



**Supplementary Table 1: Study Population Demographics**

Age (median (years), [IQR])	25 [13, 38]
% peditrics (less than 18yo)	35%
Gender (% female)	47%
Race (% , n = 303)	

White	82%
Black/African	6%
Asian	7%
Hispanic/Latinx	8%
Native American	1%
Pacific Islander	< 1%
Prefer not to answer	2%
State (% , n = 424)	
Colorado	44%
New York	24%
Other	33%
Living arrangement if >= 18 years old (% , n = 269)	
With family	64%
In a group home or congregate setting	17%
Supported independent living (in a house or apartment)	8%
Alone	7%
Other	4%
Type of living community (% , n = 431)	

In a city (urban)	30%
In a suburb (outside a city)	59%
Rural	12%
Developmental disability (% checked, n = 429)	
Intellectual Disability	52%
Autism Spectrum Disorder	49%
Cerebral Palsy	15%
Other mobility impairment	9%
Down syndrome	18%
Hearing impairment	10%
Visual impairment	9%
Other developmental disability	27%
Other diagnoses (% checked, n = 292)	
Anxiety	63%
Depression	29%
Obsessive Compulsive Disorder	21%
Epilepsy	20%
Dementia	1%



Socializing with friends or family	-0.2042	<.0001	0.13053	0.0072	-0.0724	0.1371	-0.04791	0.325
Sports/Exercise (like Special Olympics)	-0.19372	0.0005	0.18486	0.001	-0.12787	0.0237	-0.15206	0.0069
Volunteering	-0.35429	<.0001	0.26857	0.0003	-0.13508	0.0739	-0.13635	0.0703
Medical Care (Doctor's Visits)	-0.03375	0.496	0.08813	0.0754	-0.06161	0.2148	-0.06884	0.1652
Special Education	-0.03292	0.6654	0.13953	0.0671	-0.23191	0.0021	-0.0306	0.6877
Day programming/Supports in the community	-0.20485	0.0008	0.11632	0.0572	-0.1454	0.0177	-0.13003	0.034
Recreation/leisure activities	-0.18088	0.0002	0.09626	0.0503	0.0105	0.8313	-0.03471	0.4807
Paid Work/Employment	-0.20783	0.0102	0.18807	0.0212	0.00832	0.9195	-0.28869	0.0003
Occupational/Physical/Speech Therapy	-0.05792	0.356	0.08427	0.1798	-0.19001	0.0023	0.01374	0.8268
Mental Health Care	-0.1322	0.0476	0.03587	0.5942	-0.13173	0.0484	-0.14845	0.0263

**Supplementary Table 4: Sample Sizes for Correlations with Loss of Activities and Services**

	Mental Health	Screen Time	Exercise	Sleep	Help
Socializing with friends or family	426	425	423	423	424
Sports/Exercise (like Special Olympics)	317	316	314	313	314
Volunteering	178	177	176	176	177
Medical Care (Doctor's Visits)	411	409	408	407	408
Special Education	175	175	173	173	175
Day programming/Supports in the community	268	267	268	266	266
Recreation/leisure activities	417	416	414	414	415
Paid Work/Employment	152	152	150	150	150
Occupational/Physical/Speech Therapy	255	256	255	255	256
Mental Health Care	225	225	223	225	224

**Supplementary Table 5: Changes in Service Availability Between Children (<18) and Adults**

	I continue to do this.	I continue to do this, but less because of COVID.	I used to do this, but now I cannot because of COVID.	Total	p-value
<b>Socializing with friends or family</b>					
Children	15	89	46	150	0.2633
Adults	41	143	85	269	
<b>Sports/Exercise (like Special Olympics)</b>					
Children	8	29	55	92	0.967
Adults	21	68	129	218	
<b>Volunteering</b>					
Children	4	7	13	24	0.6522
Adults	18	36	95	149	
<b>Medical Care (Doctor's Visits)</b>					
Children	73	59	10	142	0.8318

Adults	129	116	16	261	
<b>Special Education</b>					
Children	68	62	15	145	0.0864
Adults	8	16	6	30	
<b>Day programming/Supports in the community</b>					
Children	8	34	36	78	0.2643
Adults	20	61	103	184	
<b>Recreation/leisure activities</b>					
Children	8	54	86	148	0.7695
Adults	18	89	156	263	
<b>Paid Work/Employment</b>					
Children	7	3	1	11	0.0295
Adults	44	30	64	138	
<b>Occupational/Physical/Speech Therapy</b>					
Children	52	56	19	127	0.0843
Adults	40	53	32	125	
<b>Mental Health Care</b>					
Children	29	32	11	72	0.6618
Adults	69	60	19	148	

# Impact of the Pandemic on Behavioral Health of People with Intellectual and/or Developmental Disabilities (IDD)

Please complete the survey below.

Thank you!

## Please help us understand how the COVID-19 pandemic is affecting the behavioral health of patients with intellectual and/or developmental disabilities (I/DD).

Who is completing this survey?

- I am answering for myself. (I am a person with intellectual and/or developmental disabilities.)
- I am answering on behalf of a person with intellectual and/or developmental disabilities.

For all remaining questions, you are responding ON BEHALF OF the person with intellectual and/or developmental disabilities.

What is your gender identity?

- Man
- Woman
- Other

(Optional) What is your gender identity?

\_\_\_\_\_

What is your age (in years)?

\_\_\_\_\_

What is your race/ethnicity?

- White
- Black/African
- Asian
- Hispanic/Latinx
- Native American
- Pacific Islander
- Prefer not to answer

Please check all terms which describe your developmental disability.

- Intellectual Disability
- Autism Spectrum
- Cerebral Palsy
- Other mobility impairment
- Down syndrome
- Hearing impairment
- Visual impairment
- Other developmental disability

If other, please specify. (Optional)

\_\_\_\_\_

Please check any other diagnoses which apply to you.

- Anxiety
- Depression
- OCD
- Epilepsy
- Dementia
- Other diagnoses

If other, please specify. (Optional)

\_\_\_\_\_

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What best describes the community where you live?

- In a CITY (Urban)
- In a SUBURB (outside a city)
- Rural

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In which State do you live?

- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- Florida
- Georgia
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky
- Louisiana
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- Missouri
- Montana
- Nebraska
- Nevada
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- North Dakota
- Ohio
- Oklahoma
- Oregon
- Pennsylvania
- Rhode Island
- South Carolina
- South Dakota
- Tennessee
- Texas
- Utah
- Vermont
- Virginia
- Washington
- West Virginia
- Wisconsin
- Wyoming
- Washington D.C.
- Other

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If other, please specify.

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What is your living arrangement?

- With family  
 In a group home or congregate setting  
 Supported independent living (in a house or apartment)  
 Alone  
 Other

If other, please specify.

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How would you rate your overall PHYSICAL health right now?

- Excellent  
 Good  
 Fair  
 Poor

Compared to before the pandemic, my physical health is:

- Worse  
 The same  
 Better

How would you rate your overall MENTAL health right now?

- Excellent  
 Good  
 Fair  
 Poor

Compared to before the pandemic, my MENTAL health is:

- Worse  
 The same  
 Better

Think about the challenges that you had IN THE PAST TWO WEEKS.

Please tell us how your challenges are DIFFERENT NOW compared to BEFORE the COVID pandemic.

	Worse	No Change	Better	N/A (I never did this)
Worrying a lot	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling really sad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a great deal of difficulty when there were changes in routine or schedule	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty being apart from a family member or a loved staff member.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting angry or losing your temper easily	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hurting yourself or others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please share any OTHER difficulties you have had since the COVID-19 pandemic:

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Did you take medication to manage these problems BEFORE the pandemic?

- Yes  
 No

Have any medications to manage these problems CHANGED since before the pandemic?

- Yes  
 No

How have your medications changed?

- Added new medication for MENTAL health (mood/behavior)  
 INCREASED dose of existing medicine  
 DECREASED dose of existing medicine  
 STOPPED medication  
 Other

(Optional): If OTHER,, please explain how your MEDICATIONS have CHANGED during the covid pandemic: \_\_\_\_\_

Please tell us how your services/activities have CHANGED because of the COVID pandemic.

	I continue to do this.	I continue to do this, but LESS because of COVID	I USED to do this, but now I CANNOT because of COVID.	I NEVER did this.
Paid Work/Employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Day programming/Supports in the community	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sports/Exercise (like Special Olympics)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational/Physical/Speech Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental Health Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical Care (Doctor's Visits)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Volunteering	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Socializing with friends or family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recreation/leisure activities (like going to the movies/bowling/hobbies)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Special Education (Individualized Education Plan, IEP, services)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please share additional thoughts about how your services/activities have CHANGED because of the COVID pandemic: \_\_\_\_\_

How much would the following IMPROVE your BEHAVIORAL HEALTH during the pandemic?

	Would not help at all	Would help a little bit	Would help somewhat	Would help very much
Continuous access to a day program or job	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to activities in the community (like shopping, going to the mall, sports)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fewer changes in support staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- |  |                       |                       |                       |                       |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| Access to behavioral therapy   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| More time with friends/family  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| More time outdoors   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Access to religious services (like church, temple, mosque, other spiritual practice) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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Please share anything else that would HELP you DURING the pandemic:

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COMPARED to BEFORE the pandemic:

- |   | less                  | the same              | more                  |
|---|-----------------------|-----------------------|-----------------------|
| How much HELP do you NOW need getting dressed, brushing your teeth, showering, or eating? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| How much difficulty do you have sleeping?   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| How much do you exercise?   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| How much time are you spending watching TV, or other screen time?                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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During the pandemic:

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Have you been able to use video technology such as ZOOM, Skype, FaceTime, or any other video programs to ACCESS activities or services?

- Yes  
 No

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Do you PREFER having MEDICAL APPOINTMENTS in-person or by video?

- In-person  
 Video  
 Other

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If OTHER, please explain:

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Do you PREFER having SERVICES/ACTIVITIES (like day program, job training) in-person or by video?

- In-person  
 Video  
 Other

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If OTHER, please explain:

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How much are you doing VIRTUAL social activities?

- Never  
 Once a month  
 Once a week  
 Every day  
 Other  
 ((For example, Zoom, FaceTime, or other video applications.))

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Do you feel your SOCIAL needs are being met with the virtual options available?  Yes  
 No

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(OPTIONAL) Tell us more about your social needs during the pandemic and how they are/are not being met. \_\_\_\_\_

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Has your WEIGHT changed during the pandemic?  Decreased  
 No change  
 Increased

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How much DIFFICULTY do you have wearing a MASK when you leave the house?  NO difficulty  
 A LITTLE BIT of difficulty  
 A LOT of DIFFICULTY  
 IMPOSSIBLE to wear a mask

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If wearing a mask is difficult, why?  Sensory challenges  
 Anxiety  
 Breathing problems  
 Other

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OTHER: \_\_\_\_\_

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Has difficulty wearing a mask prevented you from participating in ACTIVITIES or being able to access SERVICES?  Yes  
 No

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Have you been diagnosed with COVID-19 since the pandemic began?  Yes  
 No

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If so, were you admitted to a hospital overnight or longer?  Yes  
 No

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If so, did you require a VENTILATOR (breathing machine) to help you breathe during your illness?  Yes  
 No

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Do you have any ongoing health problems as a result of illness from COVID-19?  Yes  
 No

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If yes, ongoing health problems include:  Breathing problems  
 Fatigue/feeling tired  
 Stroke  
 Weakness  
 Walking problems  
 Other

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If other, please specify \_\_\_\_\_

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Is there anything you want to share about your experience being ill with COVID-19? \_\_\_\_\_

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Has a caregiver or family member been diagnosed with COVID-19 since the beginning of the pandemic?  Yes  
 No

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Have you received a vaccine against COVID-19?  Yes  
 No

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If so - when did you receive your first vaccine injection?  
XX/XX/XXXX (please give your best guess if you don't remember the exact date)

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Do you plan to get a COVID vaccine when it becomes available to you?

- Yes
- No

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Why or why not?

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Please share with us any thoughts about how your life has changed since the COVID-19 pandemic.

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Is there anything you would like to tell us about this survey?

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Thank you for taking our survey! We would like to follow up with you in 3 to 6 months. If you are willing, please provide your email. Email will be kept confidential and will only be used for the purpose of the survey.

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E-mail address:

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