Our Olmstead Survey: Highlights of the Responses

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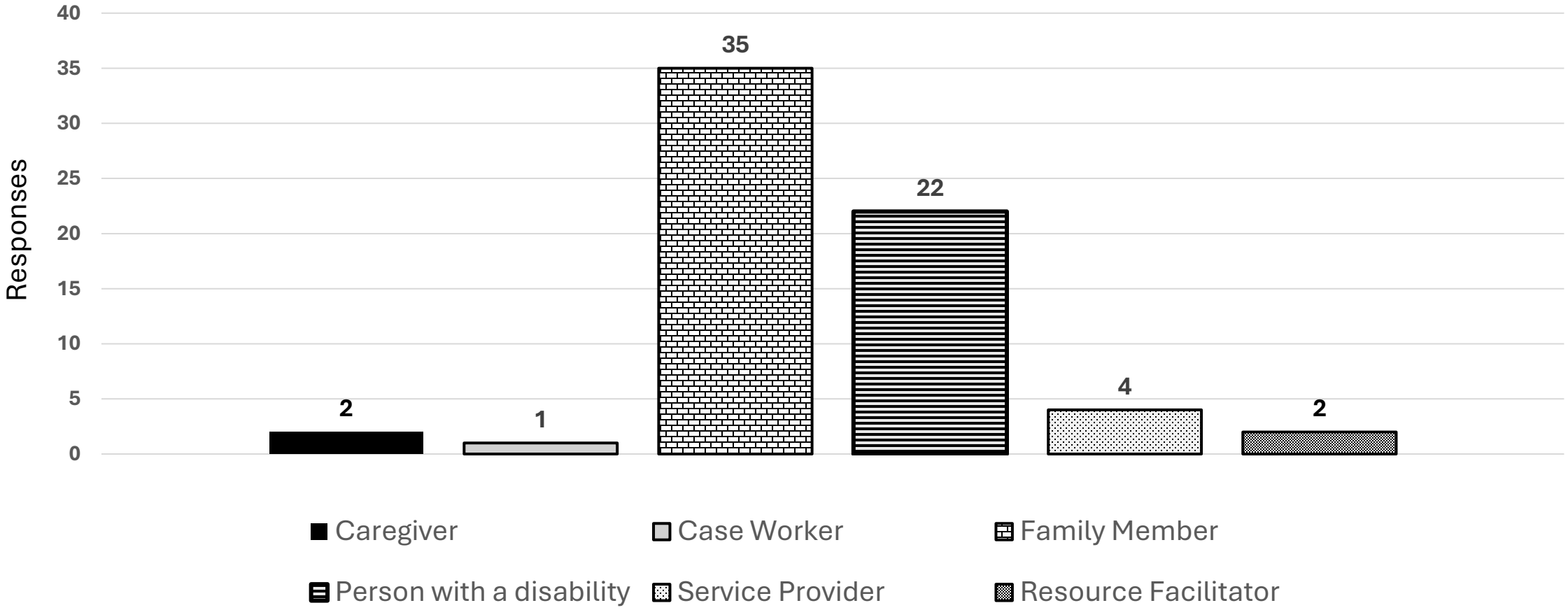
Background

- We created a small, non-scientific survey to collect the experiences of, and feedback from, Nebraskans with disabilities regarding community living. We included family members, providers, advocates, and others as well.
- We distributed this survey to our respective networks and contacts. In turn several contacts put a link to our survey on their respective social media platforms. We received 96 respondents ranging from Omaha to Sidney.
- Our intent was to provide an opportunity for Nebraskans with disabilities (and relevant others) who would not be able to testify at the September 18th Olmstead Plan public hearing to share their experiences and perspectives on issues essential for community living.
- It was a place to start the conversation.

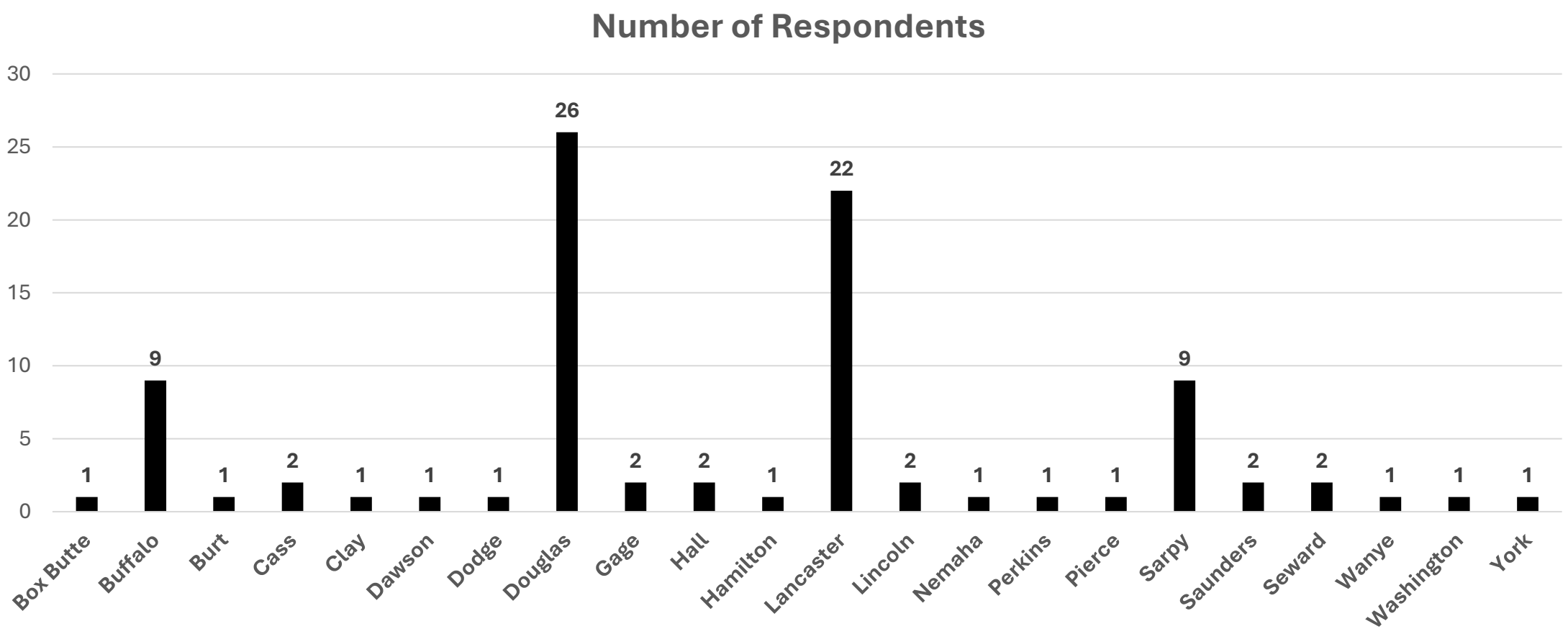
The Results

The following slides provide a snapshot of the survey answers that caught our attention. We hope that this input will help give Nebraska policymakers a more robust understanding of what community living looks like for Nebraskans with disabilities, their experiences (both positive and negative), and some ideas for policy reforms.

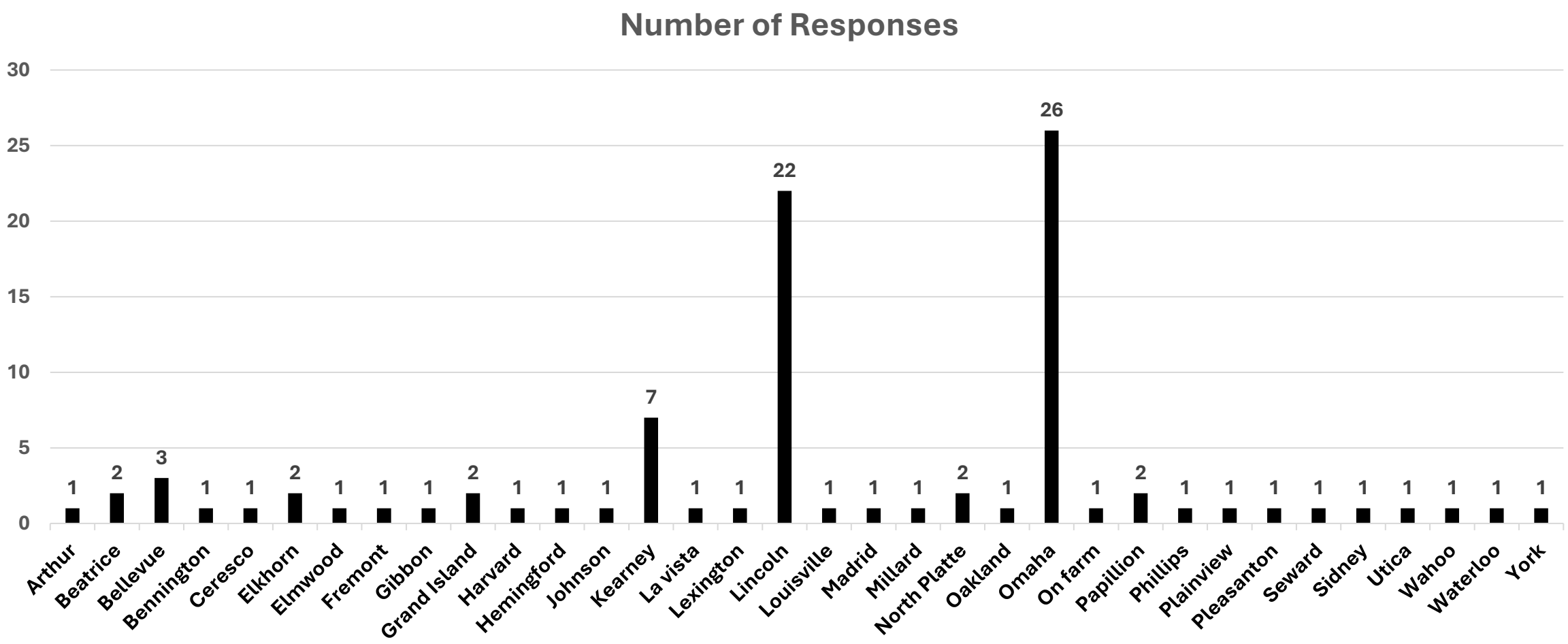
Responses by Personal Category



90 Responses from 22 Counties

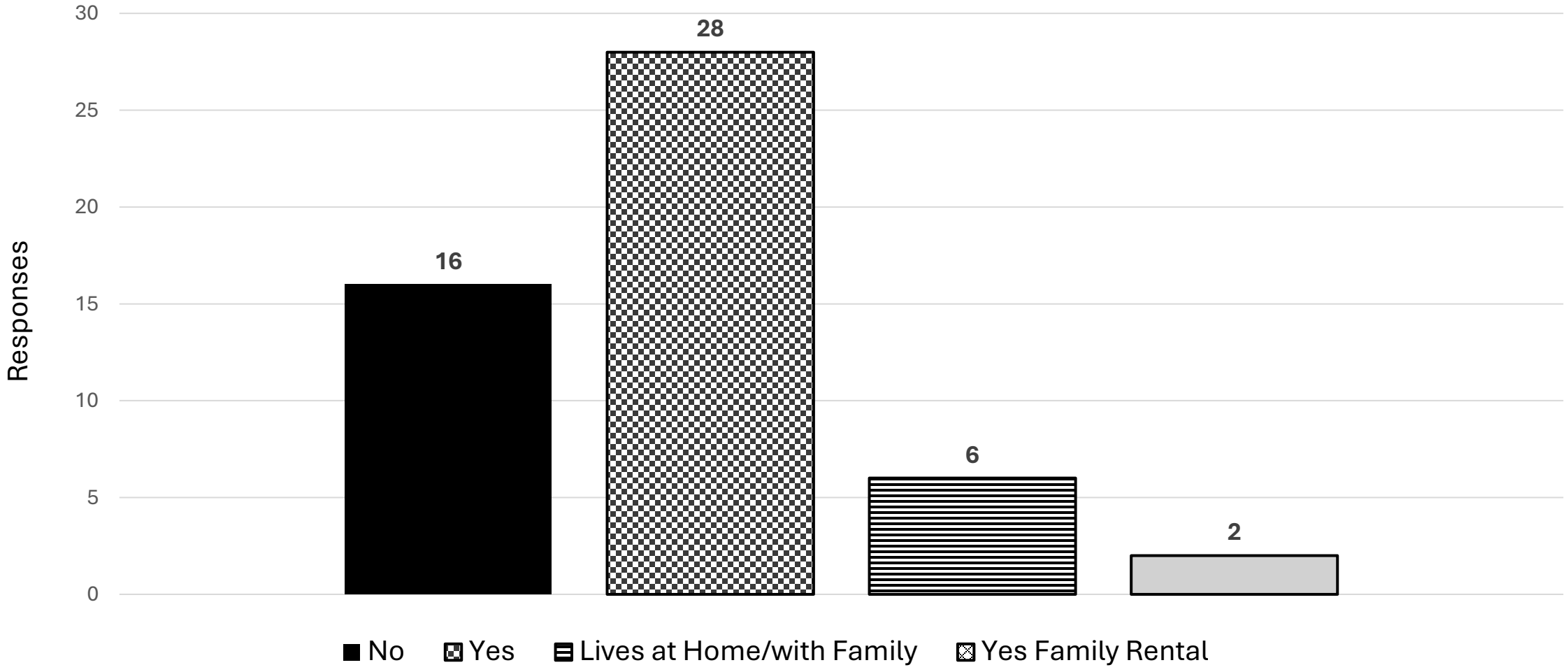


94 Responses from 35 Cities/Towns/Villages

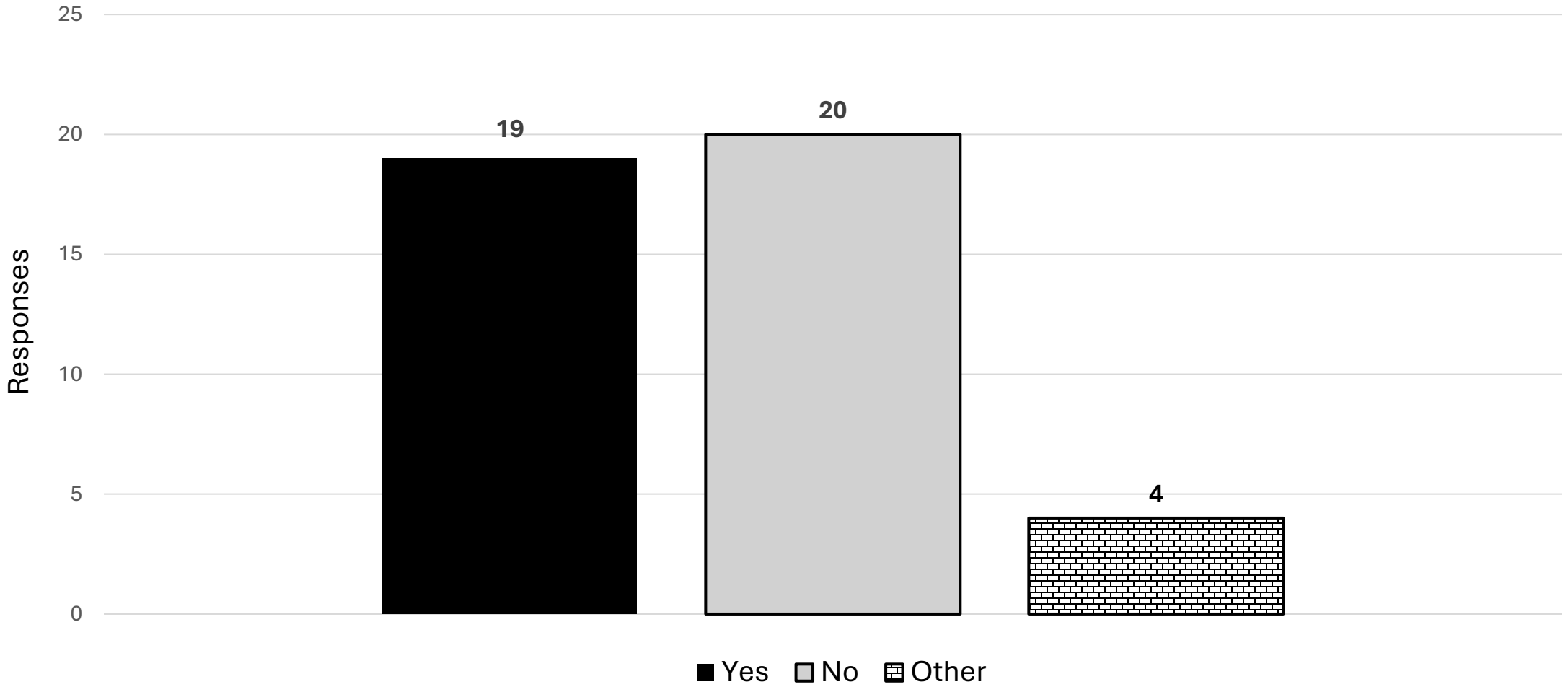


Housing

Have you been able to obtain affordable housing in your area?



Have you been able to obtain housing that is accessible to persons with disabilities?



What would you say about your current housing situation?

- There's not a lot of other options so we stay where we are
- Housing for people with Intellectual/Developmental Disabilities (I/DD) is hard to find in price range needed
- Not good. Not any places for people with cognitive and executive function disability for 19- to 55-year-olds
- Living with parents
- I do not know that I would consider it affordable to have to work multiple jobs to maintain housing
- Yes, but it is difficult to afford
- Yes…. but only because we purchased our home many years ago, now it would be impossible

What would you say about your current housing situation?

- I currently live in a full market rate apartment that is not Ada accessible and I've had to make my own modifications in order to make it somewhat functional

  My kitchen is still quite difficult to navigate and I often go without meals because of this, in addition to the level of difficulty around receiving Home Care it's just easier to skip food in order to keep my housing

  I need to maintain four and a half times the income rate to stay qualified to live here this means that I am working various jobs in addition to having to navigate the transportation to these jobs

- My current housing situation is safe but as I become more disabled, I will have to move homes due to the stairs. I’m concerned for my ability to buy a new home or rent a new home due to costs.
- She lives independently with a roommate in an Arc apartment, but we haven't been able to fill all the hours she needs for supported living.

What would you say about your current housing situation?

- I have been able to find an apartment. It isn't accessible, there is one flight of stairs. I actually moved here because my old house had 2 flights of stairs to do my laundry. I live in the bottom level/basement, where the laundry is located. However, it has been flooded when the rain is severe.
- Our current housing has been adapted for my daughter (wheelchair accessible).
- I live with my parents/guardians/conservators. It is the best housing environment any individual could have. They help me with EVERYTHING, because that's how much I matter to them. They receive an SSI budget for this from the Social Security Administration, but they receive NOTHING from DHHS for doing this.
- Most of my clients struggle quite a bit with housing, and the majority are in shelters
- Our housing situation meets the needs of our daughter, keeping her at home and in our community.
- My disabled son lives with me so that I can help be a part of his life/care management.

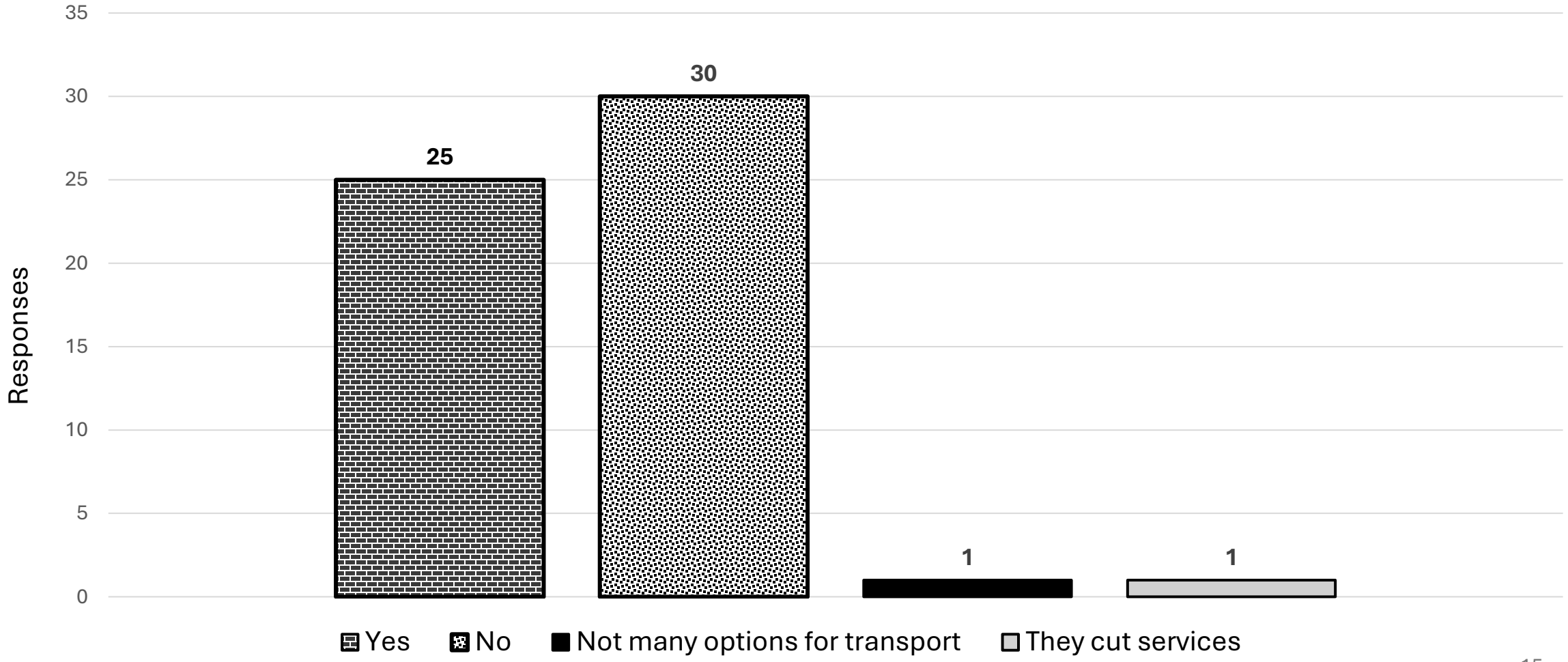
What barriers exist for people with disabilities to obtain housing?

- Cost and Accessibility
- Inventory of houses or apartments with accommodations
- Ramps, lower sinks and ovens for people in wheelchairs
- Finding affordable housing that can accommodate their disability
- Many of our clients lack the appropriate independent living opportunities and reside either in shelters or in assistive living homes that are not conducive to their therapeutic progress or life satisfaction
- Availability, affordability, landlords not willing to rent to those with disabilities, what is affordable is in poor condition or less attractive neighborhoods
- Lack of wheelchair accessible housing and the high price of the few homes that are already adapted

  The cost and lack of accessible apartments in safe neighborhoods
- New housing is being constructed but it is not affordable. Income is not increasing with rise in living expenses like utilities, gas, insurance, and groceries

Transportation

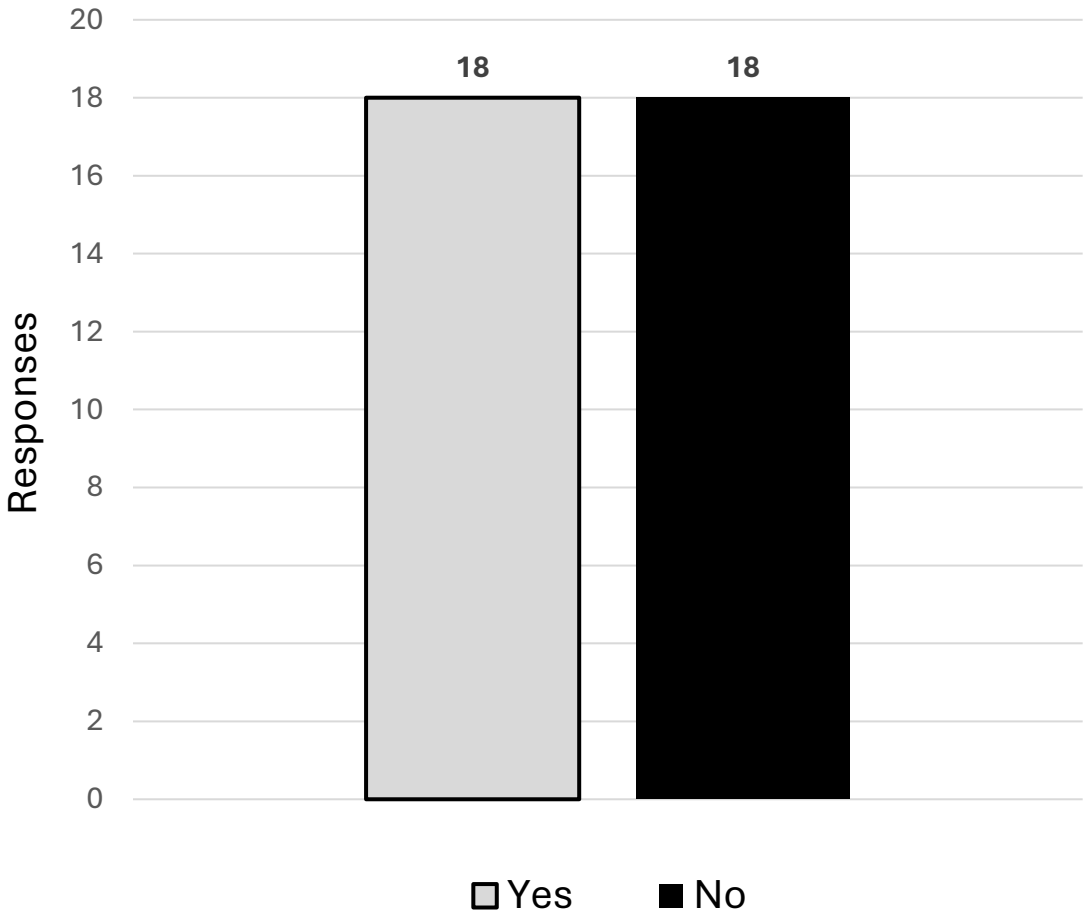
Do you use paratransit or transportation services provided by a government agency, service provider, or other organization?



Suggestions to improve transportation or expand transportation options for people with disabilities

- Expand transportation routes to west Omaha. Provide a safe Uber or Lyft option for people with IDD
- Access during evening hours to accommodate for evening shifts for work
- Buses to run later and on weekends
- Expanding public transportation to more rural areas not just in Kearney
- Online app scheduling
- I struggle to get to Lincoln to do anything like offer public comment or attend meetings
- I try to do things on zoom but the level of exhaustion that I put forth just to manage my day-to-day transportation and Home Care needs means that sometimes I don't have the energy for setting up transportation

Do you need to make reservation for paratransit or agency transportation?



- Yes. We have to give 24 hours notice and it's not open after 5 pm so you have to use uber; which may or may not be accessible
- Yes. They are limited. Only certain days and times. And that’s not including anything late in the evenings after 5:00. Ubers aren’t always an option if you have a walker or wheelchair either.
- [Aged and Disabled] waiver participants report limitations (e.g. RYDE won’t take them to the YMCA), early scheduling, and rides being early or late
- Issues with transport being late and sometimes leaving a person waiting for hours for pick up from an appointment.

Employment

As a person with a disability, if you have a job or had one in the past, what would you say about it?

- I have a job but my boss and coworkers do not understand my disability and are sometimes cruel. But I like working and having somewhere to go, to be needed and I like the money I earn so I can do things like bowling with my friends or going out to eat.

- Some businesses and staff in those businesses need training on how to work with job coaches. There is a lack of understanding of their role, and how they help level the playing field for persons with disabilities.

As a person with a disability, have you run into any barriers looking for work or keeping a job?

- I previously worked for the state of Nebraska for 5 years and I found receiving accommodations to be a very difficult process and there was a high level of ableism.

- Work has been okay, but my workplace is not set up for my success as a disabled person. I walk across the building to fax simple documents. I have been granted accommodations, but my manager fails to support me and my disability day to day.

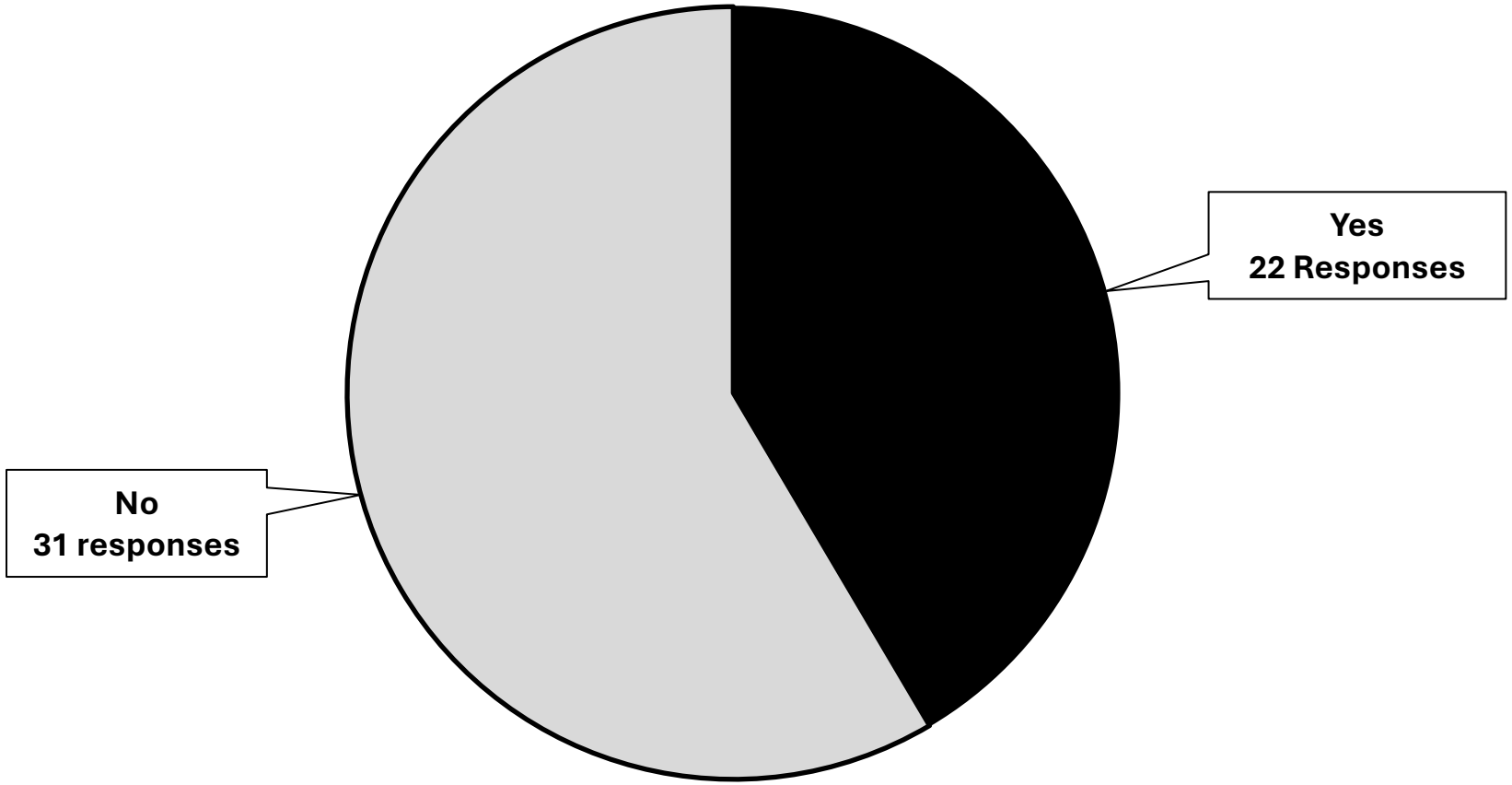
- Employers are not eager to accommodate and discourage employment.
- Very content with my job. They are very good at communicating with my mother when there are issues, but still other employees do not understand my needs
- He has a great place to work … which provides him with support but also encourages his independence where appropriate.

Suggestions to improve employment opportunities for Nebraskans with disabilities

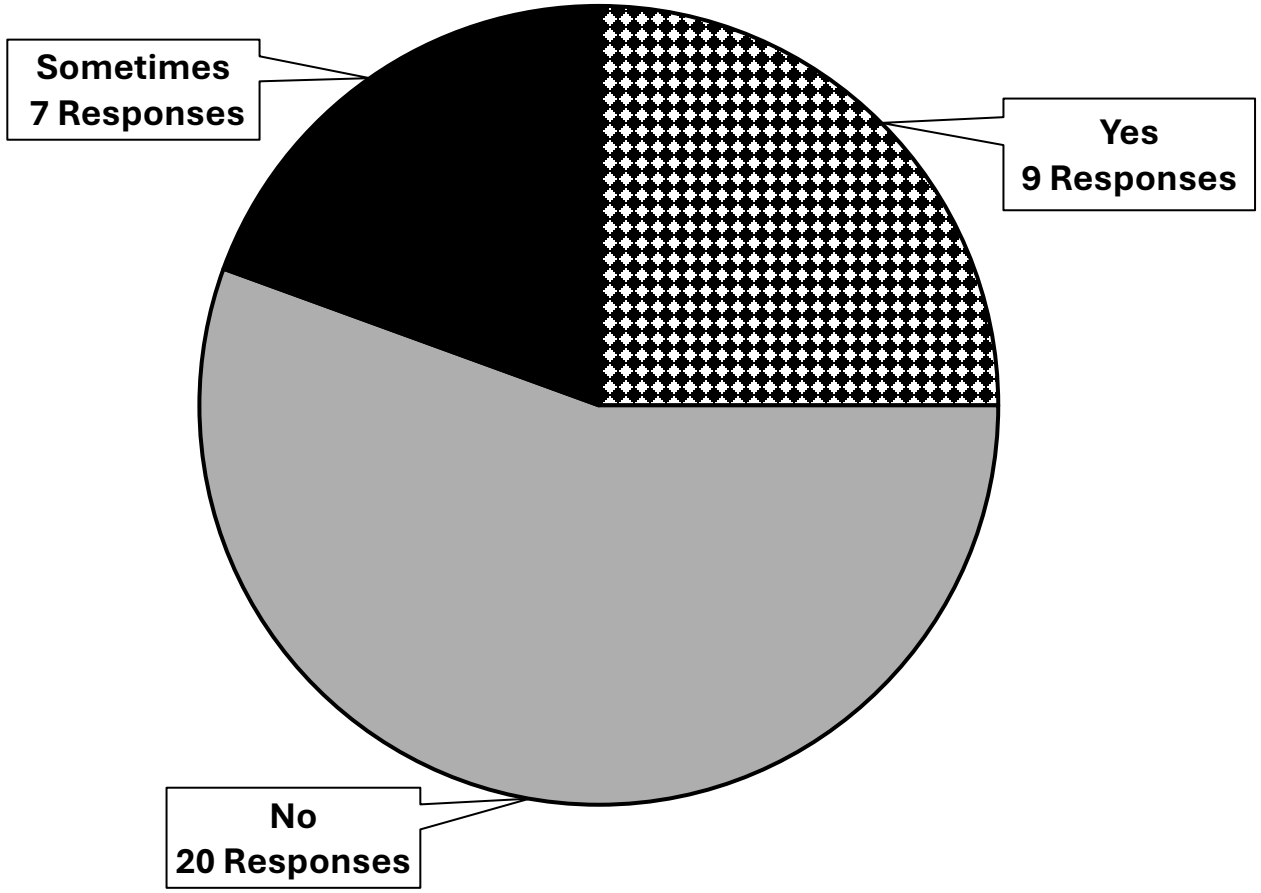
- Improve access to supported employment and recognize that people can benefit from work even if the need continued support on the job.
- Encourage city governments to encourage local businesses to hire people with disabilities.
- Hire a disability champion to ensure that people with disabilities are considered and included from the planning stages and not an after thought in their processes.
- More training on workforce development, how job coaches supplement employment, and in general, more work opportunities.
- Train not only employers but also the rest of the employees to treat individuals with [I/DD] with dignity and respect.
- Provide transportation to and from work.

Education

Do you need supports or assistance to participate in school?



If you need supports or assistance to participate in school, are you receiving them?



What would you say about education of students with disabilities in Nebraska?

- It is mixed depending on where you live.
- Some school systems are great, some need improvements.
- There is not enough staff to support the students.
- The school that she went to was awesome, amazing teachers and staff.
- We are very fortunate to live in an area that put time and effort into the education of our daughter. The hard part was that there was not an easily accessible "road map" for the educators to have as a framework. Much of it was put together over the years as time went along.
- One nurse for 3 school districts, state would not allow nurse to go with. Pulled my son out before Jr. High because it was a safety risk.

What would you say about education of students with disabilities in Nebraska?

- Individualized Education Plans (IEPs) are drafted ahead of time instead of as a result of the IEP meeting.
- Parents are pressured to agree with "professionals."
- Education does not effectively track progress on independent living skills- not all students have parents able to provide soft skill training.
- Adaptive workarounds can increase independence - e.g., no student needs to balance a checkbook but does need to know how to access bank information on-line.
- No student needs to know how to tie his/her shoes but does need to know which foot to put the shoe on.
- Classrooms need to be inclusive with supports and with a teacher who fosters a community in the classroom - resulting in genuine lifetime friendships and informal community supports.

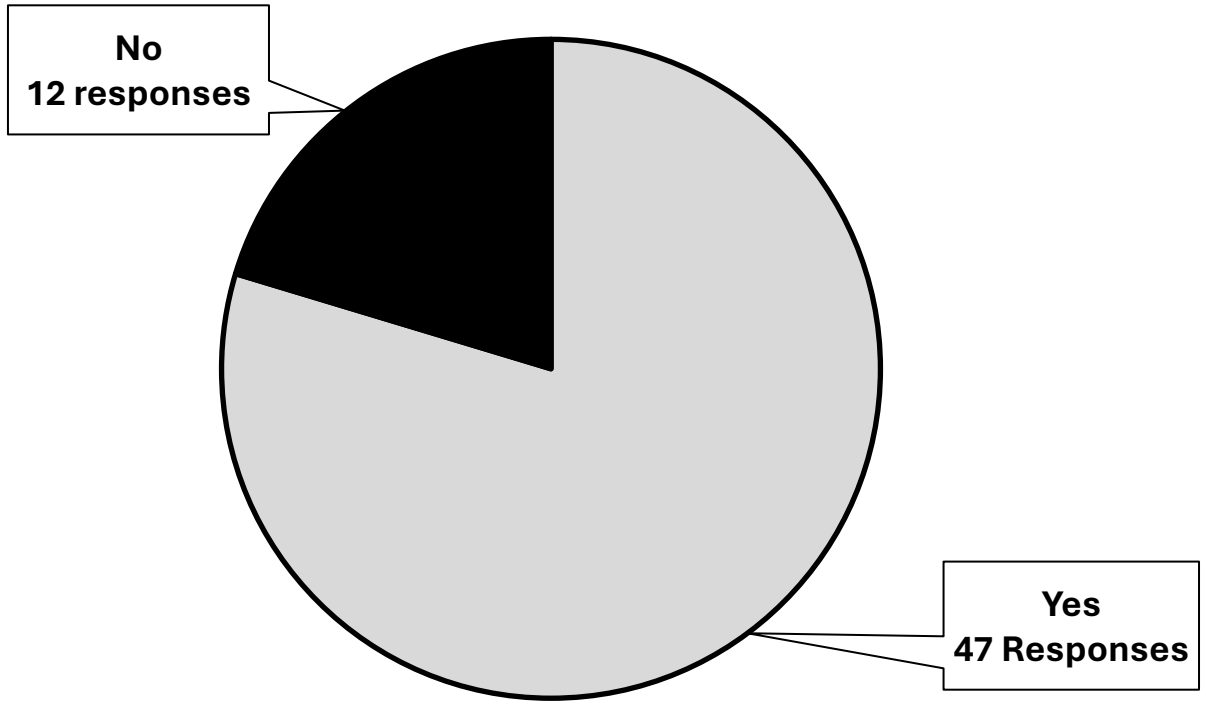
Suggestions to improve education opportunities and outcomes for students with disabilities in Nebraska

- Reduce the use of restraint and seclusion on students with disabilities.
- More special education teachers; more para's, more related services such as speech pathologist and Occupational Therapists.
- Financial support to institutions and agency that have proven to use evidence-based models to support folks with disabilities.
- Invite folks with lived disability experience in the education system to hear about barriers progress or concerns they have.
- Check-ins with the student and parent and school team for where improvements can be made for success (especially when paras are no longer available for support).
- More mental health support.

Community Supports

Using Services or Supports to Live in the Community

Are You Currently Using Services or Supports to Help You Live in Your Community



What kind of services or supports do you currently use to live in your community, if any?

- Comprehensive Developmental Disability waiver
- Using respite, community integration, supported family and LRI
- HUD housing, case management companies, day programs
- Supported employment
- Aged & Disabled waiver
- Paid parent caregiver through agency
- Day program and residential services provided
- Speech therapy
- Shared living provider
- Supported Family Living; Community Day Habilitation

What community supports or services are needed, wanted, or missing?

- Better transportation, meal prep, cleaning, community events for us older people with disabilities that are not sports focused
- Continue paid parent support, do not cut hours as full-time care is required
- Some individuals need more clinical support than a traditional Developmental Disability residential service is designed, staffed, or funded to provide
- Nursing facility may be unnecessarily restrictive and inappropriate for the person's disability, age, preferences, and quality of life

What community supports or services are needed, wanted, or missing?

- More reliable transportation, affordable and accessible housing, supported and customized employment, meaningful community opportunities, respite, assistive technology, family caregiver supports, medical coordination, home maintenance and accessibility assistance, financial management/Representative Payee support, and flexible in-home services that can increase or decrease as a person's needs change
- Specialized community-based options: skilled nursing in the home, enhanced funding for medically complex individuals, stronger coordination between healthcare and Home and Community Based Services providers, specialized Direct Service Personnel training, clinical consultation, and community residential models designed for people with significant medical needs

How could existing community supports or services be improved?

- Pausing the InterRAI assessment.
- More staff, better trained staff; there is a lack of people to go around
- Provide funding to increase the low wages paid to direct support staff; low wages and benefits discourage staff from continuing employment in this line of work.
- Providers need adequate funding for the essential supports required to keep people living in the community…transportation, support with medical care and appointments, home maintenance, financial management and Representative Payee responsibilities.
- Supported employment should be prioritized.
- More availability for accessing opportunities with community service providers.
- More integrated opportunities for adults with disabilities that are a part of the general community.
- As a young adult with disabilities the expectation and services provided mean I almost always have to just be with people with disabilities for recreation, etc. I want to be a part of the general community.
- These are not extras; for many individuals, they are what make community living possible

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Other Comments

Any Other Comments?

- Institutionalization should be seen as a last resort.

  People don't thrive there. They are costly; both monetarily and in people's value. Everyone should have the right to live in their least restrictive environment. They should have opportunities to work if they are able. They should enjoy community time with their peers, going to movies, ice cream, sports. “Disabled” does not equal “less”.

- When people with differing abilities are allowed to access their community, it expands their experiences

  Provides a way for those who aren’t considered to have a disability the chance to also learn from and include others different from themselves. We ALL benefit!

Any Other Comments?

- Encourage Nebraska to evaluate how Medicaid and Developmental Disability (DD) administrative dollars are being spent. DHHS invests significant resources in contracted oversight and review functions… From a provider perspective, these processes can be extremely burdensome, lack transparency and consistency, and often feel more focused on reviewing compliance after the fact than on actually helping providers improve the quality of services.

- Oversight and accountability are absolutely necessary, particularly given concerns about abuse, neglect, and service quality. However, Nebraska should evaluate whether the resources devoted to administrative review are producing measurable improvements in people's lives.

Any Other Comments?

- [Redirect] resources toward direct quality improvement: provider technical assistance, workforce development, behavioral and clinical expertise, prevention of abuse and neglect, transportation, and other supports that strengthen community-based services.

- Quality oversight should help build a better system, not simply measure whether providers complied with it.

Additional Things to Consider

The specter of institutionalization is advancing. Federal commitment to enforce and support the right of people with disabilities to live in the community, enshrined in Olmstead, has evaporated: DOJ Opinion, DOJ Guidance Clarification, Texas v Kennedy Final Decision

Increasingly States will be left responsible and holding the bag

- Enforcing the civil right of people with disabilities to live in their community
- Establishing true opportunities for disabled Nebraskans to exercise this civil right
- Securing funding for said opportunities.

Additional Things to Consider

Is there existing legislation or are there existing programs that could be leveraged (Federal or State)?

- What legislation, policy, or program(s) need to be created?
- Would additional Medicaid Waivers be useful?