



**UW LEND Trainee – Leadership Project Proposal  
2023-2024**

**Program:**

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**Project Title:** Best practices for engaging self-advocates and family members in consumer advisory councils.

**Describe the Need:**

UCEDDs (and other organizations like Developmental Disability Councils) are required to have consumer advisory councils that include a majority of people with IDD or family members. There are some old guidelines for how to do this in a meaningful way (e.g., [Beyond Tokenism: \(aucd.org\)](#), [2019 SCDD Facilitation Guide \(ca.gov\)](#)), but no newer products exist.

**Brief Description of Proposed Project:**

Work with Mark Harniss to develop a plan to identify and summarize research literature and gray literature (materials/research outside of traditional academic publishing) about the involvement of self-advocates and family members in the leadership of consumer advisory councils. Based on this activity, identify organizations who have strong consumer advisory councils and reach out to interview leaders of those councils. Summarize findings from interviews. Based on findings, develop a guide for UCEDD CACs recommending best practices for supporting consumer-driven CACs.

**Project Goal and/or Desired Outcome:**

The goal would be to develop a draft guide that identifies practices that support consumer advisory councils to be consumer-driven, respectful, effective, and meaningful. The guide would highlight practices and strategies to be implemented.

**Proposed Roles/Responsibilities of the UW LEND Trainee(s):** *Include number of trainees desired*

- Literature search and summarization of findings
- Lead interviews, record and summarize information shared
- Write a guide supporting best practices for implementing a consumer advisory council with strong engagement and leadership from self-advocates and family members.

**List Any Desired Trainee Prior Experiences or Skills:**

Any of the following would be helpful:

- Experience as a member of a consumer advisory council
- Experience working with self-advocates
- Experience as a family member of someone with IDD (e.g., sibling, parent, relative)
- Experience searching for literature and summarizing it
- Experience interviewing people to learn about their work