People with Disabilities Disproportionately Impacted During the Coronavirus Pandemic and Shutdown

Survey conducted by Disability Voices United
April/May, 2020
NUMBER OF SURVEY RESPONDENTS

- 435 people with disabilities and family members responded to the survey
- 13% are people with disabilities
- 87% are family members of people with disabilities
DISABILITIES OF SURVEY RESPONDENTS

- Autism Spectrum Disorder
- Cerebral Palsy
- Intellectual disability
- Down syndrome
- Epilepsy
- Other development disability
- Blind or Low Vision
- Deaf or Hard of Hearing
- Physical disability
- Mental health disability
- Chronic illness
- Medically fragile
- Brain injury
- Genetic disorders
- Learning disabilities
- Apraxia
MOST RESPONDENTS LIVE WITH FAMILY

Living situation of person with disability

<table>
<thead>
<tr>
<th>Living situation</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>With family</td>
<td>80%</td>
</tr>
<tr>
<td>In own place without support staff</td>
<td>8%</td>
</tr>
<tr>
<td>In own place with support staff</td>
<td>7%</td>
</tr>
<tr>
<td>With others in a group home/facility</td>
<td>3%</td>
</tr>
</tbody>
</table>

Living situations reported by respondents
Racial/Ethnic Makeup of Respondents

- **Latino**: 34.8%
- **Other/No Answer**: 16.9%
- **Native American**: 1.3%
- **Asian**: 6.2%
- **Black**: 7.3%
- **White**: 33.5%
MOST RESPONDENTS ARE REGIONAL CENTER CLIENTS

- 84% have a developmental disability and qualify for regional center services
- Represented all 21 regional centers throughout California

Regional centers are non-profits contracted with the California Department of Developmental Services to arrange and pay for services people with autism, cerebral palsy, intellectual disability, epilepsy, and other developmental disabilities
Despite regional centers’ claims they have reached out to all of their clients:

- 42% of respondents reported they had never been contacted
- 60% reported that they had recently tried to reach their regional center to get help during the crisis
- Almost ¼ of those hadn’t gotten a response
- Individuals run risk of falling through the cracks
PEOPLE NEED MORE SERVICES, BUT DON’T GET THEM

❖ 40% asked for more services or supports from regional center to help them during pandemic

❖ 47% of those had not receive the services they requested

❖ Reasons: No response, told they had enough services, couldn’t find staff
LATINOS HAVE MUCH GREATER NEED FOR SERVICES

Percentages of respondents who asked for additional regional center services or support by ethnicity

- Latino: 52%
- White: 30%
- Black: 26%
- Asian: 32%
- Native American: 5%
**People Need Support, But Are Afraid**

- 54% expressed concerns about having support workers in their home
  - Fear of being exposed to virus
  - Person is medically fragile
  - No personal protective equipment
  - Person with disability won’t wear mask
  - Staff not knowledgable
California has agreed to continue to pay for programs experiencing absences due to COVID-19; however, they must continue to provide services in person or remotely.

- 45% report they attend a congregate group day program.
- Of those, 93% said their day program was closed due to the coronavirus outbreak.
- Only 51% said they were continuing to receive services.
Almost Half of Students with Disabilities Not Accessing Education

Half of respondents reported their family member was a student with an IEP (Individualized Education Program)

Of those:

- 49% were not receiving education services since schools closed
- 16% did not have access to a computer or device to receive special education services
REASONS FOR NOT ACCESSING EDUCATION

- No direct teaching, even remotely
- Speech therapy through telehealth still not approved
- Took over a month for teacher to contact family
- Student can’t sit for online learning
- Teacher only provides weekly worksheets
- No school work provided – just referral to websites
- Student is non-speaking and can’t participate without communication support
Barriers Worsen for Self-Determination Program

- 14% of respondents were part of the Self-Determination Program
- Barriers mentioned include:
  - No response from regional center
  - Can’t get budget certified after months of trying
  - Dangerous to get staff fingerprinted
  - Afraid to have virtual person-centered plan
  - Independent facilitator not getting paid
FAMILIES NOT PREPARED FOR COVID-19

❖ 39% don’t know what to do if someone in their household gets infected with coronavirus
❖ 44% have no one to care for them or their family member if they get sick
❖ 35% have no access to personal protective equipment, like gloves and masks, in their home
❖ Biggest concerns in the Latino community
MORE LATINOS NOT PREPARED FOR COVID-19

Percentage of respondents who reported they don't know what to do if someone in their household contracts coronavirus

- Latino: 52%
- White: 29%
- Black: 31%
- Asian: 32%
- Native American: 40%

Race/ethnicity
LATINOS LESS LIKELY TO HAVE SOMEONE TO CARE FOR THEM IF THEY GET SICK

Percentage of respondents who have somebody to take care of them/their family member in case their main caregiver gets sick

<table>
<thead>
<tr>
<th>Race/ethnicity</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Latino</td>
<td>44%</td>
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<tr>
<td>White</td>
<td>62%</td>
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<tr>
<td>Black</td>
<td>58%</td>
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<tr>
<td>Asian</td>
<td>60%</td>
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<tr>
<td>Native American</td>
<td>20%</td>
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Fewer Latinos Have PPE in their Homes

Percentage of respondents who report having personal protective equipment, such as masks and gloves, in their homes

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<thead>
<tr>
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<tbody>
<tr>
<td>Latino</td>
<td>51%</td>
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<tr>
<td>White</td>
<td>74%</td>
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<tr>
<td>Black</td>
<td>65%</td>
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<tr>
<td>Asian</td>
<td>72%</td>
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<tr>
<td>Native American</td>
<td>80%</td>
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EXTREME WORRIES ABOUT ACCESS TO HEALTH CARE

❖ 67% are worried that they or their family member won’t get appropriate medical care during this time
❖ 54% are concerned about having staff in their homes
❖ Specific concerns include:
  ❖ Not being allowed in hospital with family member
  ❖ Staff not trained, won’t take time needed
  ❖ No communication support
  ❖ “Doctors won’t talk to me as adult”
Most Experiencing Mental Health Effects from Isolation

❖ 59% report experiencing effects on their mental health from isolation and the coronavirus pandemic

❖ Effects mentioned:
  ❖ Loneliness, anxiety, depression
  ❖ Increased challenges with coping
  ❖ Overwhelmed with worry and uncertainty
  ❖ Want routine to come back
  ❖ “Sad that I missed my prom”
CONCERNS EXTEND TO LOSS OF INCOME FOR DISABILITY FAMILIES

❖ 38% of households have experienced job loss in their household due to the coronavirus
❖ 38% are concerned about having enough money to pay rent or their mortgage
❖ 34% are concerned about having enough money to pay for food
Latinos More Likely to Have Lost Jobs

Percentage of respondents who have experienced job loss in their household due to coronavirus:

- Latino: 45%
- White: 34%
- Black: 29%
- Asian: 32%
- Native American: 40%
FAMILIES OF COLOR MORE CONCERNED ABOUT PAYING RENT

Percentage of respondents concerned about paying rent or mortgage due to the coronavirus epidemic

- Latino: 53%
- White: 22%
- Black: 38%
- Asian: 48%
- Native American: 40%
Families of Color More Concerned about Paying for Food

Percentage of respondents concerned about paying for food due to the coronavirus

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<tr>
<td>Latino</td>
<td>51%</td>
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<tr>
<td>White</td>
<td>12%</td>
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<tr>
<td>Black</td>
<td>54%</td>
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<tr>
<td>Asian</td>
<td>44%</td>
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<tr>
<td>Native American</td>
<td>20%</td>
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40% of Asians report racial discrimination