

# Intro to Special Commission on State Institutions

Emily Lauer, PhD, MPH  
Associate Professor, Director of CDDER



---

Center for Developmental  
Disabilities Evaluation and  
Research (CDDER)

# Eunice Kennedy Shriver Center

- Part of the University of Massachusetts Chan Medical School
- Dedicated to understanding and improving the challenges faced by individuals with intellectual and developmental disabilities (IDD) and/or behavioral health disorders as well as supporting their families.
- Our comprehensive experience and expertise have established the Shriver Center as an international leader, devoted to supporting the full participation of people with disabilities in community life.



# Our Mission

- To transform systems, policy, and practice by engaging in innovative research, education, training, and service so that people with intellectual/developmental disabilities and/or behavioral health conditions may lead self-determining lives.

# Examples of relevant prior work

- Fostering Social Inclusion and Community Engagement among people with IDD
- MA Healthy People 2020 Autism Roadmap Report: Understanding Needs & Measuring Outcomes
- Experiences of Aging Caregivers in Supporting Family Members
- Evaluation of new service models with Person-Centered Evaluation
- Creation of advocacy tools for self-advocates and family members on preventive health screenings
- Teaching medical students about the lived experiences of people with disabilities – including people with disabilities
- Studying when and how people with IDD died

# Areas we can support

- Support in running commission
  - Meetings
  - Updates/Reporting
- Lists of places where they were buried, information about cemeteries
- Papers
  - Where are the papers? Who has them?
    - We can do as much as we can during the time we have
  - Process of requesting papers, what happens when you try, how do other places give access to papers

# Areas that may be challenging

- Legally-related processes to find papers and who has what; what papers are gone
  - It may take a long time to get this information (after report is due)
- You asked to find:
  - *Tell us how people were buried when they died. What were the rules? Were their families told? Did they get a gravestone with their name? Was there a funeral?*
  - *Find out if anybody was buried in a place they were not supposed to be buried.*
- This may be up to where the info is, who has it, how we can get it, and whether we need the help of lawyers to do so.