



August 2017

Introduction

End-of-life care is a complex moral issue that refers to the health care of individuals not only at the final moments of their lives, but also the general care of those approaching the final years of life. End-of-life decision-making resources specifically for adults with significant intellectual disabilities provide them and their guardians with information about the impacts of developmental disabilities, home and community based services, hospice and palliative care, and end-of-life planning.

Purpose

The purpose of this questionnaire is to survey the capacity within the UCEDD/LEND programs to support people around end-of-life decision making. Information from responses will be summarized in this paper to provide a synthesis of results and recommendations to the Association of University Centers on Disabilities (AUCD).

Methods

The survey was created on *Qualtrics* that asked for responders' contact information and whether or not their program address end-of-life decision making (Y/N). If responder answered "Yes", they were directed to more questions about the resources provided.

Responses were collected over a duration of 4 weeks, with reminders to non-responders sent twice within that time.

Results

There were a total of 53 responses. Out of the 53 responses, 15 responded "Yes" to the question "Q6 - Does your program address end-of-life decision making in any way (e.g., providing individual patient/family support, providing resources on your website, training community providers, etc.)?" The 15 responses characterize 13 UCEDDs/LENDs (two had replied twice and one didn't finish responding) out of 78 total UCEDDs/LENDs.



Additionally, 7 UCEDDs/LENDs did respond to the survey but indicated that there was no one available at their organization who could answer the questions posed.

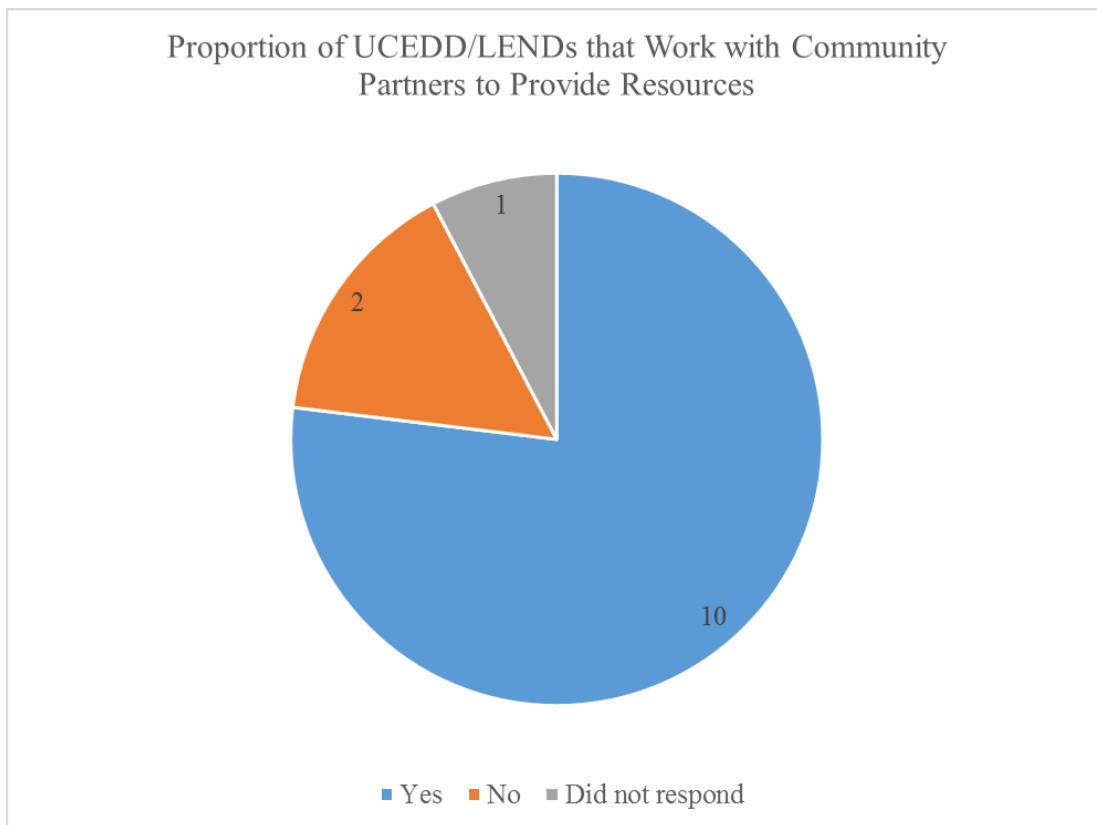


Figure 1

Types of Resources

- 3 programs stated that they provided some sort of online resource
 - AZ-Sonoran UCEDD
 - DC- Georgetown University Center for Child & Human Development, UCEDD
 - MO- University of Missouri, UCEDD/LEND



- 5 programs stated that they provided discussions/trainings among medical or health providers (hospital/board/committee meetings)
 - AZ- The University of Arizona, LEND
 - FL- Mailman Center for Child Development, UCEDD/LEND
 - IL- Institute on Disability & Human Development, UCEDD/LEND

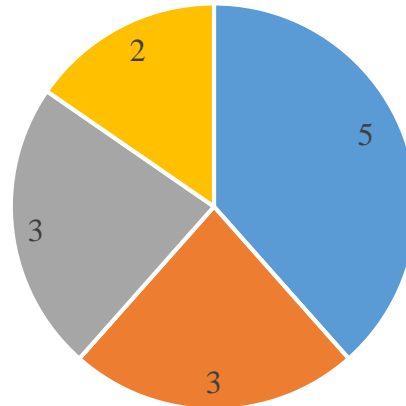
 - NJ- The Boggs Center on Developmental Disabilities, UCEDD/LEND
 - NY- Rose F. Kennedy Center, UCEDD/LEND
- 7 programs responded that they provided consultations with patients and/or guardians
 - AZ- The University of Arizona, LEND
 - DC- Georgetown University Center for Child & Human Development, UCEDD
 - MO- University of Missouri, UCEDD/LEND
 - NJ- The Boggs Center on Developmental Disabilities, UCEDD/LEND
 - NY- Rose F. Kennedy Center, UCEDD/LEND
 - SC- Center for Disability Resources, UCEDD/LEND
 - TN- Boling Center for Developmental Disabilities, UCEDD/LEND
- Did not respond
 - CO- JFK Partners/ University of Colorado Health Sciences Center, UCEDD/LEND

Challenges

- Limited resources (time, funding, staff)
 - DC- Georgetown University Center for Child & Human Development, UCEDD
 - NJ- The Boggs Center on Developmental Disabilities, UCEDD/LEND
 - NY- Rose F. Kennedy Center, UCEDD/LEND
 - TN- Boling Center for Developmental Disabilities, UCEDD/LEND
 - VI- Virgin Islands UCE, UCEDD
- Difficult to talk to families/family reluctance
 - AZ- Sonoran UCEDD
 - AZ- The University of Arizona, LEND
 - TN- Vanderbilt University, UCEDD/LEND
- Narrow reach of services (contacts and geographically)
 - FL- Mailman Center for Child Development, UCEDD/LEND
 - MO- University of Missouri, UCEDD/LEND
 - SC- Center for Disability Resources, UCEDD/LEND
- Did not respond/Not Applicable
 - IL- Institute on Disability & Human Development, UCEDD/LEND
 - CO- JFK Partners/ University of Colorado Health Sciences Center, UCEDD/LEND



Challenges as Reported by UCEDD/LENDs*



- Limited Resources
- Difficult to talk to families/family reluctance
- Narrow reach of services (contacts and geographically)
- Did not respond/Not Applicable

Figure 2

Working with Community Partners?

- 10/12 Yes, 2/12 No

Recommendations

- Send out a list of online resources (from the Georgetown UCEDD) to other UCEDD/LENDs that responded “Yes”
 - Contact information on spreadsheet (Tab 1)
- Send out a list of the online resources from Georgetown to UCEDD/LENDs that had responded “No” (in a differently worded email)
 - Contact information on spreadsheet (Tab 2)