discussed.
 - v. A few days prior to lab meeting, meet with your working group (in person or on-line). Allocate responsibilities for talking through answers to particular working group questions as part of lab presentations. See below.
 - vi. Approximately 1-2 weeks in advance of the working group presentation date, lab members should work with each other to determine who will discuss your group's progress on the "scavenger hunt" – your provisional answers to the working group questions assigned for that week.
 - vii. Your job is to figure out how the topics addressed bear on major questions and themes that were posed to various working groups. Work with other lab members to divide the labor of finding answers to one or more questions posed to the related working groups.
 - viii. Note: I will be soliciting an informal peer review/input of individuals' contributions to the presentation and question-answering efforts.
 - ix. All Working Group members are expected to contribute to preparing presentations. However, members are not necessarily expected/required to speak or present (though it is encouraged to do so at each opportunity). Instead, members willing to present should self-identify within the Working

Group; the number of presenters for a given week is left entirely up to the group. Leadership in presentation efforts will be noted over time and rewarded. It is expected that member contributions will be different over time and not necessarily the same for any one week.

- c. Topicalization. At the beginning of your group's presentation, set the stage – what is the “big picture” of the topic/questions for the lab? For the professional field?
- d. Framing around working group questions. For each working group area, I have attempted to identify specific questions that I would like your group to attempt to answer in lab group presentations. Other supplemental questions are also presented which your group need not answer in lab meetings but which should be addressed in written responses/assignments for the end of the semester.
 - i. In lab group meeting presentations, frame your group presentations around your collective attempts to answer the specific questions given for the working groups that intersect with the research papers and resources under discussion for that week. It is understood and expected that your knowledge is developing, and provision; just do your best to communicate concepts clearly and accurately based on your group's collective level of understanding. Over the semester, different papers will circle back to various of these questions and will help give us distinct perspectives on the issues.
 - ii. As you prepare your presentations, keep more detailed notes on the topics for development of your written responses to the working group questions. Individuals are encouraged to turn in drafts of answers to questions early for informal feedback toward a better end-product.
- e. Work-in-progress. What is presented in fall in lab will be works-in-progress! You're not expected to review or cover all papers suggested in the presentations, nor to have all the answers. You are expected to make a *good-faith effort* to figure out accurate, basic answers to the questions posed to working groups, and help each other figure out increasingly sophisticated, informed, and nuanced ways of looking at the issues. We will aim for ample discussion and feedback to supplement what you learn. You are encouraged to develop your own questions following your readings.
- f. Using notes for presentations. It is highly encouraged to *make and use notes* for your presentation to foster accuracy in your communication. Reading from them is OK for our purposes! Even though you are encouraged to use notes, strive to be engaging and clear in your presentation. You are asked to turn your notes/outline after the presentation – see below.
- g. Recording lab presentations. The goal is to have recorded discussions/presentations of cutting-edge topics that could be shared. Therefore, lab presentations on these topics will be video-recorded. Don't worry – these are just drafts/dry runs for lab internal use, likely on the way to more polished videos. (Lab members may be requested/assigned to assist with video editing, as skills and training permit.) Recordings will be made available to lab members. Good presentations may be shared as lab products as part of teaching and learning materials.
- h. Slides. Slides are encouraged, but not required. If you use slides, go with the “1 minute per slide” rule of thumb. Don't put too much text – just highlight the big points and ideas. Pictures are good.
 - i. Direct quotes can be useful when they illustrate particular points well. These are good for specificity and accurate transmission of information – our focus is on understanding different perspectives so exact word choices can be helpful. However, don't overdo the detail!
 - ii. After the presentation, *upload your slides* and other materials (such as notes) to D2L so all lab members can benefit from them and provide feedback.
- i. Collegiality, participation, and responsibility. Every lab member is expected to have scanned relevant references in advance of the lab meeting/presentation. At the meeting, should take notes and treat the material presented like you would concepts for a class, as if you will be quizzed on it. (You might be!) All the working group topics are related in some way. Information that one group presents, other groups should plan to incorporate in their own working group to the extent that it is deemed relevant. Note: Your working group should focus on its own questions first and foremost, but draw when possible from converging discussion/concepts in related groups. *It's not expected that groups will address overlapping topics in the*

same degree of depth. Your group's assigned questions, however, should be addressed in depth by the end of the semester.

- j. As best you can, identify the general fields/disciplines that corresponded to papers you examined and terms that these fields preferentially or habitually use.
 - i. Consider terms that need to be defined ahead of time, versus terms that need to be returned to “debrief” and consider the broader implications of the terms.
 - k. Make sure to give credit by mentioning sources that you used which informed your presentation. Also, highlight names and briefly mention contributions of researchers or resources which have been particularly influential in the field/area.
 - l. Time limits. For lab presentations, aim to stay approximately within specified time limits. Ideally, time yourself during practice session(s) ahead of the lab meeting. Don't try and tell us everything. Focus on aspects of resources that were most helpful to you and your group in understanding the “big picture” and answering questions posed to working groups. More detail can (and should) be given in your written summaries and products.
 - m. Other deadlines
 - i. Groups should be continually revising, improving, and updating their answers to questions and their structures for written summary answers to those questions. As your group makes progress with “low-lying fruit” in answering questions, please seek input and suggestions for additional resources and leads to help you make progress on the questions that are a more challenging reach/stretch. I will have plenty of thoughts for you.
- ii. By Nov. 8:**
- 1. Each working group should turn in an outline of research knowledge accumulated as it relates to the different questions asked of each group – which are intended to merely focus attention on key points. This should include a complete-as-possible-to-date list of related references.
 - 2. Have presented on your topic in the lab, received and incorporated feedback into your products and communications.
 - 3. Develop written concepts around 2-4 research project ideas (in consultation with Dr. Dilley)
 - 4. Each group turns in a draft list or paragraph summary discussion of scholarly outreach and engagement ideas. This should consider and mention possible scholarly outlets where systematic reviews or results could be published.
 - 5. Understand the “gist” of concepts and topics in assigned/key research and review articles for the respective working groups. Be able to associate author names for a research citation or source with the content and ideas. Be prepared to discuss (or be quizzed on) this content.
- iii. By the end of the semester (Dec. 13):**
- 1. Written products/summaries
 - a. Each working group will turn in a report to D2L – this should include references – as well as written text carefully answering the questions that are posed. Groups should seek input about preferred format for the responses to questions, particularly as they relate to evolving plans for drafting overview/summary topical systematic review articles as possible lab products. The paper/report should include a section that documents how each individual contributed to the group effort – who worked on what questions/sections, etc.
 - b. Written products/reports should comprehensively address all questions posed to your working group(s) in as clear, well-referenced and reasoned a manner as possible, using the best principles of composition.
 - c. Written products/reports should be as comprehensively referenced as possible and should make connections to related topics targeted as questions in other working

groups. More instructions about the format for written products will be shared in lab meeting.

- d. Updated slides and materials for short (~5-min) topical presentations (updated from drafts to incorporate feedback) will be due, along with notes documents, which address specific working group questions, as further directed.

2. Development ideas

- a. Plan for at least one (up to 3) research project ideas (finalized) in consultation with Dr. Dilley). These ideas should be written up describing the possible research design, the questions being addressed, and the proposed methodology.
- b. Proposals for outreach and engagement ideas. *This should include scholarly outlets where systematic reviews or results could be published.*

3. Further lab organizational tasks.

- a. By the end of the semester, all references downloaded to Dropbox(es)
- b. By the end of the semester, key references providing pointed answers addressing working group questions should be uploaded by group members to the respective Working Group folders on D2L. Note: some papers may fit well with topics in more than one working group – duplication across modules is OK.

- n. Descriptions of the specific working group topics and charges follow.

WORKING GROUP #1: Neurodiversity and Communicative/Cognitive Differences

- I. Key topics: Neurodiversity, terminology, communicative sciences and disorders, stuttering, hearing loss, autism, disability
- II. Specific questions to be addressed in lab presentations
 - a. Broadly, how do concepts of *sociality*, *social brains*, and *social hierarchy* relate to concepts of speech and language processing by neurotypical and neuro-atypical groups (as historically studied in PI Dille's research lab)? Briefly, what are some ways in which *sociality* and *social roles* are important for speech-language communication? (Post-doc led discussion point.)
 - b. What is *neurodiversity*? How was the term coined? How is the concept of "neurodiversity" related to, or not related to autism?
 - c. In what ways has "neurodiversity" been defined in (quasi-)biological terms? In what ways is it being defined in social terms, including social constructs and social identity?
 - d. What are some initial ideas of differences and disorders within the field of communicative sciences and disorders that fit in with neurodiversity, with suggestive supporting evidence? Suggested resource(s): Constantino (2018)
 - e. In what ways is neurodiversity an "identity" concept? How do different groups of people define it or talk about it?
 - f. How does neurodiversity relate to other forms of diversity? Suggested resource(s): Chun & Fisher
 - g. How do models and theories of "disability" relate to neurodiversity? Hint: Consider the debate between the "medical model" and "social model" in disability theory/studies.
 - h. What distinct viewpoints about neurodiversity are highlighted in the editorial by Bhandari and Khanal (2016)? What sources or evidence do they point to, in order to make their points? What central tenet do they advise be given up by neurodiversity advocates?
- III. Further questions to be addressed, especially in written summaries
 - a. Broadly, how do cognitive differences and mental health issues conceivably fit in with neurodiversity?
 - b. In what ways is neurodiversity similar to, or different from, other kinds of diversity?
 - c. Develop a comprehensive list of how concepts related to mental difference/cognitive/mind/body concepts as envisioned in "neurodiversity" intersect with so-called disorders or impairments in communication, grouped in a way that makes sense to you. Identify scholarly resources which support the applicability of concepts of neurodiversity to communicative disorders. Attempt to critically evaluate the extent to which authors have expressly characterized each of these communicative disorder categories in terms of neurodiversity constructs. Which communicative impairments or differences might be considered to fall under the rubric of "neurodiversity" and which do not? Why?
 - d. How prevalent is autism? How about other conditions that could fall under "neurodiversity"? See Lyall et al. (2017).
 - e. How are concepts of autism and/or neurodiversity similar to, or different from, concepts of sexual orientation? See, for example, Thomas and Boellstorff (2017).
 - f. To what extent is neurodiversity "accepted" or "controversial" as applied to different mental/cognitive differences? What are some areas of controversy?
 - g. To what extent do you agree with Bhandari and Khanal's (2016) assessment of the tenets of neurodiversity and the representativeness or authority of sources they point to? Discuss these. What are some ways or methodologies that one could assess the matter of representativeness of viewpoints they characterize, particularly with respect to the extent of involvement or opinions of non-speaking neurodiversity advocates?
 - h. In your opinion, what are some reasons that "neurodiversity," as a word and concept, are worthy of study in a communicative sciences and disorders department and speech-language therapy-related professions?
 - i. What are some potential benefits of neurodiversity concepts? Potential/perceived drawbacks?
 - j. What research and/or outreach and engagement activities have potential to promote positive aspects of neurodiversity?

- k. How can we give visibility to neurodiverse people? Why is “visibility” important? Why are personal stories important in this regard?
- l. What are some possible and actual methods for studying what people think about “neurodiversity” – what they believe the word means or implies, how its usage may have changed over time, etc.? What are some special challenges to studying a new and dynamic concept like “neurodiversity”? In particular, what special challenges and/or opportunities are presented in cases where concepts are defined primarily through internet resources (like blogs or Twitter) as opposed to traditional media like journal articles and books? What are best practices for researching such resources?
- m. How have “neurodiverse” individuals historically been treated in society? How do you think that perceptions of “neurodiverse” individuals has related to communication (dis)abilities?
- n. Why do you think that usages differ – with some people preferring to say “neurodiverse individuals” and others prefer “neurodivergent individuals”? What are some other language differences around how people talk about neurodiversity?
- o. To what extent has neurodiversity been applied to areas of difference or disorder for conditions other than autism? How could we quantify or systematically review the extent to which neurodiversity has been applied to conditions other than autism?
- p. What are the basic principles of social identity theory and self-categorization theory? How do these relate to the concept of “identity” as in neurodiversity?
- q. What are some arguments that have been put forward “for” or “against” neurodiversity? What “messaging frames” have communication researchers discovered or studied for how concepts of neurodiversity can be effectively communicated to different kinds of audiences?

IV. Goals

- a. Systematic review of some kind of the extent to which neurodiversity has been applied to CSD topics. Identify key areas for development.

V. Additional Notes, References, and Resources

- a. See Armstrong (2010) and Rothstein (2012) as one place to start to understand how neurodiversity has been applied to other conditions intersecting with communicative sciences and disorders, like dyslexia. These are not necessarily the best resources, and further literature review searches are recommended.
- b. Since Neurodiversity is a current topic, a fair bit of info exists in more dynamic, informal writings and productions – such as blogs and Youtube videos. Beware variability in quality and reliability of information!

WORKING GROUP #2: Disability Studies, History, and Theory Working Group

- I. Key topics: “social” model of disability; “medical” model of disability; development of diagnostic tools: the DSM (Diagnostic and Statistical Manual), ADOS, etc.; key historical legislation around disability: ADA and IDEA.
- II. Specific questions to be addressed in lab presentations
 - a. What are the historical concepts and debates in disability studies and theory? In particular, what is the “medical” model of disability? What is the “social” model of disability? Which has been favored by disability studies researchers and disability rights activists? Why? What does Shakespeare (2014) have in mind by the “disability” vs. impairment” distinction? Suggested resource(s): Shakespeare (2014), Chs. 1-2.
 - b. What are some limitations of the “social” model of disability? What seem to be the reasons for most neurodiversity advocates who focus on autism favoring it? Why do some neurodiversity “detractors” favor the medical model?
 - c. What proposals have been offered for combining elements of *both* a “medical” origin for disability (where brain/body/biology is affected) *and* a “social/environmental” origin for disability? What appear to be some key features of each?
 - d. How do these topics apply specifically to communicative challenges, disorders, and differences?
 - e. How has the so-called “medical model” of disability factored into concepts around neurodiversity and autism? In what specific ways is the “medical model” view used in language conceptions of autism in a manner that tends to support ABA? See Shyman (2016), Shakespeare (2014).
 - f. Recap the arguments of Goldiamond (1974), discussed in Shyman (2016), in relation to perceptions of disability and therapy. Indicate how these apply to ABA therapy in autism.
 - g. How does the ‘medical model’ relate to what Bennett et al. (2018, Ch. 5) call the ‘autism can be cured’ myth? What do they see as the path forward toward overcoming this myth and fostering a more “proactive and productive” approach for autistic children and adults to be their most successful selves?
- III. Further questions to be addressed, especially in written summaries
 - a. In brief, what are some key diagnostic tools relevant to neurodiversity and communication disorders concepts? What is the DSM, and how has it changed over time? How is it relevant to communication differences and neurodiversity concepts?
 - b. In general, what is the ADA? What is IDEA? How do these relate to disability rights and access concepts? Communication disorders concepts? Speech-language professional practice? How is the IDEA related to individualized education plans (IEPs)? What are good resources for learning about these historical pieces of legislation?
 - c. How do concepts of “reasonable accommodations” afforded under the ADA relate to neurodiversity and communication differences/impairments?
 - d. How is the concept of ‘classroom acoustical design’ related to accommodation of difference for autistic children? See Kanakri et al. (2017)
 - e. Note: A key goal for this working group – and for the lab as a whole – is to identify existing theoretical frameworks which combine elements of *both* a “medical” (in the sense of brain/body/biology) origin for disability/impairment *and* a social/environmental origin. Critique the strengths and weaknesses of each theoretical framework/approach which your group has identified in terms of how it applies to (a) different forms of neurodiversity, and (b) different communicative disorders. Suggested resource(s): Shakespeare (2014), esp. Ch. 4 but also Ch. 3; additional medical and social models reviewed by Carrill (2016), PhD dissertation.
 - f. Are there researchers who adhere to a strictly social model of disability in autism? What is the basis of their arguments? See discussion in Gaffney (2017) Ph.D. Dissertation. Provide a critical evaluation of the strength of these positions relative to arguments you have found in favor of a combined (“medical” + “social”) theoretic approach to the origins of disability.
 - g. Discuss why a “medical” model in which doctors, clinicians, or professionals “diagnose” clients/patients assigning them a disorder label can really be thought of as an extension of social/environmental disabling effects. Stated differently, what is the relationship among (a) receiving a “social” diagnostic label, and (b)

concepts like stigma, barriers/opportunities, and mental health? How should we clarify concepts associated with the “medical” model to eliminate such circularities and false dichotomies with respect to a “social” model? What scholarly resources can you find to draw on existing arguments or find evidence in support of your interpretation? Suggested resource(s): Hatzenbuehler, Phelan and Link (2013)

- h. How have people with disabilities historically been treated? How are they treated today? (Barriers, services, access?)
- i. Consider the range of professional occupations (doctors, speech-language therapists, mental health professionals) pertinent to performing the social function of assigning individuals a diagnostic label according to some diagnostic criteria. What does this imply about the range of disciplinary areas relevant to understanding neurodiversity and the origins of impairment/disability?
- j. How do these “combined” theories apply to mental (brain/mind) vs. physical (body) health concepts? Can some theories better accommodate “neurodiversity” concepts associated with persistent or transient mental differences?
- k. What are some additional concerns about biomedical explanations of “psychopathology” and their implications for attitudes and beliefs about mental disorder/difference? See Lebowitz and Appelbaum (2019). Define ‘psychological essentialism’ (Prentice & Miller, 2007). Relatedly, how are concepts of biological origins of difference (such as race) versus socio-cultural concepts of such differences, related to prejudice and discrimination? See discussion and references in Busso and Pollack (2015), p. 174.
- l. What are some of the elements of Cascio’s (2017) ‘biopolitical’ theory? What is the role of ‘normalizing language’ and how do these issues relate to ‘identity politics’?
- m. Bonus. What are your thoughts about some ways of “framing” concepts related to disability, that might appeal to different groups? What scholarly resources are pertinent to these issues?
- n. How has the DSM changed over time, and what are some criticisms of it? Suggested resource(s): article - DSM and death of phenomenology

WORKING GROUP #3: Social Status and Stigmas

- I. Specific questions to be addressed in lab presentations
 - a. What are some historically well-studied concepts in social psychology relative to status differences? What are some ways in which researchers have started to study and conceptualize status with greater nuance and topical breadth?
 - b. How is the concept of social “status” similar to, and different from, social “stigma”?
 - c. What are some arguments for why the concept or identity label of “neurodiversity” potentially reduces stigma? What is the evidence for stigma being reduced by neurodiversity-related concepts? Key papers: Kapp, Gillespie-Lynch et al. (2013); other papers co-authored by Gillespie-Lynch
 - d. What is ‘dehumanization’? How is it related to ‘stigma’? How has language terminological use been shown to be related to dehumanization? What is the concept of ‘denial of human uniqueness’? How have these concepts been studied or researched in relation to being Black, having autism, and/or having intellectual disability? See papers coauthored by Howell; Cage et al (2019); Goff et al. (2008). What are some take-home messages of Cage et al. (2019) for stigma reduction toward people with autism?
 - e. What were the findings of Gillespie-Lynch et al. (2015) in their study of on-line training of autism for university students, which included a discussion of neurodiversity? (See also summary and comments in Cage et al., in press.) Also discuss findings of Someki et al. (2018) and Obeid et al. (2015).
 - f. How does the concept of “stigma” apply to thinking about usage of different medical/health/diagnostic labels (i.e., different neurodiverse conditions)? Key papers: Reynaert & Gelman (2007)
- II. Further questions to be addressed, especially in written summaries
 - a. For each condition/disorder/disability which relates to CSD neurodiversity concepts (e.g., stuttering), do a literature search to find evidence/papers that address the issue of stigma for that condition/disorder/disability. For example, find any papers that document that stuttering is associated with stigma (or that people who stutter feel stigmatized), that dyslexia is associated with stigma, etc. Critically evaluate the extent to which evidence may support that some conditions are more stigmatized than others.
 - b. What were the take-home findings of Gillespie-Lynch et al (2019) about stigma and cross-cultural difference?
 - c. What are “social contact interventions”, and how might they reduce stigmas? How does this potentially relate to personal narratives as a tool for communication?
 - d. What are social identity theory and self-categorization theory?
 - e. What are the neurocognitive origins for implicit bias? How do they relate to social categorization and complex social hierarchies?
 - f. How are concepts of stigma related to autism? (See Leveto (2018) for brief discussion, and other working group topics for further consideration.)
 - g. In what ways do social stigma concepts apply to cases of communication difference and/or mental difference? Visible vs. invisible (or hidden) difference?
 - h. What is the Implicit Association Test? How has it been applied to study concepts of difference as it relates to race, gender, (dis)ability, etc.? What are some benefits of Implicit Association Tests relative to explicit report measures?
 - i. To what extent do you think that the kinds of web-based interventions employed to educate people about autism and neurodiversity could be employed with other neurodiverse conditions? What would such education look like?
- III. Additional Notes and References
 - a. See work by H. Gerlach for the notion of “concealable stigmatized identity” as applied to stuttering
 - b. Relevant work by McGill et al. (2018), AJSLP

WORKING GROUP #4: Autism Spectrum Disorders and Self-Advocacy

- I. Key topics: ASD diagnostic concepts and tools – strengths and weaknesses; autism self-advocacy; autism and stigma; augmentative and alternative communication (AAC); professional practice
- II. Specific questions to be addressed in lab presentations
 - a. *Neurodiversity.*
 - i. What is autism self-advocacy? How does it relate to concepts of neurodiversity? In what ways have such efforts converged with, or in some cases conflicted with, professional groups and autism-focused organizations?
 - ii. What were the issues investigated in the case study of usage of the #boycottautismspeaks hashtag on Twitter? What is Autism Speaks, and why did people want to boycott it?
 - b. *Autism diagnosis.*
 - i. What are some ways in which autism can be diagnosed? Who counts as ‘autistic’?
 - c. *Stigma, disability, and/or personal narrative*
 - i. In what ways is the concept of stigma relevant to autistic individuals and their families? (See Leveto (2018) for brief discussion, and other working group topics for further consideration.)
 - ii. Verhoeff (2015) argues that basic autism research should focus on experiences of impairment and distress. Why does Verhoeff make this argument, and what is the basis of his argument? Also, how are concepts of impairment and distress related to topics addressed more focally in other working groups, such as disability and stigma?
 - iii. What are some other ways in which autistic traits have been studied? Suggestion: Pfuhl & Ekblad (2017)
 - iv. What are the arguments presented by Gobbo and Shmulsky (2016) about why neurodiversity concepts should be emphasized in post-secondary settings for students developing an identity around the autism spectrum?
 - v. What evidence is provided by Gillespie-Lynch and colleagues (2017) about relationships among concepts of autism “acceptance”, neurodiversity, stigma, and greater endorsement of the importance of normalizing autistic people? How do the findings of Cage et al. (2018) further contribute to understanding of the role of others’ attitudes for the mental health of autistic people?
 - vi. What is ‘culture’? How is it similar to, or different from concepts of ‘identity’? In what sense do people sharing a diagnosis – like autism spectrum disorder – share a common ‘identity’ or ‘culture’? Suggested article: Botha & Frost (in press/2019)
 - vii. How do the two types of home environments described in Sarrett (2015) – what they call ‘a custodial home’ vs. a ‘therapeutic home’ – reflect different levels of autism acceptance? How are these different approaches to home environments related to culture? What is the connection to concepts of neurodiversity, according to Sarrett?
 - d. *Language*
 - i. What are issues around the choice of person-first vs. identity-first referential terms for individuals on the autism spectrum?
 - ii. What is Facilitated Communication (FC) and the Rapid Prompting Method (RPM)? What are the histories of these methods, and why and how were they discredited? How are they different from other *augmentative and alternative communication (AAC)* methods for use in autism?
 - e. *Professional practice and treatment*
 - i. What is Applied Behavior Analysis (ABA)? What are some criticisms that have been made by autistic people/neurodiversity advocates about ABA? What are the general arguments posed by Shyman (2016)?
 - ii. What kind of intervention was proposed by Politis et al (2019)? (Notice where the researchers are from! Connections should be noted by your group for further possible follow-up.)
- III. Further questions to be addressed, especially in written summaries

- a. What is the history of Applied Behavior Analysis (ABA)? How common is it as a method of intervention for autism? What are some criticisms that have been made by autistic people/neurodiversity advocates about ABA? In your opinion, what are the strengths and/or weaknesses of these arguments? What are the implications for culturally sensitive and evidence-based professional practice? See also Dillenburger (2015), Shyman (2016)
- b. What are the broader implications for speech-language pathology/therapy of autism self-advocacy efforts and/or representative efforts like usage of the #boycottautismspeaks hashtag on Twitter? What are best practices for students and professionals in the field, in light of these controversies?
- c. Are there subgroups of autistic individuals that might have a more cohesive identity and culture who share a diagnostic label? How do you interpret the notion of “multicultural competence” within speech-language therapy/pathology in relation to concepts like ‘autistic culture and identity’? (Consider ASHA position statements, materials, and tools such as <https://www.asha.org/practice/multicultural/self.htm>.) How do these cultural concepts inform thinking about intervention approaches and techniques which have been controversial in some quarters, like ABA?
- d. What are themes of the lived experiences of people with autism and their families?
- e. What are some of the problematic aspects of language related to autism diagnosis described by Timimi et al. (2019)? Why did the authors feel this language was problematic? Also consider Milton et al. (2019), Chown et al (in press).
- f. For variables investigated by Gillespie-Lynch and colleagues (2017), what can we conclude about correlations among variables they investigated? About causal relationships among those variables?
- g. What are the strengths and weaknesses of different diagnostic tools?
- h. How do individuals on the autism spectrum differ from one another?
- i. What are the affected areas of function? How common or uncommon are clusters of deficits, and how do we know (or how can we know)?
- j. What are the implications of terms like “non-verbal”, “non-speaking”, “low-functioning”? What are the strengths and weaknesses of these?
- k. What do we know, and not know, about preferred terms for autism among different groups of individuals? (Example: US vs. UK)
- l. How have people with autism historically been treated? How do you think this has been related to individuals’ communication abilities, and what evidence and arguments can you provide?
- m. What is the difference between functional communication and augmentative and alternative communication?

IV. Other resources

- a. ASHA website and professional statements
- b. Autism self-advocacy network
- c. Blogs

WORKING GROUP #5: Personal Narratives and Empowerment

- I. Key topics: personal narratives, life challenges, empowerment, phenomenology, mental health
- II. Specific questions to be addressed in lab presentations
 - a. What kinds of research findings and approaches/methodologies exist to support the ideas that:
 - i. Personal narratives are compelling ways of communicating concepts and information?
 - ii. Personal narratives can be empowering?
 - iii. Personal narratives can be transformative?
 - b. What is phenomenology, and how is it similar to or different from personal narrative? How has phenomenology been neglected in modern diagnostic practice? What are some responses to criticisms of phenomenology? Suggested resource(s): Varela (1996)
 - c. What is “empowerment”? What is the role of language in “empowerment”? What are some examples of how language has been used to empower (or disempower) people? How does empowerment relate to concepts like stigma, lower social status, implicit bias, and barriers to access?
 - d. What are some notable examples of how personal narratives/stories of neurodiverse individuals and/or those with communicative impairments have been leveraged to foster inclusion and opportunity for those individuals? Highlight and consider especially non-speaking autistic individuals, including notable examples like DeeJ and Carly Fleischmann. See also blogs by non-speaking advocate who goes by Mel Baggs. Ideally, create an appendix of links and or short descriptions of the stories of noteworthy individuals. Why are these individuals’ stories remarkable and/or noteworthy?
 - e. What is “camouflaging”? (Cage et al., 2018)
 - f. How can personal narratives be applied (or how have they been) to shed light on understanding or sympathy for particular neurodiverse conditions? How are they related (or not) to understanding points of view of particular methods, like ABA? (See Kirkham 2017.)
 - g. What are some examples of research methods used to study personal narratives? In particular, what is “mixed methods” research and how does it permit bringing out elements of both qualitative and quantitative research? What are some benefits of quantitative research? Qualitative research?
 - h. What are some evidence-based “language tips and tricks” which are beneficial for mental health and well-being? (Hint: see papers co-authored by Moser.)
 - i. What did the article by Hollin and Pearce (2019) reveal about challenges perceived by scientists for studying autism? What was the specific nature of challenges for public engagement posed by autistic impairments? What did the article reveal about potential power in autistic individuals’ personal narratives for possible positive influences on research? Also consider Pellicano et al. (2014a, b). How do the findings of Pellicano et al. (2014b, PLoS One) support the usefulness of alternative, non-traditional options for scientific communication by researchers to engage with community members? (Traditional options would be journal articles and conference presentations.) See also Pellicano and Stears (2011).
 - j. How do the above topics relate to the notion of participatory service offering for neurodiverse students as discussed in Gillespie-Lynch et al (2017, Frontiers in Psych)?
 - k. What first-person perspectives on neurodiversity are offered in the article by Lambert et al. (2019)?
 - l. What are the five tenets of participatory research outlined in Fletcher-Watson et al (2019)?
 - m. What are some themes that emerge from narratives about autism from self-identified autistic people on YouTube? (Angulo-Jimenez & DeThorne, 2018, AJSLP)
 - n. What is the #saytheword movement? (Andrews et al. 2019) Moreover, what are the notions behind the #stopcombatingme hashtag? (Benham, 2015)
 - o. How is the concept of ‘empathy’ as articulated by Kapp (2013) related to both perspectives of individuals with autism and physical accommodations for them? How do these notions in turn relate to equal access and removing barriers to opportunity?
- III. Further questions to be addressed, especially in written summaries
 - a. How did the study by Heasman and Gillespie (2019) shed light on the notion of ‘neurodivergent intersubjectivity’?

- b. How do you think that descriptions of autistic people about gender shed light on the social construction of gender roles and the social learning skills necessary to learn those roles? Might some neuroatypical individuals have more difficulty abstracting away those gender roles? See Davidson & Tamas (2016).
- c. What are additional resources for these topics?
- d. How does the issue of genetic testing for autism bear on the perspectives of autistic individuals? See DeThorne and Seman (2018).
- e. What is involved in the process of disclosure of a concealable stigmatized identity? How are concepts of neurodiversity related to the idea of revealing a concealable stigmatized identity?
- f. How is the process of “coming out” with a concealable stigmatized identity associated with an invisible or concealable disorder, condition, impairment, or disability, similar to, or different from, revealing one’s sexual orientation or gender identity? See for example Thomas and Boellstorff (2017).
- g. What are the pros and cons of revealing a concealable stigmatized identity?
- h. What are the basic principles of social identity theory and self-categorization theory? How do these relate to the concept of “identity” as in neurodiversity?
- i. What is intersectionality?
- j. In what ways can personal narratives about revealing a hidden stigmatized identity contribute to empowerment or disempowerment?

Suggested Reading List –Speech, Language & Neurocognition Lab (PI Dilley) - Fall 2019

Items marked with (**) are strongly suggested for presentation in lab meeting as they pertain to questions posed to working groups. All other papers are of variable relevance for discussion in lab presentations as time permits and as useful to answering questions. Attempts should be made to incorporate all these references, and more, into written summaries and reference lists for end-of-semester assignments. What is provided below is only a starting point and should be considered a small portion of relevant materials. In order to provide optimal, accurate, thorough answers to working group questions, *you're encouraged to incorporate other materials beyond those listed below to assist formulating your answers; additional materials may come from among papers shared on the Dropbox (and just not listed here due to time constraints) and/or that you identify through article searches*. Further, PI Dilley reserves the right to assign Working Groups at any time one or more papers which are deemed especially pertinent for their additional inclusive research/professional consideration.

Social and Linguistic Communication; Social Status and Hierarchy; Neuroscience

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Rabiner, L. R., & Schafer, R. W. (2007). Introduction to digital speech processing. Foundations and Trends® in Signal Processing, 1(1–2), 1-194.

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Neurodiversity, Communicative Disorders & Autism Spectrum Disorders

**Silverman, C. (2015). Review of *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity* by Steve Silberman. *Anthropological Quarterly*, 88(4), 1111-1121.

**Constantino, C. D. (2018, September). What Can Stutterers Learn from the Neurodiversity Movement?. In *Seminars in Speech and Language* (Vol. 39, No. 04, pp. 382-396). Thieme Medical Publishers.

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Chun, M., & Fisher, M. E. (2014). Crossroads: The intersection of affirming cultural and neurological diversity. *NYS TESOL Journal*, 1(2).

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****Rothstein, A. (2012). Mental Disorder or Neurodiversity?.The New Atlantis.**

****Armstrong, T. (2010). Neurodiversity: Discovering the extraordinary gifts of autism, ADHD, dyslexia, and other brain differences.**

Social status and stigma concepts

****Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27(1), 363-385.**

****Lucas, J. W., & Phelan, J. C. (2012). Stigma and status: The interrelation of two theoretical perspectives. *Social Psychology Quarterly*, 75(4), 310-333.**

****Mattan, B. D., Kubota, J. T., & Cloutier, J. (2017). How social status shapes person perception and evaluation: A social neuroscience perspective. *Perspectives on Psychological Science*, 12(3), 468-507.**

****Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, 49(1), 59.**

Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health*, 103(5), 813-821.

****Gerlach, H., Chaudoir, C., & Zebrowski, P. (In preparation). The Role of Stigma-Identity Constructs in Psychological Health Outcomes among Adults who Stutter.**

****McGill, M., Siegel, J., Nguyen, D., & Rodriguez, S. (2018). Self-report of self-disclosure statements for stuttering. *Journal of fluency disorders*, 58, 22-34.**

Phelan, J. C., Link, B. G., & Dovidio, J. F. (2008). Stigma and prejudice: One animal or two?. *Social science & medicine*, 67(3), 358-367.

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****Shakespeare, T. (2014). Disability rights and wrongs revisited. Routledge.**

Lebowitz, M. S., & Appelbaum, P. S. (2019). Biomedical Explanations of Psychopathology and Their Implications for Attitudes and Beliefs About Mental Disorders. *Annual Review of Clinical Psychology*, 15, 555-577.

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Busso, D. S., & Pollack, C. (2015). No brain left behind: Consequences of neuroscience discourse for education. *Learning, Media and Technology*, 40(2), 168-186.

Autism and language; autism diagnosis; autism and stigma

**Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462.

**Spillers, J. L., Sensui, L. M., & Linton, K. F. (2014). Concerns about Identity and Services among People with Autism and Asperger's Regarding DSM-5 Changes. *Journal of Social Work in Disability & Rehabilitation*, 13(3), 247-260.

Milton, D., Kapp, S., Bovell, V., Timimi, S., & Russell, G. (2019). Deconstructing diagnosis: multi-disciplinary perspectives on a diagnostic tool. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(6).

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**Kapp, S. K. (2018). Social support, well-being, and quality of life among individuals on the autism spectrum. *Pediatrics*, 141(Supplement 4), S362-S368.

**Brownlow, C., & Thompson, D. M. (2017). The construction of difference. *Education and New Technologies: Perils and Promises for Learners*.

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Personal Narratives; Language, Health, and Identity Concepts

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