

Personal Narratives in Leadership Education in Neurodevelopmental and related Disabilities (LEND) Audiology Supplement Seminar at the University of Connecticut

Torri Ann Woodruff, M.S. and Kathleen M. Cienkowski, Ph.D.

INTRODUCTION

What is the LEND?

The CT LEND is one of 52 programs nationwide to improve the healthcare systems for individuals with neurodevelopmental disorders such as autism and their caregivers¹. The CT LEND also received a supplemental grant in audiology to enhance efforts to train pediatric audiologists in the State of CT². Both of these projects were made possible through funding received by the [Maternal and Child Health Bureau \(MCHB\)](#) of the [Health Resources and Services Administration's \(HRSA\)](#)³.

Purpose

1. Describe the UCONN LEND audiology supplement seminar.
2. Critically examine this seminar's use of narrative healthcare
3. Evaluate the feasibility of implementing elements of narrative healthcare in your classroom, or clinical practice.

Acknowledgements

The LEND Audiology Seminar was conducted before and during the COVID-19 pandemic. We would like to thank all the guest facilitators, LEND Fellows, and students who have taken part in this seminar. Their hard work has benefited us all.

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LEND AUDIOLOGY SEMINAR

Audiology Supplement at the University of Connecticut

The CT LEND training program requires the completion of coursework, research studies, advocacy projects and community practicum assignments with infants, children and youth and adults with developmental disabilities, including autism, and their families¹. The pediatric audiology supplement also gives rise to a seminar that is designed around personal stories as a way to introduce students to topics related to individual differences such as hearing, autism, vision, etc.

Since 2016, ten students have completed their LEND fellowships under this supplement at the University of Connecticut and now serve children and families across the country in various hospital, clinical, and educational settings².

Use of Narrative Care

In this seminar we follow Zaharias (2014) and the notion that the foundation for listening to stories and engaging in narrative care is so that providers can understand the meaning that is derived from the stories that patients tell us.

In narrative care, the focus is on creating space and learning from patients as they describe their symptoms and experiences³. The focus is listening to understand, not listening to solve a problem³. Providers may view a diagnosis as something to treat, where a patient sees this diagnosis in the context of their lives³.

This goal is achieved through applying the seven "C"s to interactions³.

These narratives are infused into the seminar via guest facilitators and popular media

Through these interactions students have the opportunity to practice the seven Cs with a focus on the underlying story, not providing care.

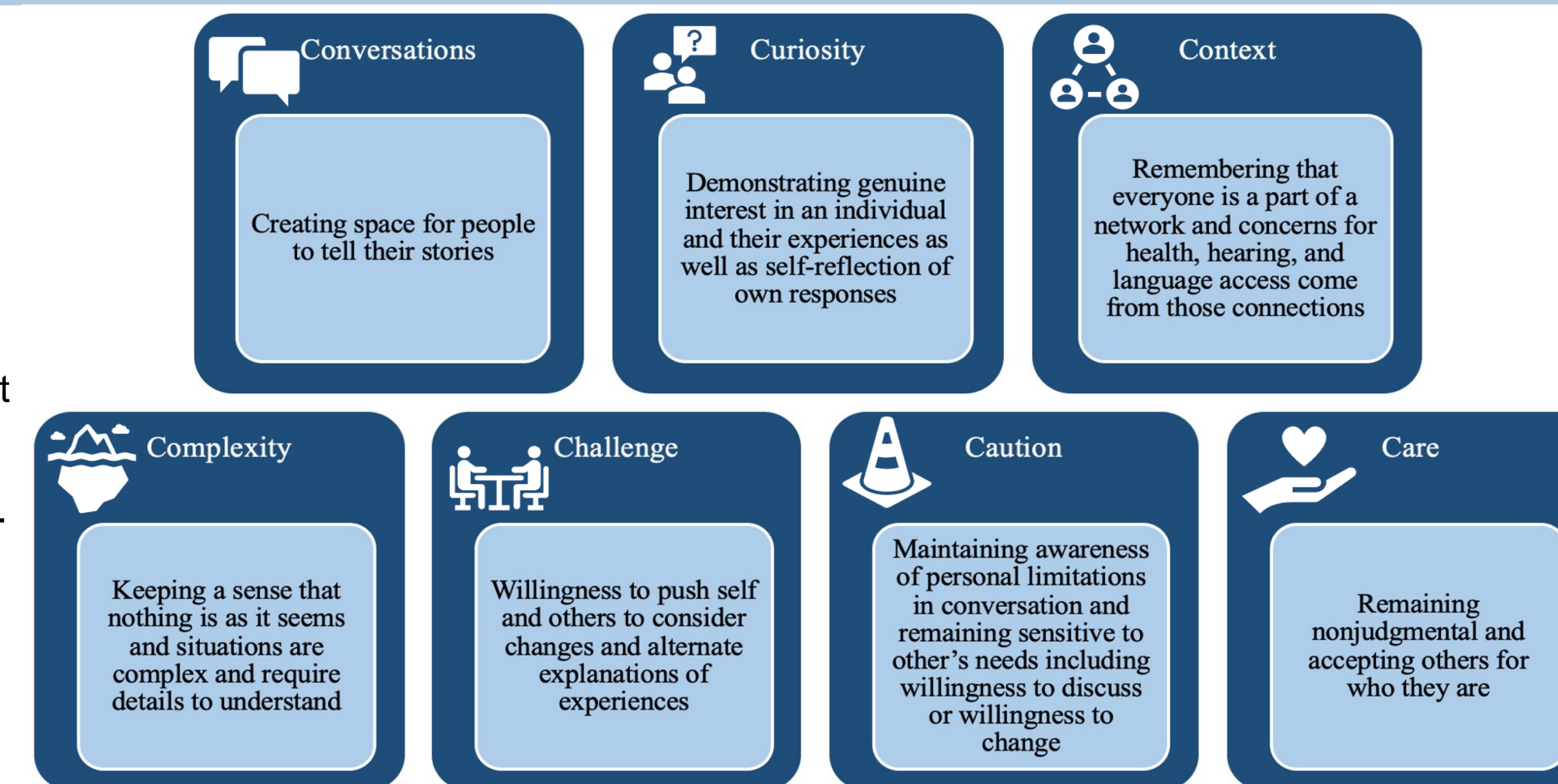


Figure 1. The seven "C"s of narrative care from the provider perspective³

Seminar Structure

The seminar is student-driven with a focus on fostering critical thinking and individual agency. It is led by a former LEND Trainee. At the beginning of the semester students provide feedback and select the topics they would like to examine through the lens of the LEND. Topics that remain constant each year include Autism and CMV/ZIKA. Over the course of the seminar 6-7 diagnostic labels are discussed. Most topics are discussed for two weeks.

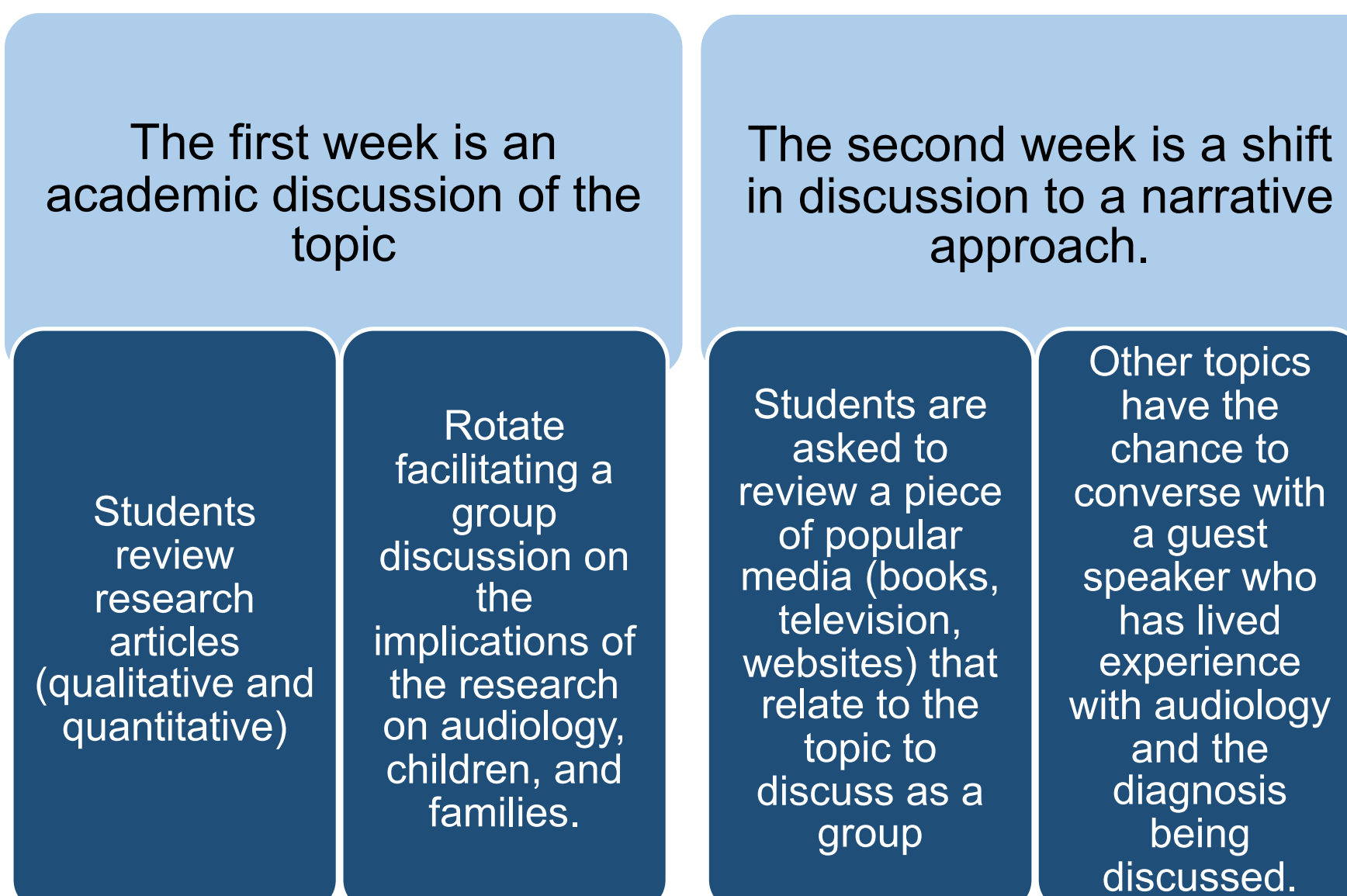


Figure 2. Organization of topic information in the seminar

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- 5 Amazon. (n.d.). *Because We Are Bad: OCD and a Girl Lost in Thought*. Amazon. <https://www.amazon.com/Because-We-Are-Bad-Book/dp/B075331196>
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- 7 IMDb. (2022). *Atypical*. IMDb. <https://www.imdb.com/title/tt5111964/>
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Guest Facilitators

Guest facilitators are a staple in the seminar. When invited into the seminar, there are no prescriptive questions. Individuals are prompted to share "what they want to make sure the next generation of care providers know about..."

It is critical to recognize the power differential that exists (implied or acted upon) in a quasi-medical setting.

- Not scripting what a guest can or should share allows the individual to drive the conversation based on the context of the moment and allows for more nuanced reflections on the complications of their diagnosis.
- This is also a critical time for the head facilitator to model caution, care, and curiosity for students.

Guests to our seminar have included individuals with various diagnoses, parents of children with identified disabilities, advocates, healthcare professionals with disabilities, and service dog teams.

Popular Media Representations

Popular media representations of various diagnoses (books, movies, television, websites, blogs, etc.) are another avenue to narrative involvement within the seminar. Students facilitate discussions on these pieces of media as a means of understanding the larger cultural narrative around a given diagnosis and gaining additional insight into unique experiences.

Materials selected from the popular media are typically

- Works recognized in mainstream media (from major networks)
- Those that have received awards (New York Times best sellers, Academy Award nominations)
- Recommendations from individuals with that diagnosis

Works by or with individuals with a given diagnosis are favored in the selection process as a means of highlighting the work of those in the media industry who are working towards inclusion and accurate depictions. This also provides an opportunity to discuss representation.

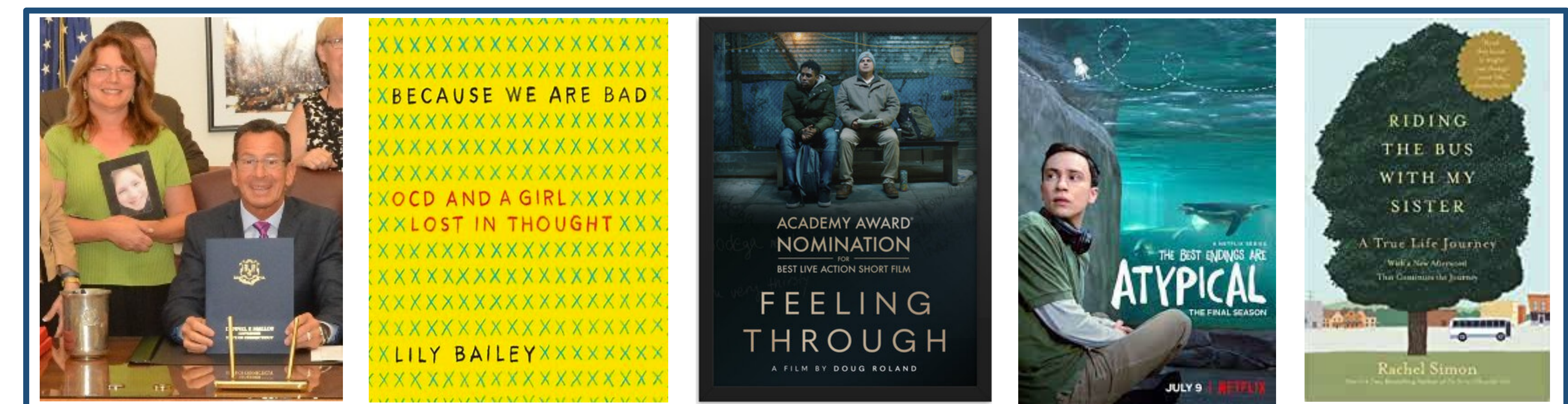


Figure 3. Examples of guests and materials used for narrative discussion^{4, 5, 6, 7, 8}

What our participants have to say

During the seminar

The importance of having conversations with our patients and other health care professionals to ensure the highest quality care for our patients.

Each person is unique, has their own stories, and has their own needs. Don't make assumptions, just ask.

The discussions were excellent and allowed for us to really understand that topics better. I really liked that each week someone lead a discussion and we were able to spend the time sharing stories and discussing research and books that we had read.

After graduation

The seminar ... was excellent. It was the best discussion based class I've ever participated in. We read really interesting, insightful, and thought provoking novels that we would not normally have the opportunity to delve into in our typical AuD curriculum. We always had good-flowing conversations that were full of unique perspectives from each of the students in the class. [Instructor] always had the students lead the conversation and would chime in as necessary. I really enjoyed the course!

[Instructor] creates an open and safe environment to discuss the impact having a disability, visible or invisible can have on individuals as a society as a whole. She pushes you to explore disability from multiple perspectives and different forms.

Instructor

This seminar is my favorite course to lead. Watching each student's conceptualization of what the LEND is and how various identities interact grow is very fulfilling. As a seminar course, the focus stays on the students and that leads to a lot of wonderful conversation that might not be possible in a more didactic setting.

Figure 4. Participant reflection on the seminar