



## 2018 Participant Experience Survey Executive Summary

### Background

The Division of Developmental Disabilities (DDD) conducted its first Participant Experience Survey in 2018. DDD developed the Participant Experience Survey to gather feedback from Home and Community-Based (HCBS) Waiver participants. The survey grew from Nebraska's results in the 2016-2017 National Core Indicators (NCI) Adult Consumer report, the first year Nebraska participated in NCI. The purpose of the NCI Adult Consumer survey (renamed the In-Person Survey in 2017) is to support public developmental disabilities agencies by collecting a standard set of developmental disability related metrics to measure and track performance and to compare with other states. Because the NCI Adult Consumer survey is based on a set of standard questions used nationwide, DDD focused its Participant Experience Survey to focus on areas that the NCI Adult Consumer survey found Nebraska to be below the national average. Those areas included participants' rights, choices related to their living environment, treatment by support staff, health and access to the community. The Participant Experience Survey also gathered information on participants' satisfaction with services.

In 2017 DDD received a Preventative Health and Health Service Block Grant from the Division of Public Health for its quality team to conduct at least 50 in-person surveys in partnership with self-advocates with developmental disabilities.

The DDD quality team recruited self-advocates by directly contacting stakeholder organizations to notify them of the opportunity and by presenting the opportunity at events such as the People First of Lincoln and Omaha Chapter meetings. The DDD quality team also created a flier that was posted on the public DDD website and sent out to the DDD email list serve. The DDD quality team trained a total of 11 self-advocates. The grant allowed DDD to compensate self-advocates for each survey they helped DDD conduct.

### Survey Administration

To select HCBS waiver participants to take the survey, DDD randomly generated a sample of those living in Lincoln and Omaha. The DDD quality team contacted those in the sample, or their guardian, if applicable, to request their consent to participate in the survey. In this first year, the survey was limited to two geographic areas because those were the only locations where the DDD quality team was available to conduct surveys at the time. Future Participant Experience Survey will be conducted throughout the state.

The Participant Experience Survey questions were finalized after the 2016-2017 NCI Adult Consumer report was released in May, 2018. The DDD quality team completed 74 face-to-face surveys between May and September, 2018, 53 were conducted in partnership with the self-advocates. The survey respondents were HCBS participants and their guardians.

There were 46 questions in the Participant Experience Survey. Twenty-two questions were primary and the rest were follow-up questions based on the answers respondents gave. The categories of the questions were as follows:

- Satisfaction with Services (7 questions)
- Service Coordination (5 questions)
- Support Staff (5 questions)
- Transportation (3 questions)
- Participant Goals (6 questions)
- Participant Health (2 questions)
- Living Environment (10 questions)
- Relationships (4 questions)
- Access to the Community (4 questions)

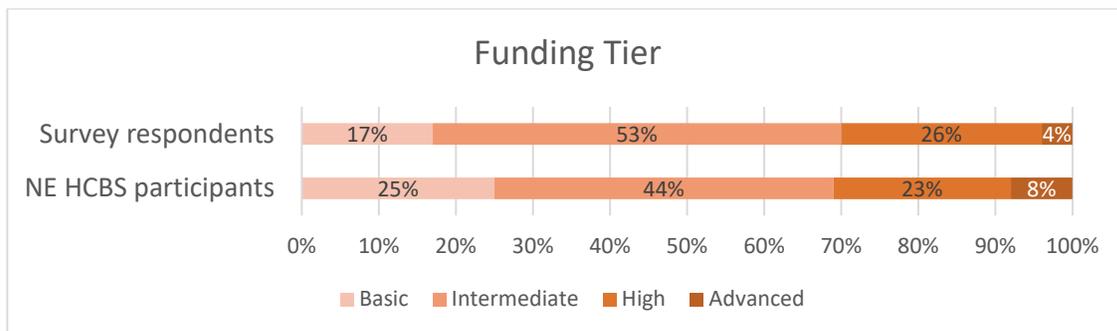
### Demographics Characteristics

The demographic characteristics of the survey respondents generally aligned with the demographic characteristics of the HCBS participant population in their age, gender, waiver type and funding level. However, a higher percentage of survey respondents (44%) had no guardian, compared to the overall HCBS participant population (26%), and a higher percentage of respondents were in Lincoln (82%), compared to the percentage in the HCBS population (22%), because of DDD quality team staffing during the survey period.

Demographics		
66%	59%	Are male
86%	87%	Are on the Comprehensive waiver

The characteristics of the survey respondents were as follows:

- Respondents ranged in age from 14 to 70 years and the average age was 39.
- Sixty-six percent were male.
- Eighty-six percent were on the Comprehensive Developmental Disabilities waiver and 13% were on the Developmental Disabilities Adult Day waiver.
- Most of the respondents (82%) lived in the Lincoln area and 18% lived in the Omaha area.
- Forty-four percent had no guardian.
- Eighteen percent were in the basic funding level, 53% were in the intermediate funding level, 26% were in the high funding level and 4% were in the advanced funding level.



## Survey Results

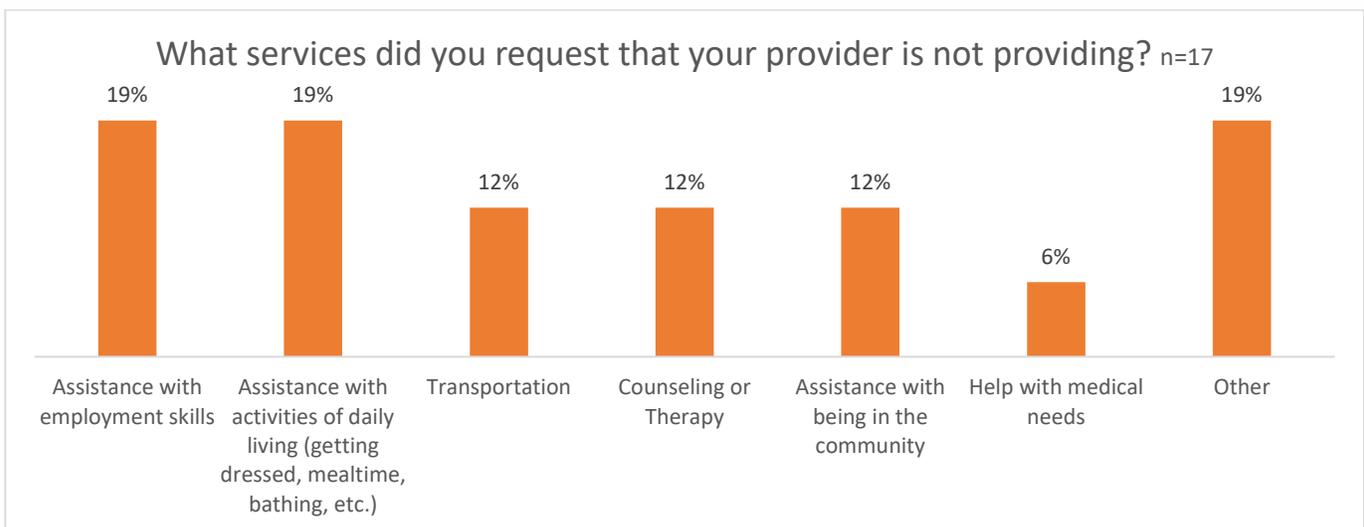
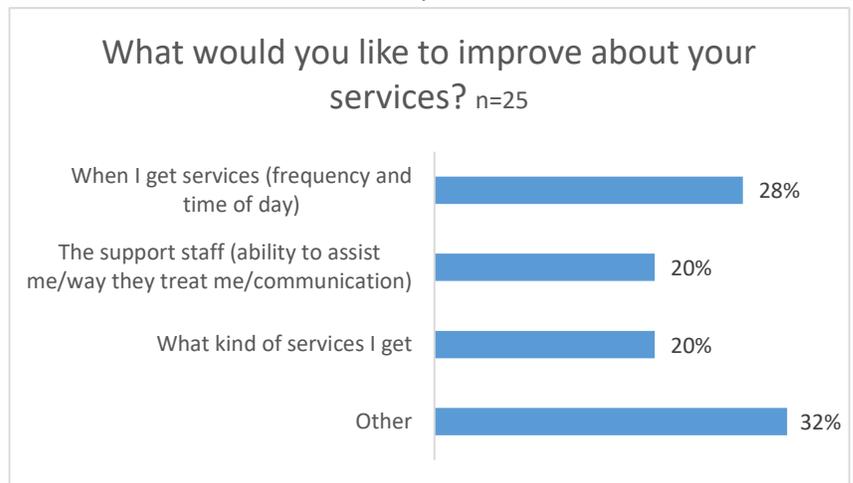
The following are the highlights from each section of the survey.

- **Services**

- This section asked about the services that the respondent received, how satisfied the respondent was his/her services and if he/she was dissatisfied, what improvements the respondent would like.

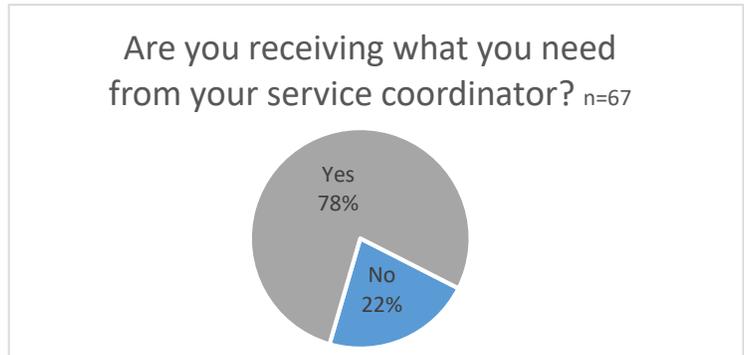


- Three-quarters of respondents (76%) stated that they were involved with choosing the services they have and 75% said they were satisfied with the services they receive.
- A higher percentage of respondents with no guardian said they were involved in choosing their services compared to respondents with no guardian (83% compared to 71%).
- Some service improvements that respondents requested were to have more services to assist them with employment skills.



- **Service Coordination**

- This section asked how satisfied the respondent was with their DDD Service Coordinator and how the DDD Service Coordinator could be of more assistance.
  - The majority of respondents (78%) stated that they are receiving what they need from their DDD Service Coordinator.
  - A higher percentage of respondents with no guardian (86%) said were receiving what they needed from their DDD Service Coordinator compared to respondents with a guardian (71%).
  - Respondents requested assistance from their DDD Service Coordinator in areas such as:
    - more frequent contact to check on how things are going;
    - more information on what choices are available or advice on what to do; and
    - better communication (such as notification to the team when the DDD Service Coordinator could not attend a scheduled meeting or more follow through on questions that are asked).



- **Support Staff**

- This section asked the respondent about his/her Support Staff.
  - Very few respondents (11%) said there were problems with support staff.
  - Those who mentioned an issue referenced areas such as:
    - support staff not having knowledge or skills to address the respondent's needs;
    - support staff not letting the respondent leave the house when they want to, and;
    - having trouble communicating with support staff.

- **Transportation**

- This section asked the respondent about his/her transportation use and his/her satisfaction with transportation services.
  - The majority of respondents (70%) said they were satisfied with their transportation options.
  - Those who were dissatisfied with their transportation services mentioned issues such as:
    - not knowing what transportation options were available; and
    - wanting to take the bus, but not being able to (either because the respondent did not know how or the routes had changed)

- **Goals**

- This section asked what goals the respondent was working on and his/her progress on meeting the goal(s).

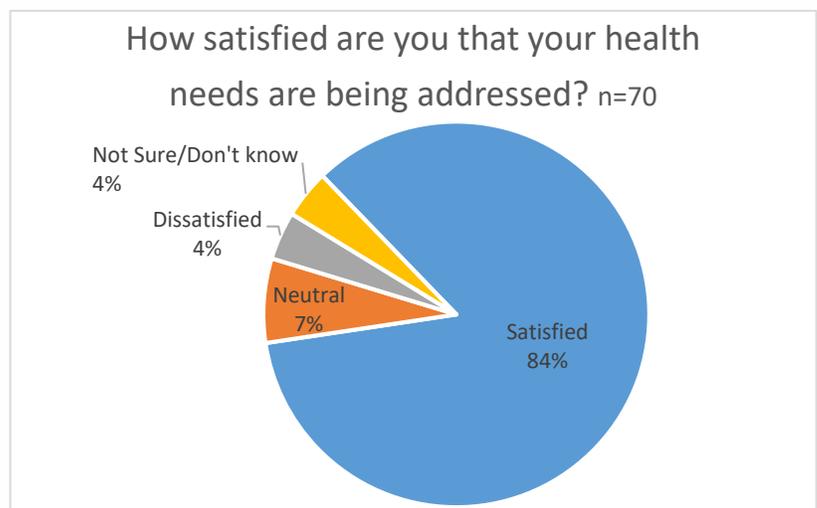
- Respondents could indicate having as many goals as they would like. Almost half of respondents (49%) reported that they were working on a social skills (behavior/communication) goal and 41% reported they were working on an activity of daily living goal.
- A third of respondents (33%) say that they have been working on their goal more than 2 years and 55% say they are not sure or don't know how close they are to meeting their goals.



- **Health**

- This section asked about the respondent's satisfaction that his/her health needs were addressed.

- The majority of respondents (84%) stated that they were satisfied that their health needs were being addressed.



- **Living Environment**

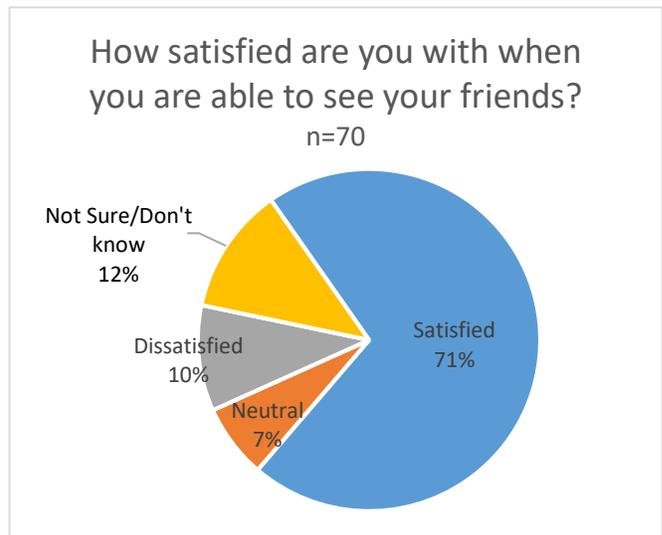
- This section asked about the respondent's living environment and what choices he/she could make.

- Eighty-five percent of respondents lived with one of three types of people: parents/relatives (27%), roommates (31%) or with support staff (27%).
- A higher percentage of respondents with no guardian (87%) said they chose who they lived with compared to respondents with a guardian (64%).
- Thirty-eight percent of respondents lived in their current home five years or more.
- Ninety-one percent of the respondents said they feel safe in their homes or living environments. However, respondents who lived with roommates were the group with the highest percentage (15%) who reported feeling unsafe at home.

- Seventy-five percent of respondents said when they are at home they can do everything they would like. A higher percentage of older respondents said they could do everything they would like to. An equal percentage of respondents with and without guardians said they could do what they want at home.
- The respondents who identified why they were not able to do what they wanted at home said this was because of reasons such as: rules, needing to do chores first, and issues with health, safety or supervision.

- **Relationships**

- This section asked how satisfied the respondent was with how much he/she was able to see his/her family and friends and if applicable, the reasons for why he/she was not be able to.



- Seventy-one percent of respondents said that they were satisfied with the amount of time that they get to see their friends. Those living with support staff had the highest percentage (20%) who said they were dissatisfied with when they are able to see their friends.
- Sixty-eight percent of respondents said they were satisfied with the amount of time they could see their family. The highest percentage of respondents (42%) said the reason they were not able to see their family was because they did not live near them.

- **Access to the Community**

- This section asked what respondents liked to do in the community and whether they could go out when they wanted to.
  - One third of respondents (30%) say they are not able to go out into the community when they want to. A higher percentage of older respondents said they could go out when they wanted to.
  - Those who indicated why they could not go out when they want mentioned reasons such as:
    - support staff or family not helping to take the respondent out in the community;
    - not having transportation;

- not having time to be independent; or
- having safety or behavior-related limitations to going out in the community.

- Respondents said that when they go out into the community they like to do things such as: go shopping for fun, go out to eat, go to the library, the zoo, swimming and going to the club.

