

Demographics

See below for a step-by-step video for completing this survey, for a person with IDD

See below for a step-by-step video for completing this survey, for a parent or supporter for a person with IDD.

See below for a step-by-step video for completing this survey, for a parent or supporter of a person with IDD AND a person with IDD yourself.

Please answer the following questions about yourself before you share your health priorities.

Please answer the following questions about yourself and the person you support before you share your health priorities.

YOU Which best describes how you identify or see yourself?

- Asian
- Black or African American
- Hispanic or Latinx/o/a or Chicano/a
- Native American or Alaskan Native
- Native Hawaiian or Pacific Islander
- White

PERSON WHO YOU SUPPORT Which best describes how they identify or see themselves?

- Asian
- Black or African American
- Hispanic or Latinx/o/a or Chicano/a
- Native American or Alaskan Native
- Native Hawaiian or Pacific Islander
- White

YOU Is there another way you describe yourself?
Please describe how you identify:

PERSON WHO YOU SUPPORT Is there another way they describe themselves?
Please describe how they identify:

YOU What is your gender identity?

- Female
- Male
- Non-binary, not exclusively male or female
- Transgender Male / Trans Man
- Transgender Female / Trans Woman
- An identity not listed
- I do not want to say

PERSON WHO YOU SUPPORT What is their gender identity?

- Female
- Male
- Non-binary, not exclusively male or female
- Transgender Male / Trans Man
- Transgender Female / Trans Woman
- An identity not listed
- I do not want to say

YOU Which of the following best represents how you think of yourself?

- Straight or Heterosexual
- Lesbian, Gay or Homosexual
- Bisexual
- Not listed
- Don't know
- Prefer not to say

PERSON WHO YOU SUPPORT Which of the following best represents how they think of themselves?

- Straight or Heterosexual
 Lesbian, Gay or Homosexual
 Bisexual
 Not listed
 Don't know
 Prefer not to say

YOU Do you speak any languages other than English?

- Yes
 No

PERSON WHO YOU SUPPORT Do they speak any languages other than English?

- Yes
 No

YOU Which language is most comfortable for your communication?

- English
 Spanish
 American Sign Language
 Other

PERSON WHO YOU SUPPORT Which language is most comfortable for their communication?

- English
 Spanish
 American Sign Language
 Other

YOU Do you use augmentative or alternative methods to communicate? (e.g., assistive technology, voicer)

- Yes
 No

YOU Please tell us what type of augmentative or alternative method you use to communicate.

PERSON WHO YOU SUPPORT Do they use augmentative or alternative methods to communicate? (e.g., assistive technology, voicer)

- Yes
 No

PERSON WHO YOU SUPPORT Please tell us what type of augmentative or alternative method they use to communicate.

YOU Do you have any of the following conditions? (Please choose all that apply - you can pick more than one)

- Developmental Disability (any lifelong impairment in physical function, learning, language and/or behavior that impact life activities and occurred prior to age 22)
 Intellectual disability (e.g., cognitive disorder)
 Autism Spectrum Disorder (ASD)
 Down syndrome
 Learning disability (e.g., dyslexia, dysgraphia, processing disorder)
 Emotional or mental health diagnosis (e.g., ADHD, bipolar disorder, schizophrenia, OCD, PTSD)
 Physical impairment (e.g., spinal cord injuries, cerebral palsy, epilepsy)
 Sensory impairment (e.g., Deaf, hard of hearing, visually impaired)
 Speech or language impairment (e.g., aphasia, apraxia, stuttering, speech sound disorder, voice disorder)
 Traumatic Brain Injury (TBI)

PERSON WHO YOU SUPPORT Do they have any of the following conditions? (Please choose all that apply - you can pick more than one)

- Developmental Disability (any lifelong impairment in physical function, learning, language and/or behavior that impact life activities and occurred prior to age 22)
- Intellectual disability (e.g., cognitive disorder)
- Autism Spectrum Disorder (ASD)
- Down syndrome
- Learning disability (e.g., dyslexia, dysgraphia, processing disorder)
- Emotional or mental health diagnosis (e.g., ADHD, bipolar disorder, schizophrenia, OCD, PTSD)
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- Sensory impairment (e.g., Deaf, hard of hearing, visually impaired)
- Speech or language impairment (e.g., aphasia, apraxia, stuttering, speech sound disorder, voice disorder)
- Traumatic Brain Injury (TBI)

YOU Other chronic health conditions (Please choose all that apply - you can pick more than one)

- Asthma
- Diabetes
- Cancer
- Obesity (overweight)
- High blood pressure
- Other
- No other chronic health conditions

YOU Please tell us about your other chronic health conditions.

PERSON WHO YOU SUPPORT Other chronic health conditions (Please choose all that apply - you can pick more than one)

- Asthma
- Diabetes
- Cancer
- Obesity (overweight)
- High blood pressure
- Other
- No other chronic health conditions

PERSON WHO YOU SUPPORT Please tell us about their other chronic health conditions.

YOU Are there any other aspects of yourself that you would like to share?

PERSON WHO YOU SUPPORT Are there any other aspects about the person you support that you would like to share?

Please choose the topics that are important to the Person with IDD who you support from your perspective as their caregiver. Choose at least two topics.

Then we will ask you five to ten questions about each topic you chose.

- Physical Health Concerns (for example, heart, lung, or stomach problems)
- Mental Health Concerns (for example, having to do with your mood, thinking, and behaviors)
- Health Services and Coordination (for example, talking to your doctors, paying for health care)
- Lifestyle/Community Living (for example, getting a job, participating in physical activities)
- Caregiving/Supporting people with Disabilities

Please choose the topics that are important to YOU.
Choose at least two topics.

Then we will ask you five to ten questions about each
topic you chose.

- Physical Health Concerns (for example, heart, lung, or stomach problems)
- Mental Health Concerns (for example, having to do with your mood, thinking, and behaviors)
- Health Services and Coordination (for example, talking to your doctors, paying for health care)
- Lifestyle/Community Living (for example, getting a job, participating in physical activities)

Please tell us how important the following topics are to YOU

Cardiovascular and Respiratory Systems (Heart, Blood Vessels, Blood, Lungs) -- brings food and oxygen to your body

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to YOU.

- Blood pressure (too high or too low)
- Cholesterol (when it is too high, a doctor diagnoses this after a blood test)
- Heart problems
- Respiratory related issues (e.g., asthma, COPD, issues from smoking tobacco)
- Stroke
- None of the above

Digestive and Urinary Systems (Mouth, Stomach, Small and Large Intestines, Bladder)--how you get energy from the food you eat and get rid of things that you do not need

Please choose TOP 1, 2, 3 or 4 priorities from the list, that are most important to YOU.

- Bladder problems (e.g., peeing your pants, peeing too often, pain when you pee)
- Bowel problems and GI: Gastrointestinal diseases (e.g., GERD: Gastroesophageal reflux Disease, Crohn's, Celiac, IBS: Irritable bowel syndrome)
- Dental health and hygiene (brushing your teeth, flossing every day, tooth aches)
- Dehydration/hydration (drinking enough water throughout the day)
- Diabetes (a doctor diagnoses this condition)
- Nutrition
- Obesity/overweight/underweight (e.g., bulimia, anorexia. This is diagnosed by a doctor)
- None of the above

Gender Specific (care unique to your gender) & Preventative Care

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to YOU.

- Gender inclusive health education and care across the lifespan (e.g., men's health, women's health, trans health care)
- Prenatal/postnatal care (these are conditions that happen because you are pregnant)
- Preventative care (e.g., cancer screening, well person-check)
- Reproductive care (e.g., birth control, pregnancy testing, menopause, breast cancer screening)
- Sexual health/education/care
- None of the above

How We Interact with the World (Brain, nervous systems, hearing, vision)

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to YOU.

- Alzheimer's disease (a doctor diagnoses this disease)
- Hearing loss (this can include ringing in the ears)
- Mobility issues (balance, getting in and out of a chair, falling)
- Pain
- Seizures
- Vision problems (e.g., short or far sighted, cataracts, floaters)
- None of the above

Immune System- how your body keeps you healthy and fights sickness

Please choose TOP 1, 2, 3 or 4 priorities from the list, that are most important to YOU.

- Arthritis (pain in your joints e.g., your knees, fingers)
- Auto immune conditions (a doctor diagnoses these conditions e.g., Addison disease, Celiac disease - sprue (gluten-sensitive enteropathy), Multiple sclerosis)
- Cancer
- COVID-19
- Immune dysfunction (recurrent experiences of pneumonia, bronchitis, sinus infections, blood disorders and more)
- Neuromuscular conditions (e.g., MS, CP, ALS, Multiple sclerosis)
- Thyroid issues diagnosed by a doctor (e.g., overactive, underactive) can be
- Vaccination access, hesitancy and adherence
- None of the above

General Health Concerns

Please choose TOP 1, 2, 3 or 4 priorities from the list, that are most important to YOU.

- Aging related cognitive decline, functional decline, and health changes (these are changes that happen the older you get, your brain might start to forget things, or it's harder to do things because your body is older)
- Co-occurring conditions specific to people with IDD (e.g., regression, EDS, dysautonomia, PANS/PANDAS)
- Co-occurring conditions that are common in the general population (e.g., metabolic disorder)
- Family health history (family members who have had heart attacks, cancer, strokes)
- Heat health education (heatstroke, heat exhaustion, from being in high temperatures)
- Sleep concerns, including sleep apnea (e.g., not being able to sleep at night because...)
- Medical equipment (e.g., wheelchair, catheter, hospital bed)
- None of the above

Please tell us how important the following topics are to the Person with IDD who You Support

Cardiovascular and Respiratory Systems (Heart, Blood Vessels, Blood, Lungs) -- brings food and oxygen to your body

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to the person with IDD who you support.

- Blood pressure (too high or too low)
- Cholesterol (when it is too high, a doctor diagnoses this after a blood test)
- Heart problems
- Respiratory related issues (e.g., asthma, COPD, issues from smoking tobacco)
- Stroke
- None of the above

Digestive and Urinary Systems (Mouth, Stomach, Small and Large Intestines, Bladder)--how you get energy from the food you eat and get rid of things that you do not need

Please choose TOP 1, 2, 3 or 4 priorities from the list, that are most important to the person with IDD who you support.

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- Preventative care (e.g., cancer screening, well person-check)
- Reproductive care (e.g., birth control, pregnancy testing, menopause, breast cancer screening)
- Sexual health/education/care
- None of the above

How We Interact with the World (Brain, nervous systems, hearing, vision)

Please choose TOP 1, 2, 3 or 4 priorities from the list, that are most important to the person with IDD who you support.

- Alzheimer's disease (a doctor diagnoses this disease)
- Hearing loss (this can include ringing in the ears)
- Medical equipment (e.g., wheelchair, catheter, hospital bed)
- Mobility issues (balance, getting in and out of a chair, falling)
- Pain
- Seizures
- Vision problems (e.g., short or far sighted, cataracts, floaters)
- None of the above

Immune System- how your body keeps you healthy and fights sickness

Please choose TOP 1, 2, 3 or 4 priorities from the list, that are most important to the person with IDD who you support.

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- Vaccination access, hesitancy and adherence
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- Family health history (family members who have had heart attacks, cancer, strokes)
- Heat health education (heatstroke, heat exhaustion, from being in high temperatures)
- Sleep concerns, including sleep apnea (e.g., not being able to sleep at night because...)
- None of the above

**The following mental health concerns affect a person's mood, thinking, and behaviors.
Tell us how important are these listed items for YOU.**

	NOT IMPORTANT _____	A LITTLE IMPORTANT _____	VERY IMPORTANT _____
Feeling positive or happy most of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling sad all the time (for example, depression)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Handling strong feelings of worry or fear all the time (for example, anxiety)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Handling strong feelings of worry or fear for a specific thing/a situation (for example, fear of getting on a bus, speaking in public, flying, being in crowds: phobias)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thinking about something sad or scary that happened to me in the past (for example, ACES: adverse childhood experience, traumatic stress, PTSD: post traumatic stress disorder)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feelings and worries make it hard for me to do the things I want to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thinking about hurting myself or others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling painful emotions after losing someone who has died (for example, feelings of grief and loss)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knowing what is happening and deciding what is the best thing for me to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having ideas for how to help myself when I have strong feelings of worries and fears	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**The following mental health concerns affect a person's mood, thinking, and behaviors.
Tell us how important are these listed items for the person with IDD who you support :**

	NOT IMPORTANT	A LITTLE IMPORTANT	VERY IMPORTANT
Feeling positive or happy most of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling sad all the time (for example, depression)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Handling strong feelings of worry or fear all the time (for example, anxiety)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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Feelings and worries make it hard for me to do the things I want to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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Knowing what is happening and deciding what is the best thing for me to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having ideas for how to help myself when I have strong feelings of worries and fears	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please tell us how important the following topics are to the YOU:

1) Healthcare Coordination: Understanding my needs, making appointments, and going to appointments.

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to YOU

- Making appointments with different doctors and therapies.
- Having someone who can take me to the doctor and therapy appointments.
- Figuring out if I have good and helpful DDD or health services to meet my life goals
- Figuring out what new or different types of services (for example, doctors and therapies, and insurance who pays for my services) can help me when what I have is not working.
- Figuring out how to work with different types of services (for example, behavioral health, aging service, different types of doctors) and people (for example, support coordinators, medical offices).
- None of the above

2) Healthcare Visit: Problems at medical appointments

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to YOU

- Having a doctor spend enough time with me at my appointment
- Getting along with my doctor and having a good relationship
- Seeing my doctor on time so I don't have to wait too long in the waiting room
- Having someone with me at my appointment who knows my health history
- Having someone help understand the medications and treatments at the doctor's office
- Having help with what to do when/if I miss my appointment
- None of the above

3) Communication: Talking and understanding doctors and others

Please choose 1, 2 or 3 things from the list that are most important or interesting to YOU

- Having doctors listen to me when I talk about my problems, and listening to the people who take care of me
- Having a doctor or a specialist try to directly communicate with me, even if I don't speak
- Having a doctor and a specialist who can ask and find right questions and tests that help them figure out how and why I am feeling sick
- Having a doctor explain choices of medicine and treatment, and how they may impact what is important to me in my life
- Having a doctor make sure I understand what steps I should take to get well
- Having a doctor explain and show options for how my lifelong illness, like pain, will be supported/treated.
- None of the above

4) Healthcare System: Problems you might have with insurance and support

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to YOU

- Having a doctor understand my disabilities and how these affect my health
- Having a doctor help figure out why I feel and/or act this way and what may help
- Having a doctor listen to and understand that there are other things making me sick, and it's not just my disability causing the problems.
- Having doctors who work together and care about me as a whole person (for example, my feelings, body, thinking, spirituality, social life), not just focusing on fixing one health condition.
- Having a doctor understand how getting older might change my body and the disability I have
- Having a doctor figure out what to do when there are not enough medicine or treatment options because of things like COVID-19
- None of the above

5) Healthcare System: Problems you might have with insurance and support

Please choose TOP 1 or 2 priorities from the list, that are most important to YOU

- Being able to easily make one-time and scheduled appointments with my doctors and other treatments (for example, physical therapy, counseling)
- Having a lot of changes in my doctors, staff and caregivers
- Understanding what doctors, medications and/or treatments (for example, physical therapy, counseling) are covered by insurance
- Seeing a doctor, a specialist or other medical treatments (for example, physical therapy, counseling) when I live outside of a big city/town
- None of the above

Please tell us how important the following topics are to the Person with IDD who You Support

 1) Healthcare Coordination: Understanding my needs, making appointments, and going to appointments

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to the person with IDD who you support

- Making appointments with different doctors and therapies.
 - Having someone who can take me to the doctor and therapy appointments.
 - Figuring out if I have good and helpful DDD or health services to meet my life goals
 - Figuring out what new or different types of services (for example, doctors and therapies, and insurance who pays for my services) can help me when what I have is not working.
 - Figuring out how to work with different types of services (for example, behavioral health, aging service, different types of doctors) and people (for example, support coordinators, medical offices).
 - None of the above
-

 2) Healthcare Visit: Problems at medical appointments

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to the person with IDD who you support

- Having a doctor spend enough time with me at my appointment
 - Getting along with my doctor and having a good relationship
 - Seeing my doctor on time so I don't have to wait too long in the waiting room
 - Having someone with me at my appointment who knows my health history
 - Having someone help understand the medications and treatments at the doctor's office
 - Having help with what to do when/if I miss my appointment
 - None of the above
-

 3) Communication: Talking and understanding doctors and others

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to the person with IDD who you support

- Having doctors listen to me when I talk about my problems, and listening to the people who take care of me
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 - None of the above
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 4) Healthcare System: Problems you might have with insurance and support

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to the person with IDD who you support

- Having a doctor understand my disabilities and how these affect my health
- Having a doctor help figure out why I feel and/or act this way and what may help
- Having a doctor listen to and understand that there are other things making me sick, and it's not just my disability causing the problems.
- Having doctors who work together and care about me as a whole person (for example, my feelings, body, thinking, spirituality, social life), not just focusing on fixing one health condition.
- Having a doctor understand how getting older might change my body and the disability I have
- Having a doctor figure out what to do when there are not enough medicine or treatment options because of things like COVID-19
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5) Healthcare System: Problems you might have with insurance and support

Please choose TOP 1 or 2 priorities from the list, that are most important to the person with IDD who you support

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- Understanding what doctors, medications and/or treatments (for example, physical therapy, counseling) are covered by insurance
- Seeing a doctor, a specialist or other medical treatments (for example, physical therapy, counseling) when I live outside of a big city/town
- None of the above

Please tell us how important the following topics are to YOU

1) Living in My Community

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to YOU.

- Using a wheelchair/a cane, an iPad/a set of flash cards, and other things that help me do what I like.
- Having staff at home, a day program, therapies, job support, and other things that help my daily activities and being part of a community.
- Having a home that feels safe and comfortable
- Having my own home/apartment, away from my family home
- Having good public transportation, like a bus/van to get to places
- None of the above

2) Changes and Choosing Things for Myself

Please choose TOP 1, 2, 3 or 4 priorities from the list, that are most important to YOU

- NOT having too many (busy/stressful) or too few things in my schedule (boring)
- Trying new things
- Remembering and getting to my appointments/activities on time
- Speaking up for what is important to me
- Having someone help me make important decisions (choices), so that I understand what my choices are and what happens.
- Making small decisions for my daily life
- Making big life plans and decisions (make choices) for when my life changes, like where I live, what friends I keep, how I use my money and who helps me when I need to make choices
- None of the above

3) My Job and How I Can Help in My Community

Please choose TOP 1 or 2 priorities from the list, that are most important to YOU

- Having a job that pays me money
- Learning new things in community classes and/or activities
- Helping others, volunteering
- Being part of a community
- None of the above

4) Healthy Living

Please choose TOP 1, 2, 3 or 4 priorities from the list, that are most important to YOU

- How to choose healthy food
- Opportunities for physical exercise (like biking, jogging, walking, and yoga)
- Staying safe in my life
- Staying safe physically and emotionally in relationships or with other people
- How to have safe sex
- Safely using social media, texting, email and other websites/apps
- Spirituality such as going to church, temple, mosques
- Understanding the risks of cigarettes, alcohol, vaping, and other drugs
- None of the above

5) Relationships

Please choose TOP 1, 2 or 3 priorities from the list,
that are most important to YOU

- Being treated with kindness
- Going out for dates
- Having good friends
- Having romantic/sexual relationships
- Socializing with my friends (in person, through social media, games, phone, computer, and iPad)
- Laughing and having fun in my life
- None of the above

Please tell us how important the following topics are to the Person with IDD who You Support

1) Living in My Community

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to the person with IDD who you support

- Using a wheelchair/a cane, an iPad/a set of flash cards, and other things that help me do what I like.
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- Having a home that feels safe and comfortable
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 - Laughing and having fun in my life
 - None of the above
-

1) Caregiver/Supporters (parents/siblings/other people who provide practical and emotional support)

Please choose TOP 1 or 2 priorities from the list, that are most important to YOU as a caregiver/supporter of a person with a disability:

- Maturing of person with I/DD, adjusting support based on the changing emotional needs of the person
 - Caregiver's own aging, realizing you are no longer able to provide care for the person with I/DD
 - Future care planning, when the family member is no longer available to care for the person with I/DD
 - Options for community living
 - None of the above
-

2) As a Health Advocate

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to YOU as a caregiver/supporter of a person with a disability:

- Addressing the person with a disability's behavioral and mental health support needs from a holistic perspective
 - Education on what to expect with treatment (for example, what they can do and how it may work)
 - Quality and availability of services (for example, having access to services that meet the needs of a person with a disability)
 - Navigating systems and services (for example, having information about and access to services)
 - Trauma informed care (for example, having information and access to trauma informed services)
 - None of the above
-

3) Caring for Self

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to YOU as a caregiver/supporter of a person with a disability:

- Attending to my own needs (for example, being alone, social or outdoor activities, exercise)
 - Eating well
 - Having good insurance and good health care providers who can attend to caregiver physical and emotional wellbeing
 - Knowing which caregiver responsibilities to let go of and when to ask for help
 - Stress management
 - Peer support networks
 - None of the above
-

4) Daily Life

Please choose TOP 1, 2 or 3 priorities from the list, that are most important to YOU as a caregiver/supporter of a person with a disability:

- Keeping the person you support, engaged or entertained
- Having a normal day, without any incidents or lots of appointments
- Getting things done (for example, housework, errands)
- Misplacing your frustration on a person with disabilities due to an unsolvable or difficult situation related to their health or disabilities.
- Support for you (for example, respite)
- None of the above