Purpose:
The goal of this Division of Services for People with Disabilities (DSPD) study is to understand the impact that short-term and long-term services have on quality of life for individuals and caregivers who are waiting for ongoing services.

Study Population & Type:
This is a longitudinal study of people/caregivers currently on the the DSPD wait list or people/caregivers recently moved into DSPD services. This means that DSPD will email this survey to eligible individuals/caregivers at regular intervals to understand how answers change over time.

Colors:
Question responses are color coded by the group who answered the question(s). Individuals’ with disabilities responses are displayed in Blue-Teal colors and caregivers’ of individuals with disabilities responses are displayed in Orange-Red colors.

Key Findings:
A total of 5544 email invitations were sent out and 1655 surveys were completed between March 30-April 12, 2022 (29.85% response rate). Five percent (n=91) of the surveys were completed by people with disabilities (PwD) on the DSPD waiting list and 95% (n=1564) of the surveys were completed by caregivers of a person on the DSPD waiting list. The median time to complete the survey was 3.35 minutes for PwD and 6.13 minutes for caregivers. The disabilities most represented in this survey were: 1) intellectual or developmental disabilities; 2) autism; and 3) physical disabilities. An overwhelming majority of primary-caregiver survey respondents were a parent of a PwD.

People with Disabilities
Only 22.99% of PwD reported that they get to do things in the community as much as they want. While 26% of those surveyed reported having a job in the community and no one reported disliking their job. Of those without a job, 74% reported that they would like a job or aren't sure if they would like a job. The most common barriers reported for not having a job were help needed finding the right job, transportation difficulties, and support needed for developing occupational and social skills.

Caregivers
Only about a fourth (25.91%) of primary caregivers (PCs) reported being satisfied with their quality of life and only 4% reported not feeling stressed about caring for their family member with a disability. Over a third (37.76%) of PCs reported that they have had to quit a job and 62.75% of PCs have had to reduce work hours to care for their family member with a disability. PCs ranked the most beneficial services for their families and loved ones with disabilities as respite services, including summer programming and weekend respite, and day program services. When asked what PCs would do if they were compensated for caring for their loved one with disabilities (i.e. caregiver compensation), most reported that they would reduce their work hours (37.15%) and only 16.39% reported that they would quit their jobs. Eighty-five percent of PCs believed caregiver compensation would have a positive impact on their financial well-being, 12% believed it would have no impact, and 3% believed it would have a negative impact.
Who is responding to this survey?

95% Caregiver of PwD

5% PwD

What type of disability do you, as a **person with a disability**, have? (check all that apply)

<table>
<thead>
<tr>
<th>Disability Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID/DD*</td>
<td>41%</td>
</tr>
<tr>
<td>Autism</td>
<td>32%</td>
</tr>
<tr>
<td>Physical</td>
<td>31%</td>
</tr>
<tr>
<td>Mental/Emotional</td>
<td>29%</td>
</tr>
<tr>
<td>Visual</td>
<td>12%</td>
</tr>
<tr>
<td>Hearing</td>
<td>7%</td>
</tr>
<tr>
<td>Age Related</td>
<td>3%</td>
</tr>
<tr>
<td>SUD**</td>
<td>0%</td>
</tr>
<tr>
<td>Other</td>
<td>17%</td>
</tr>
</tbody>
</table>

What type of disability does **your family member** have? (check all that apply)

<table>
<thead>
<tr>
<th>Disability Type</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID/DD*</td>
<td>1,172</td>
</tr>
<tr>
<td>Autism</td>
<td>760</td>
</tr>
<tr>
<td>Physical</td>
<td>441</td>
</tr>
<tr>
<td>Mental/Emotional</td>
<td>321</td>
</tr>
<tr>
<td>Visual</td>
<td>155</td>
</tr>
<tr>
<td>Hearing</td>
<td>95</td>
</tr>
<tr>
<td>Age Related</td>
<td>16</td>
</tr>
<tr>
<td>SUD**</td>
<td>9</td>
</tr>
<tr>
<td>Other</td>
<td>190</td>
</tr>
</tbody>
</table>

* ID/DD=Intellectual Disability/Developmental Disability; ** SUD=Substance Use Disorder
Do you feel that your child or family could benefit from any of the following services:

(Rank 1-5, 1=most beneficial)

1. Respite
2. Summer Programming/Respite
3. Weekend Respite
4. Day Programming
5. Help with Household Tasks
6. Family or Individual Therapy
7. Employment Support and Training
8. Peer Support
9. Parent and Family Training
10. Transportation Assistance
11. Home Health Services
12. Stable Housing Resources
13. Public Transportation Access
14. Other

1365 Responses
Individuals : Choice Questions

Where do you live?*
*Group home [0%]

88 Responses

- Family's home [72%]
- Own home by yourself [15%]
- Own home with roommates [2%]
- Other [10%]
- ICF or other institution [1%]

Do you feel like you have enough choice in your daily schedule?

88 Responses

- Yes: 30
- Sometimes: 40
- No: 18
Do you get to do things in the community as much as you want?

87 Responses

- Yes: 20
- Sometimes: 38
- No: 29

Do you get to choose how to spend your free time?

88 Responses

- Yes: 50
- Sometimes: 30
- No: 8

Do you have enough activities you like to do when you are home?

87 Responses

- Yes: 28
- Sometimes: 41
- No: 18

Do you have friends outside of your family members?

87 Responses

- Yes: 51
- Not Sure: 13
- No: 23

Are you able to meet up with friends and family when you want?

87 Responses

- Yes: 21
- Sometimes: 38
- No: 28
Individuals: Employment Questions

Do you have a job in your community?

88 Responses

- Yes [26%]
- No [74%]

Enjoyment

23 Responses

- I mostly like my job [52%]
- I like my job sometimes [48%]

Time: I feel like I...

23 Responses

- work too much [13%]
- do not work enough [22%]
- work the right amount [65%]

Compensation: I feel like I...

23 Responses

- do not get paid enough [30%]
- get paid the right amount [70%]
Those who do not have a job were asked...

Would you like a job in the community?

64 Responses

- Yes [36%]
- Not sure [38%]
- No [27%]

If you would like a job, what barriers do you have to getting one? (check all that apply)

60 Responses

- I need help to find the right job for me: 26
- Transportation: 26
- I need support for job skills: 23
- In need support for social skills: 22
- I do not want a job: 14
- I am under 14 years old and can't get a job yet: 12
Caregiver: General Questions

What is your relationship to the person on the waiting list?

- Parent or legal guardian: 1,456 responses
- Child: 40 responses
- Sibling: 30 responses
- Spouse: 5 responses
- Other: 25 responses

Are you the primary caregiver for the person on the waiting list?*

- No [4%]
- Yes [96%]

*Only those answering "Yes", they are the primary caregiver, were asked the remaining questions.
Caregiver : Quality of Life Questions

Are you satisfied with your overall quality of life?

1478 Responses

- Yes: 383
- Sometimes: 726
- No: 369

Do you feel stress over caring for your family member with a disability?

1482 Responses

- Yes: 64%
- Sometimes: 32%
- No: 4%
Legend: Yes Sometimes No N/A

Do you have enough time to yourself?

- Yes: 10%
- Sometimes: 38%
- No: 52%

Do you have enough time to take care of your personal health?

- Yes: 21%
- Sometimes: 48%
- No: 31%

Do you have enough time your daily responsibilities?

- Yes: 20%
- Sometimes: 52%
- No: 27%

Do you have enough time to spend with your partner/spouse?

- Yes: 11%
- Sometimes: 37%
- No: 40%

Do you have enough time to spend with your children?

- Yes: 19%
- Sometimes: 46%
- No: 25%
Caregivers: Employment Questions

Are you, or have you been, employed in the past three months?

1476 Responses

- Yes [57%]
- No [43%]

Have you ever had to quit a job in order to care for your family member with a disability?

1475 Responses

- Yes
- No
- Other (e.g. Work from home)

Have you ever had to reduce your work hours to care for your family member with a disability?

1463 Responses

- Yes
- No
- Other
If you were given the option to be compensated for caring for your family member with a disability, would you change your employment decisions or commitments?

848 Responses

- Yes, I would quit my job: 139 responses
- Yes, I would reduce my hours: 315 responses
- No, I would continue working: 136 responses
- I am not sure: 191 responses
- Other: 67 responses

Caregivers: Financial/Caregiver Compensation Questions

How do you think being paid to provide care for your family member with a disability would impact your overall financial well-being?

1435 Responses

- Negative impact [3%]
- No impact [12%]
- Positive impact [85%]
How do you feel about your current financial situation?

1448 Responses

- Never stressed [3%]
- Rarely stressed [10%]
- Occasionally stressed [22%]
- Sometimes stressed [28%]
- Often stressed [38%]

Are you currently able to save enough money for future expenses?

1448 Responses

- Yes [17%]
- Somewhat [38%]
- No [45%]

In the past six months, have you had to change your spending habits to meet the needs of your family member with a disability?

1445 Responses

- Often: 406
- Sometimes: 388
- Occasionally: 270
- Rarely: 254
- Never: 127