

**UC Davis**  
**Pediatrics**

**Title**

Transition to adulthood for youth with neurodevelopment disorders- family/caregiver survey and needs assessment

**Permalink**

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**Data Availability**

The data associated with this publication are not available for this reason: NA



## Introduction

- Transition to adulthood is a challenging process that is especially difficult for youth with neurodevelopmental disorders (NDD) and their caregivers.
- Due to transition age youth with NDD having complex medical and behavioral health needs, youth and their caregivers have to navigate several systems of care to support them.
- Despite these challenges, there has been limited research into the needs of this population during transition to adulthood from a quality improvement perspective.

## Methods

- Caregivers of individuals ages 15-26 with NDD ranked medical care and community service concerns in order of importance using a single anonymous online survey.
- Survey was offered in English and Spanish.
- 4472 surveys were distributed to participants recruited from Alta California Regional Center, UC Davis MIND Institute registry, and the UC Davis MIND Institute family navigator program.
- Demographic information from survey respondents was also collected.
- No incentive was offered for survey completion.

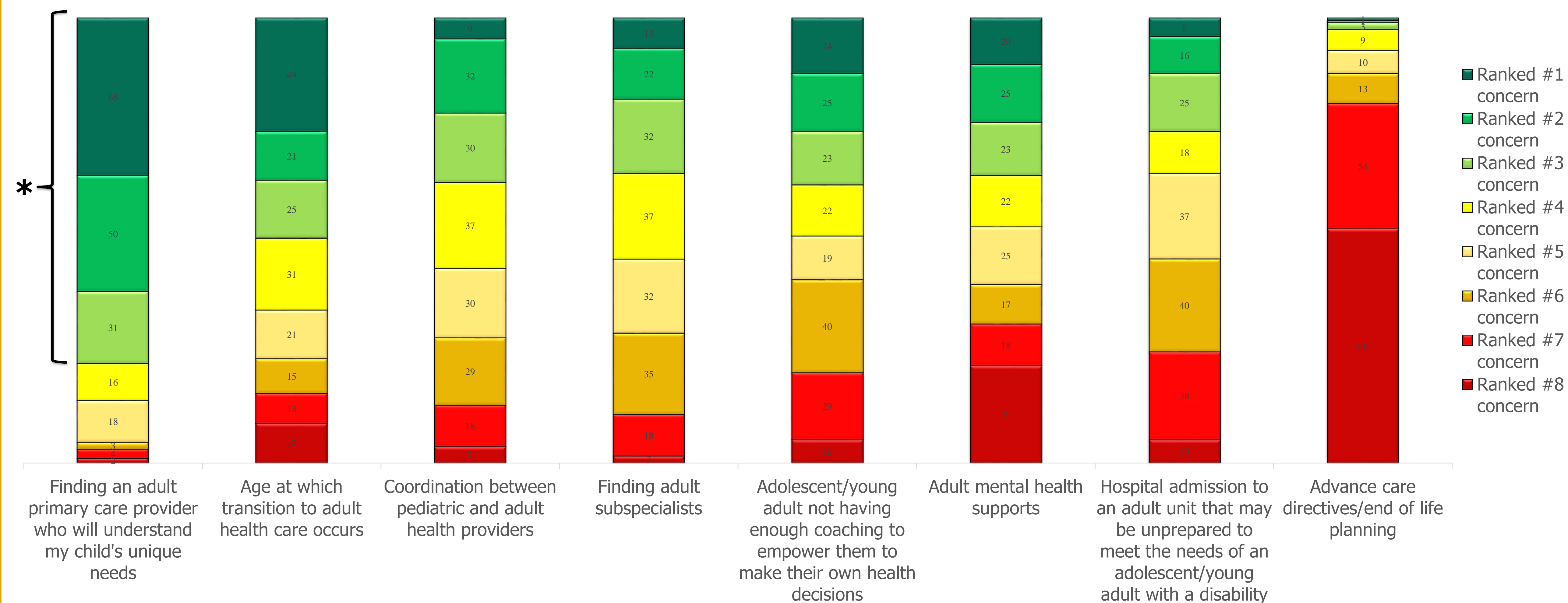
## Goal

- Responses may provide a family-centered framework for support to caregivers of youth with NDD during the transition to adulthood.
- Demographic data from the survey cohort may further direct services to specific populations, including for youth with NDD and co-occurring mental health diagnosis.

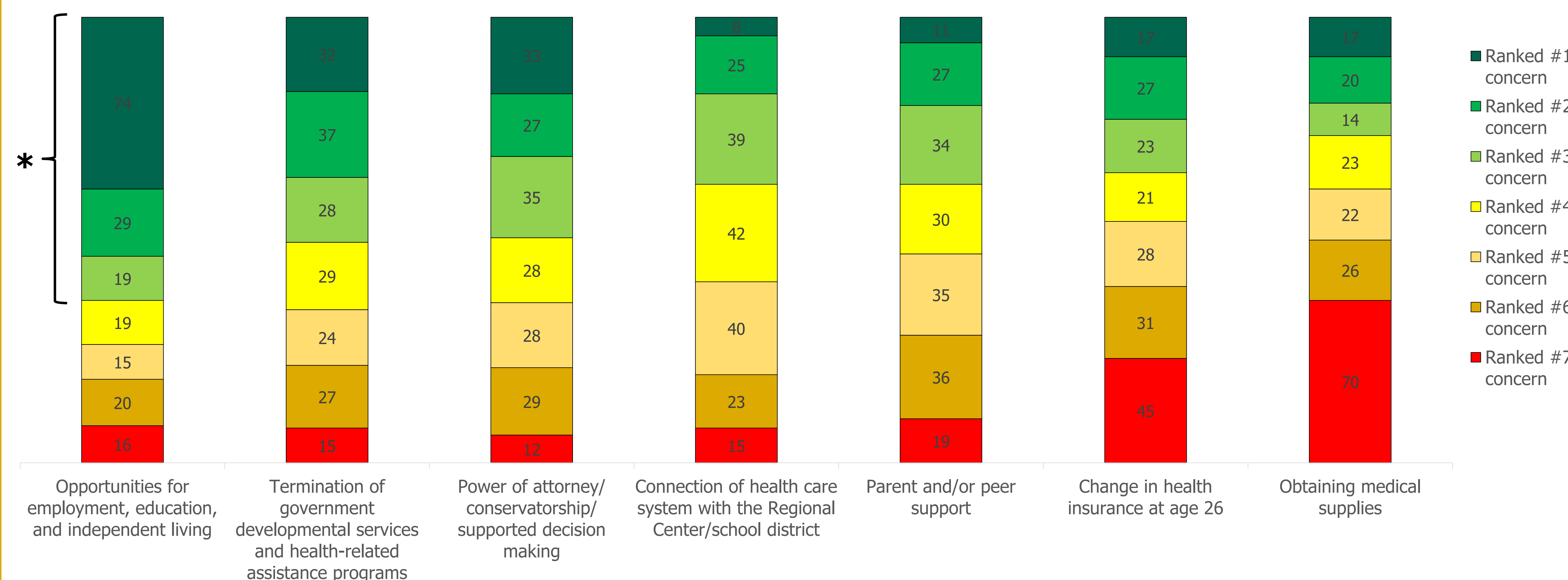
## Ranked Concerns- Frequency

\*= #1 overall concern ranked by caregivers of individuals with NDD (ages 15-26). Left to right: greatest to least overall concern.<sup>4</sup> A total of 192 surveys were completed (4.29% response rate).

### Medical Care Concerns

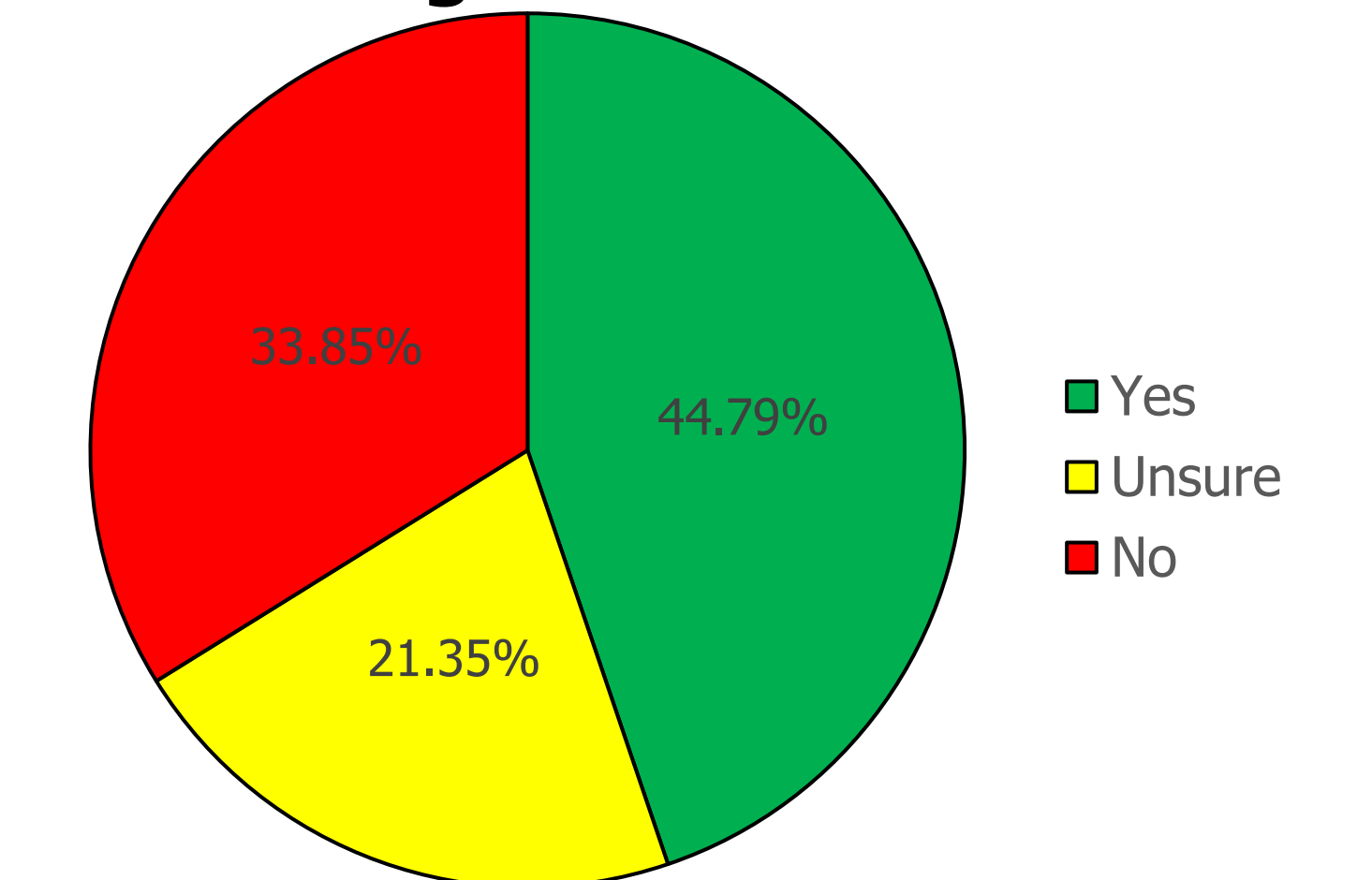


### Community Service Concerns



## Cohort Subset- Mental Health Diagnosis

### Co-occurring mental health diagnosis



For caregivers of youth with NDD and co-occurring mental health diagnosis, the #1 ranked medical care concern is "Age at which transition to adult health care occurs" (31.40%), followed closely by "Finding an adult primary care provider who will understand my child's unique needs" (29.07%).

## Discussion

- Need to improve physician comfort caring for patient population with NDD by increasing engagement with this population during medical training.<sup>5</sup>
- Begin transition planning as early as age 12.<sup>6</sup>
- Medical team should foster partnerships with schools, community agencies, and social service agencies to support transition.
- Next steps for further research:
  - Improve response rate by providing incentives and sending reminders.
  - Prioritize recruiting a cohort that is more representative of the diverse population served.
  - Expand the survey to include the voices of youth with NDD.

## References

- <sup>4</sup>SurveyHero, 2024, <https://help.survehero.com/faq/how-are-scores-calculated-on-the-ranking-question/>
- <sup>5</sup>Shapiro, Hannah F., et al. "Education research: Predictors of resident physician comfort with individuals with intellectual and developmental disabilities." *Neurology Education*, vol. 2, no. 1, 5 Jan. 2023, <https://doi.org/10.1212/nc9.000000000200045>.
- <sup>6</sup>White, Patience H., and W. Carl Cooley. "Supporting the health care transition from adolescence to adulthood in the medical home." *Pediatrics*, vol. 142, no. 5, 2018, <https://doi.org/10.1542/peds.2018-2587>.

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