Function

FOR INFORMATION ONLY - DO NOT SUBMIT

Thank you for completing the first part of the survey! The next several questions will provide us with a more detailed picture of your child.

If your child has not had brain surgery yet, or will not have brain surgery, you do not need to check any boxes in the columns titled "after surgery". Respond only in the columns titled "before surgery".

If your child has had more than one brain surgery to stop seizures, "after surgery" in the questions below refers to any time after the first brain surgery.

Which statement BEST describes your child's current seizures?

◯ several seizures per year
◯ several seizures per month
◯ several seizures per day
◯ several seizures per hour
◯ none that I know of

Please identify your child's current seizure types. Some children may have several seizure types during one seizure event. Check all that apply.

☐ automatisms (such as lip smacking, finger rubbing, chewing)
☐ atonic (sudden loss of muscle tone causing child to go limp and fall down)
☐ clonic (sustained, rhythmic jerking of part or the whole body)
☐ infantile spasms
☐ hyperkinetic (such as thrashing legs, pedaling, or rocking back and forth)
☐ myoclonic (brief, shock-like jerks)
☐ tonic (body, arms, or legs suddenly stiff or tense)
☐ autonomic (such as increased heart rate or blood pressure, sweating, facial flushing)
☐ behavior arrest (movement stops, sometimes called a freeze or pause)
☐ cognitive (such as impaired language, confusion, feeling of deja vu, illusions, or hallucinations)
☐ emotional (such as sudden fear or joy)
☐ sensory (such as tingling or numbness, visual symptoms, smells, sounds)
☐ typical absence (very brief lapse in awareness, sometimes with staring)
☐ atypical absence (some or no lapse in awareness, sometimes with staring. Child may be able to respond a bit)
☐ eyelid myoclonia (rapid blinking or jerks of one or both eyelids, sometimes with eyeball movements)
☐ I don't know/I'm not sure

What anti-seizure pharmaceutical medications is your child taking today? Check all that apply.

- ☐ Rufinamide (Banzel, Inovelon)
- ☐ Primidone (Mysoline)
- ☐ Pregabalin (Lyrica)
- ☐ Phenytoin (Dilantin, Epanutin, Phenytek)
- ☐ Phenobarbital (Phenobarbital)
- ☐ Perampanel (Fycompa)
- ☐ Oxcarbazepine (Oxtellar, Oxtellar XR, Trileptal)
- ☐ Lorazepam (Ativan)
- ☐ Levetiracetam XR (Keppra XR)
- ☐ Levetiracetam (Keppra)
- ☐ Lamotrigine (Lamictal)
- ☐ Lacosamide (Vimpat)
- ☐ Gabapentin (Neurontin)
- ☐ Felbamate (Felbatol)
- ☐ Ezogabine (Potiga)
- ☐ Ethosuximide (Zarontin)
- ☐ Eslicarbazepine Acetate (Aptiom)
- ☐ Divalproex Sodium-ER (Depakote ER)
- ☐ Divalproex Sodium (Depacon, Depakote, Epival)
- ☐ Diazepam (Diastat, Diazepam, Valium)
- ☐ Clonazepam (Epitril, Klonopin, Rivotril)
- ☐ Clobazam (Frisium, Onfi)
- ☐ Carbamazepine-XR (Carbatrol, Tegretol XR)
- ☐ Carbamazepine (Atretol, Carbagen SR, Epitol, Mazepine, Tegretol, Tegrital,Teril, Timonil)
- ☐ ACTH
- ☐ Prednisolone
- ☐ Prednisone
- ☐ Synacthen
- ☐ Tiagabine Hydrochloride (Gabitril)
- ☐ Topiramate (Topamax)
- ☐ Topiramate XR (Qudexy XR, Trokendi XR)
- ☐ Valproic Acid (Convulex, Depakene, Depakine, Orfiril, Valporal, Valprosid)
- ☐ Vigabatrin (Sabril)
- ☐ Brivaracetam
- ☐ Epidiolex
- ☐ Other
- ☐ None
- ☐ I don't know/I'm not sure/I don't remember

What non-pharmaceutical drugs, interventions, or therapies is your child taking today in an attempt to stop seizures?

- ☐ ketogenic diet
- ☐ modified Atkins diet
- ☐ cannabidiol (CBD)
- ☐ Omega-3 oils (such as cod liver oil, fish oil, flaxseed oil, mustard oil, soybean oil, walnut oil)
- ☐ Other
- ☐ I prefer not to answer
- ☐ none

Other: _____

Please identify all the professionals that have followed your child.

	BEFORE SURGERY	AFTER SURGERY
Neurosurgeon	☐	☐
Neurologist	☐	☐
Epileptologist (neurologist who specializes in epilepsy)	☐	☐
Pediatrician	☐	☐
Developmental pediatrician	☐	☐
Orthopedic surgeon	☐	☐
Orthotist	☐	☐
Physiatrist	☐	☐
Rehabilitation doctor	☐	☐
Psychologist	☐	☐
Neuropsychologist	☐	☐
Psychiatrist	☐	☐
Optometrist	☐	☐
Ophthalmologist	☐	☐
Neuro-Opthalmologist	☐	☐
Physical therapist	☐	☐
Occupational therapist	☐	☐
Speech therapist	☐	☐
Audiologist	☐	☐
Social worker	☐	☐
Behavioral therapist	☐	☐
Endocrinologist	☐	☐
Other	☐	☐

Other (describe): _____

What private services has or does your child receive? Include all services, even those your child does not receive anymore. DO NOT include services your child receives in school (these services will be covered in another question).

	BEFORE SURGERY	AFTER SURGERY
Physical therapy	☐	☐
Occupational therapy	☐	☐
Speech therapy	☐	☐
Behavior therapy	☐	☐
Feeding therapy	☐	☐
Hearing or listening therapy	☐	☐
Orientation and mobility training	☐	☐
Vocational (job) training	☐	☐
Vision therapy	☐	☐
Psychological services, such as mental health counseling	☐	☐
Intensive reading instruction	☐	☐
None of the above	☐	☐
Other	☐	☐

Other: _____

HYDROCEPHALUS

Has your child been diagnosed with hydrocephalus?

◯ Yes
◯ No

Are you concerned that your child may develop hydrocephalus in the future?

◯ Not at all
◯ A little
◯ Somewhat
◯ Quite a bit
◯ Very

When was your child diagnosed with hydrocephalus?

_____
(If don't know the exact date, enter the approximate date.)

What symptoms of hydrocephalus did your child have prior to diagnosis? Check all that apply.

- ☐ Headache
- ☐ Nausea
- ☐ Vomiting
- ☐ Excessive sleepiness
- ☐ Eyes fixed downward (known as "sunsetting")
- ☐ Eye deviation (one eye pointing up, down, in, or out)
- ☐ Irritability
- ☐ Change in personality
- ☐ Decline in school performance
- ☐ Decline in memory, cognition, or other thinking skills
- ☐ Change or decline in previously acquired skills, such as walking or talking
- ☐ Blurred vision
- ☐ Hearing complaints
- ☐ Gait changes
- ☐ Seizures
- ☐ Poor appetite
- ☐ Other

Other (please describe):

What tests were used to diagnose hydrocephalus?

- ☐ CT scan
- ☐ MRI
- ☐ lumbar (spinal) tap
- ☐ intracranial pressure monitoring
- ☐ other

Which procedures or interventions have been used to attempt to resolve hydrocephalus? Check all that apply:

- ☐ Temporary insertion of extraventricular drain
- ☐ Spinal (lumbar) tap
- ☐ Placement of ventriculoperitoneal (VP) shunt
- ☐ Placement of ventricularterial (VA) shunt
- ☐ Placement of ventriculolumbar (VL) shunt
- ☐ Diuretics (such as Diamox)
- ☐ Steroids (such as Decadron)
- ☐ Cranial expansion surgery
- ☐ Choroid plexus destruction
- ☐ Other
- ☐ I don't know/I'm not sure

How many shunt surgeries has your child had?

- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4
- ◯ 5
- ◯ more than 5

Are you concerned about your child's need for future shunt surgery?

◯ Not at all
◯ A little
◯ Somewhat
◯ Quite a bit
◯ Very

Are you concerned that your child's shunt may become blocked?

◯ Not at all
◯ A little
◯ Somewhat
◯ Quite a bit
◯ Very

Are you concerned that your child's shunt may become infected?

◯ Not at all
◯ A little
◯ Somewhat
◯ Quite a bit
◯ Very

HEADACHE

How often does your child have headaches?

☐ Never
☐ Sometimes
☐ Often
☐ Daily
☐ I don't know/I'm not sure due to communication barriers

30% Complete

VISION

Please identify your child's vision issues:

	BEFORE SURGERY	AFTER SURGERY
Amblyopia (reduced vision/loss of vision in one eye)	☐	☐
Strabismus (one or both eyes wander in, out, up, or down)	☐	☐
Nystagmus (eyes make repetitive, uncontrolled movements)	☐	☐
Smooth pursuit disorder (cannot track objects well)	☐	☐
Cortical vision impairment	☐	☐
Homonymous hemianopsia (loss of half the visual field) opposite the side of surgery	☐	☐
Homonymous upper quadrinopia opposite the side of surgery (loss of the top quarter of the visual field)	☐	☐
Homonymous lower quadrinopia opposite the side of surgery (loss of the bottom quarter of the visual field)	☐	☐
Nasal hemianopsia opposite the side of surgery (loss of half the visual field on the inside of both eyes)	☐	☐
Papilledema (optic nerve swelling)	☐	☐
Pale optic nerve	☐	☐
Optic nerve atrophy	☐	☐
Other	☐	☐
I don't know/I'm not sure	☐	☐
None of the above	☐	☐

Other (describe):

What eye treatments, surgeries, or interventions has your child received?

	BEFORE SURGERY	AFTER SURGERY
Eye muscle surgery	☐	☐
Eye patching	☐	☐
Botox injections to the eye muscles	☐	☐
Eye exercises	☐	☐
Prism glasses	☐	☐
Vision therapy	☐	☐
None	☐	☐
Other	☐	☐

Other (please describe): _____

HEARING AND LISTENING

Please identify your child's hearing and listening issues before and after surgery.

	BEFORE SURGERY	AFTER SURGERY
Did not pass hearing test	☐	☐
Overly sensitive to certain sounds	☐	☐
Seems overwhelmed in loud environments	☐	☐
Is unable to pay attention to a conversation if there is too much noise in the room	☐	☐
Is sometimes unable to identify where sounds are coming from	☐	☐
Uses noice cancelling or similar headphones when out in public or in a noisy environment	☐	☐
No hearing or listening issues	☐	☐

Has your child been diagnosed with any of the following?

	DIAGNOSED BEFORE SURGERY	DIAGNOSED AFTER SURGERY
Conductive hearing loss	☐	☐
Sensori-neural hearing loss	☐	☐
Mixed hearing loss (conductive and sensori-neural)	☐	☐
Central auditory processing impairment	☐	☐
Other	☐	☐
None of the above	☐	☐
I have not sought a diagnosis for my child from a hearing professional	☐	☐

EATING AND DRINKING

Which statement BEST describes how your child eats in the last month?

◯ My child is able to feed himself/herself like his/her typically-developing peers (may include breast or bottle feeding where age appropriate)
◯ My child has some difficulty feeding himself/herself
◯ My child can self-feed some foods, but otherwise requires assistance to eat
◯ My child requires almost total assistance to feed
◯ My child requires a nasogastric tube for nutrition
◯ My child requires a gastric tube for nutrition

Which statement best describes how your child drinks in the last month?

◯ My child drinks like his/her typically-developing peers (may include breast or bottle feeding where age appropriate)
◯ My child can drink from a cup, but has difficulty sipping through a straw
◯ My child can drink from a straw, but has difficulty sipping from a cup
◯ My child cannot drink from a straw or cup

Has your child exhibited any of the following? Check all that apply.

	BEFORE SURGERY	AFTER SURGERY
Avoids foods that most children the same age enjoy	☐	☐
Has an extremely limited list of foods he or she will eat (under 10)	☐	☐
Craves certain tastes	☐	☐
Becomes agitated over an unusual taste	☐	☐
Gags or gets nauseated easily	☐	☐
Prefers very spicy or hot foods	☐	☐
Strongly objects to certain textures or food	☐	☐
Doesn't like foods that are too hot or too cold	☐	☐
None of the above	☐	☐

Please describe any other feeding issues your child had before or after surgery:

60% Complete

SLEEP HABITS

How long does it take for your child to fall asleep in the evening after you put him/her to bed? (answer in hours)

◯ 30 minutes or less
◯ 30 minutes to 1 hour
◯ 1 1/2 hours
◯ 2 hours
◯ more than 2 hours

How many hours does your child stay asleep at night? (answer in hours)

◯ 1
◯ 2
◯ 3
◯ 4
◯ 5
◯ 6
◯ 7
◯ 8
◯ 9
◯ 10
◯ More than 10

Which statement best describes how your child's sleeping patterns have affected you in the last month?

◯ My child's sleeping patterns have not affected me at all this last month.
◯ There were a few days last month when my child's sleeping patterns had a negative effect on my sleep.
◯ There were several days last month when my child's sleeping patterns had a negative effect on my sleep.
◯ Almost every day last month, my child's sleeping patterns had a negative effect on my sleep.

If your child did not sleep well at any time after surgery, please describe:

YOU'RE DOING A GREAT JOB!

DO YOU NEED A BREAK? YOU CAN HIT SAVE AT ANY TIME AND RETURN WITHIN THE NEXT 30 DAYS.

SPEECH AND LANGUAGE

At what age did your child begin to babble (articulate sounds, but not words)?

◯ 6-8 months
◯ 9-11 months
◯ 1-1.5 years
◯ 2 years or more
◯ Never
◯ Child too young to babble
◯ I don't know, I don't remember

At what age did your child speak his/her first words?

◯ 6-8 months
◯ 9-11 months
◯ 1-1.5 years
◯ 1.6 - 2 years
◯ 2.6 - 3 years
◯ 3 - 3.5 years
◯ 4 - 4.5 years
◯ 4.6 - 5 years
◯ 5.1 or more years
◯ Child too young to speak words
◯ None of the above
◯ I don't know/I don't remember

At what age did your child start speaking in sentences (3 or more words)

◯ 2.1 - 2.5 years
◯ 2.6 - 3 years
◯ 3.1 - 3.5 years
◯ 3.6 - 4 years
◯ 4.1 - 4.5 years
◯ 4.6 - 5 years
◯ 5.1 or more years
◯ Child is too young to speak in sentences
◯ None of the above
◯ I don't know/I don't remember

In this question, we use the word "speech" to describe the ability to express thoughts and feelings by articulating sounds. Which statements describe your child's speech in the last month? Check all that apply.

- ☐ Speaks clearly and age appropriately
- ☐ Speaks, but not clearly or age appropriately
- ☐ Speaks, but uses only a few words
- ☐ Vocalizes and/or uses distinct vocalizations, but few or no words
- ☐ Uses an augmentative/alternative communication device (AAC) as the primary way to communicate his/her needs to others
- ☐ Uses gestures, eye gaze, facial expressions, and other behaviors as as the primary way to communicate his/her needs to others
- ☐ Uses sign language as the primary way to communicate his/her needs to others
- ☐ None of the above
- ☐ Child is too young to speak
- ☐ I don't know/I'm not sure

What languages does your child speak?

What languages does your child understand?

Which statements describe your child's conversations with others? Please check all that apply.

- ☐ My child converses with others like his/her typically-developing peers.
- ☐ My child is not interested in social interactions
- ☐ My child often takes over a conversation or goes off topic
- ☐ My child has difficulty making inferences and understanding things that are implied
- ☐ My child does not understand how to properly greet people, request information, or gain attention
- ☐ My child is often overly literal and does not understand riddles and sarcasm
- ☐ My child has trouble understanding nonverbal communication, such as facial expressions
- ☐ Child is too young to converse with others
- ☐ None of the above

SELF CARE

Which statement best describes your child's toilet training?

- ◯ Is potty trained for bowel movements (feces) and bladder (urine)
- ◯ Is potty trained for bowel movements (feces), but not bladder (urine)
- ◯ My child is toilet trained for bladder (urine), but not bowel (feces)
- ◯ My child is not toilet trained

At what age was your child toilet trained for urine (bladder)?

_____
(Answer in years)

At what age was your child toilet trained for feces (bowel)?

_____
(Answer in years)

Did your child get constipated before or after surgery?

	BEFORE SURGERY	AFTER SURGERY
Yes, several times per week	☐	☐
Yes, several times per month	☐	☐
Yes, but not often	☐	☐
No	☐	☐

How old was your child when you first noticed that he/she was getting constipated often?
(Answer in years)

◯ 1
◯ 2
◯ 3
◯ 4
◯ 5
◯ 6
◯ 7
◯ 8
◯ 9
◯ 10
◯ 11
◯ 12
◯ 13
◯ 14
◯ 15
◯ 16
◯ 17

MOBILITY

What can your child do if needed or asked?

Please read through the list first. You can answer "all of the above" or "none of the above" at the end if accurate. Otherwise, answer for the individual skills.

	BEFORE SURGERY	AFTER SURGERY	TOO YOUNG TO DO
Run unassisted	☐	☐	☐
Run assisted	☐	☐	☐
Walk unassisted	☐	☐	☐
Walk assisted	☐	☐	☐
Stand unassisted	☐	☐	☐
Stand assisted	☐	☐	☐
Sit unassisted	☐	☐	☐
Sit assisted	☐	☐	☐
Bear weight on legs	☐	☐	☐
Bottom scoot	☐	☐	☐
Classic hands and knees crawl (where the child bears weight on his/her hands and knees, and moves one arm and the opposite knee forward at the same time)	☐	☐	☐
Rolling crawl (where the child rolls to get to a location)	☐	☐	☐
Combat or belly crawl (where the child moves his/her body forward while dragging his/her belly against the floor)	☐	☐	☐
Control his/her head position	☐	☐	☐
Control his/her torso position	☐	☐	☐
All of the above	☐	☐	☐
None of the above	☐	☐	☐

Does your child use a wheelchair or adaptive stroller??

☐ Never
☐ Sometimes if fatigued
☐ Often if fatigued
☐ A wheelchair/adaptive stroller is his/her primary means of mobility. He/she is able to use the wheelchair without help from others.
☐ A wheelchair/adaptive stroller is his/her primary means of mobility. He/she requires another person to push the wheelchair/adaptive stroller.

HORMONES AND AUTONOMIC FUNCTION

Does your child exhibit any of the following?

	BEFORE SURGERY	AFTER SURGERY
Excessive weight gain	☐	☐
Excessive weight loss	☐	☐
Excessive urination	☐	☐
Infrequent urination	☐	☐
Excessive thirst	☐	☐
Lack of thirst	☐	☐
Excessive hunger	☐	☐
Lack of hunger	☐	☐
Has breast buds	☐	☐
Has breasts	☐	☐
Has pubic hair	☐	☐
Has armpit hair	☐	☐
Has body odor	☐	☐
Has acne/pimples	☐	☐
Testicles have started to grow	☐	☐
Testicles have started to drop	☐	☐
Penis has started to grow	☐	☐
Menstrual cycle started	☐	☐
Menstrual cycle is irregular or has stopped	☐	☐
Has nausea often	☐	☐
Vomits often	☐	☐
Has diarrhea often	☐	☐
Craves salty foods	☐	☐
Baseline heart rate is low	☐	☐
Baseline heart rate is high	☐	☐
Baseline body temperature is low	☐	☐
Baseline body temperature is high	☐	☐
Unexplained fevers	☐	☐

Has your child been diagnosed by a medical professional with any of the following? Check all the apply.

	DIAGNOSED BEFORE SURGERY	DIAGNOSED AFTER SURGERY
Cushing's syndrome	☐	☐
Adrenal insufficiency	☐	☐
Hypothyroidism	☐	☐
Hyperthyroidism	☐	☐
Hashimoto's disease	☐	☐
Growth hormone deficiency	☐	☐
Syndrome of inappropriate anti-diuretic hormone (SIADH)	☐	☐
Central diabetes insipidus	☐	☐
Delayed adrenarche	☐	☐
Delayed puberty	☐	☐
Early (precocious) puberty)	☐	☐
Early (precocious) adrenarche	☐	☐
Hypopituitarism	☐	☐
Polycistic ovary syndrome	☐	☐

Does your child exhibit any of the following?

	BEFORE SURGERY	AFTER SURGERY
Flushing or blotching of the face or extremities	☐	☐
Fast heart rate	☐	☐
High blood pressure	☐	☐
Unexplained sweating	☐	☐
Elevated body temperature	☐	☐
Trouble breathing	☐	☐
Increased salivation or increased mucus production and congestion	☐	☐
Increased gastric secretions	☐	☐
Shaking or tremoring	☐	☐
Changes in blood sugar	☐	☐
Extreme irritability	☐	☐
Sweats excessively	☐	☐
Does not sweat	☐	☐
Overheats easily	☐	☐
Circulation problems	☐	☐
Has high pain threshold	☐	☐
Red cheek/cheeks or neck that are warm to the touch	☐	☐
Red ear/ear flushing that is warm to the touch	☐	☐
Discolored or purple finger nails, hands, arms, feet, or legs that are cold to the touch	☐	☐
Does not feel external temperature	☐	☐
Has experienced autonomic (neuronal) storming	☐	☐
Has chronic dry eyes	☐	☐

ORTHOPEDICS

Does your child have any of the following conditions?

	DIAGNOSED BEFORE SURGERY	DIAGNOSED AFTER SURGERY
Monoplegia/monoparesis (only one limb is affected)	☐	☐
Diplegia/diparesis (legs are affected, but arms have normal function)	☐	☐
Hemiplegia/hemiparesis (arm and leg of one side of the body are affected)	☐	☐
Paraplegia/paraparesis (lower half of the body, including both legs, affected)	☐	☐
Triplegia/triparesis (three limbs are affected)	☐	☐
Double hemiplegia/double hemiparesis (all four limbs are involved, but one side of the body is more affected than the other)	☐	☐
Tetraplegia/tetraparesis (all four limbs are involved, but three limbs are more affected than the fourth)	☐	☐
Quadriplegia/quadriparesis (all four limbs are affected)	☐	☐
Pentaplegia/pentaparesis (all four limbs are involved, with neck and had paralysis accompanied by eating and breathing complications)	☐	☐
None of the above	☐	☐
I don't know/I'm not sure	☐	☐

Which statement BEST describes how your child uses his/her hand affected by hemiparesis?

◯ Does not use
◯ Uses as a stabilizing weight only
◯ Can hold onto object placed in hand
◯ Can hold onto object and stabilize it for use by other hand
◯ Can actively grasp object and hold it weakly
◯ Can actively grasp object and stabilize it well
◯ Can actively grasp object and then manipulate it against other hand
◯ Can perform bimanual activities easily and occasionally uses the affected hand spontaneously
◯ Uses affected hand completely independently without reference to the other hand

Has your child been diagnosed with any of the following?

	DIAGNOSED BEFORE SURGERY	DIAGNOSED AFTER SURGERY
Arthritis (inflammation/stiffness of the joints)	☐	☐
Osteoporosis (brittle/fragile bones)	☐	☐
Osteopenia (weak bones)	☐	☐
Scoliosis (curvature of the spine)	☐	☐

Please identify the orthopedic procedures or devices your child has had or used. Check all that apply.

	BEFORE SURGERY	AFTER SURGERY
Surgery to the muscles, bones, or nerves of the body	☐	☐
Wears orthotic devices (such as AFOs or braces) on the foot/feet, legs, or hips	☐	☐
Wears orthotic devices (such as splints) on the hand, wrist, arm, or shoulder	☐	☐

Please describe the surgeries to the bones, muscles, or nerves of the body, including approximate dates: _____

SOCIAL SKILLS AND BEHAVIORS

Please indicate how the following statements describe your child. Answer the best way you can.

	Often	Sometimes	Infrequently	Never
Outgoing and friendly	○	○	○	○
Makes good eye contact with other people and children	○	○	○	○
Repeats words or actions	○	○	○	○
Impulsive	○	○	○	○
Aware of danger	○	○	○	○
Requires supervision for safety reasons	○	○	○	○
Takes things literally	○	○	○	○
Exhibits compulsive behaviors	○	○	○	○
Makes repetitive movements	○	○	○	○
Chews on a pacifier, "Chewie" tube, washcloth, or similar object	○	○	○	○
Craves chewing, biting, or mouthing objects	○	○	○	○
Flaps his or her arms	○	○	○	○
Bites self or others	○	○	○	○
Interested in different activities	○	○	○	○
Anxious	○	○	○	○
Aware of others' emotions	○	○	○	○
Plays with other children	○	○	○	○
Sits still	○	○	○	○
Will run away if unsupervised	○	○	○	○
Talks excessively	○	○	○	○
Interrupts conversations	○	○	○	○
Overly emotional	○	○	○	○
Laughs at inappropriate times	○	○	○	○
Naive	○	○	○	○
Screams at inappropriate times	○	○	○	○
Cries at inappropriate times	○	○	○	○
Hostile or violent towards self	○	○	○	○
Hostile or violent towards others	○	○	○	○

SCHOOL AND LEARNING

Does your child have any of the following?

Please check all that apply.

	BEFORE SURGERY	AFTER SURGERY
Apraxia of speech (child unable to move lips or tongue to the right place to say sounds, even though muscles of the mouth are not weak)	☐	☐
Aphasia (impaired spoken language expression or comprehension)	☐	☐
Dysarthria (speech disorder caused by muscle weakness of the face, lips, tongue, or throat)	☐	☐
Selective mutism (inability to speak and communicate effectively in select social settings, such as school)	☐	☐
Echolalia (meaningless repetition of another person's spoken words)	☐	☐
Palilalia (meaningless repetition of child's own words)	☐	☐
Stuttering (involuntary sound repetition, abnormal hesitation, or pausing before speech)	☐	☐
Dyslexia (difficulty reading despite normal intelligence)	☐	☐
Dysgraphia (impaired handwriting)	☐	☐
Dyscalculia (difficulty learning or comprehending math despite normal intelligence)	☐	☐
Specific learning disability (difficulty speaking, listening, reading, writing, spelling, reasoning, organizing information, or doing math, despite normal intelligence)	☐	☐
Intellectual impairment (IQ 70 or under)	☐	☐
Autism spectrum disorder or Asperger's syndrome	☐	☐

Attention deficit disorder (persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development)	☐	☐
Agnosia (inability to recognize certain objects, persons, or sounds)	☐	☐
Amnesia (wholly or partially lost memory)	☐	☐
Depression (feelings of severe despondency and dejection)	☐	☐
Anxiety (excessive uneasiness and apprehension, typically with compulsive behavior or panic attacks)	☐	☐
Obsessive-compulsive disorder (uncontrollable, reoccurring thoughts (obsessions) and behaviors (compulsions) that he or she feels the urge to repeat over and over)	☐	☐
Post-traumatic stress disorder (persistent mental and emotional stress occurring as a result of injury or severe psychological shock)	☐	☐
Generalized anxiety disorder (feels extremely worried or feel nervous about these and other things-even when there is little or no reason to worry about them)	☐	☐
Anorexia nervosa (obsessive desire to lose weight by refusing to eat)	☐	☐
Bulimia (distortion of body image and an obsessive desire to lose weight, in which bouts of extreme overeating are followed by depression and self-induced vomiting, purging, or fasting)	☐	☐
Binge-eating disorder (consumption of large quantities of food in a short period of time)	☐	☐

Other	☐	☐
I don't know/I'm not sure	☐	☐
None of the above	☐	☐

Other (please describe):

How would you describe your child's cognitive ability?

◯ Above average
◯ Average
◯ Mildly impaired
◯ Moderately impaired
◯ Significantly impaired

Does your child have an Individual Education Plan ("IEP")?

◯ Yes
◯ No
◯ I don't know

Does your child have a "504" plan?

◯ Yes
◯ No
◯ I don't know

Which statement BEST describes your experience with the IEP process?

◯ Easy and straightforward
◯ Somewhat complicated, but manageable
◯ Complicated and overwhelming

Which statement BEST describes your child's current school?

◯ Public school or charter school
◯ Private school and tuition is paid by my child's public school district
◯ Private school and tuition is paid by a person (such as you, your spouse, or a grandparent)
◯ Home school
◯ My child is too young to attend school
◯ I don't know

Which statement BEST describes your child's current educational placement?

◯ My child is taught in a general education classroom/s all day
◯ My child is taught in a special education classroom or resource room less than 40% of the day, and the rest of the time is spent in a general education classroom/s.
◯ My child is taught in a special education classroom or resource room more than 40% of the day.
◯ My child attends a separate special education day school (such as a separate school that specializes in teaching students with learning disabilities, behavioral challenges, mental health challenges, or intellectual disabilities)
◯ My child is taught in a residential placement (a facility in which my child lives at the school site)
◯ My child is educated by the school district in my home, a residential health facility, or a hospital due to a temporary but extended illness or disability
◯ I don't know/I'm not sure

Which statement BEST describes your child's current reading ability as compared to typically-developing children of the same age?

◯ My child's reading skills are advanced for his/her age
◯ My child reads appropriately for his/her age
◯ My child has mild challenges in reading
◯ My child has moderate challenges in reading
◯ My child has significant challenges in reading
◯ My child cannot read
◯ My child is too young to read

Has your child received reading intervention or tutoring outside of school?

◯ Yes
◯ No

Describe the program, when your child attended, and how often:

Which statement best describes your child's current mathematics ability as compared to typically-developing children of the same age?

◯ My child's math skills are advanced for his/her age
◯ My child's math skills are appropriate for his/her age
◯ My child has mild challenges in math
◯ My child has moderate challenges in math
◯ My child has significant challenges in math
◯ My child cannot do math
◯ My child is too young to do math

In the last four weeks, what services did your child receive in school?

(If your child has been out of school for several weeks, such as for vacation, answer for the most recent full four weeks of school)

☐ Audiology
☐ Adaptive physical education
☐ Counseling services (including vocational counseling)
☐ Interpreting services
☐ Medical services for diagnostic or evaluation purposes
☐ Occupational therapy
☐ Orientation & mobility services
☐ Parent counseling and training
☐ Physical therapy
☐ Psychological services, such as mental health counseling
☐ Recreation (including therapeutic recreation)
☐ Speech-language pathology services
☐ School health services and school nurse services
☐ Social work services in schools
☐ Transportation
☐ Vision services (from a Teacher of the Visually Impaired)
☐ Intensive reading instruction
☐ Personal aide (dedicated to the child at all times)
☐ Personal nurse (dedicated to the child at all times)
☐ Other
☐ I don't know/I'm not sure

Other (please describe):

Which diploma is your child on track to receive upon graduating from high school? (Skip this question if your child is not in high school)

◯ Standard diploma
◯ Certificate of completion
◯ Other
◯ I don't know

In your opinion, will your child be able to live independently as an adult?

◯ It is too early to tell
◯ My child will be able to live independently as an adult
◯ My child will be able to live independently as an adult, with some support
◯ My child will be able to live independently as an adult, with moderate supports
◯ My child will be able to live independently as an adult, with significant supports
◯ My child will not be able to live independently as an adult
◯ I don't know

In your opinion, will your child be able to be gainfully employed as an adult?

(Gainful employment is defined here as a job where the employee receives steady work and payment from the employer and receives enough income to support oneself.)

◯ It is too early to tell
◯ My child will be able be gainfully employed as an adult
◯ My child will not be able to be gainfully employed as an adult
◯ I don't know

What is your current level of concern about the following?

	Not at all	A little	Somewhat	Quite a bit	Very
Your child's self-care skills (such as bathing, dressing, cooking)	◯	◯	◯	◯	◯
Your child's ability to maintain friendships	◯	◯	◯	◯	◯
Your child's ability to play sports	◯	◯	◯	◯	◯
Your child's ability to meaningfully participate in social or recreational activities	◯	◯	◯	◯	◯
Your child's behaviors	◯	◯	◯	◯	◯
Your child's ability to learn how to drive	◯	◯	◯	◯	◯
Your child's sexual health/relationships in adulthood	◯	◯	◯	◯	◯
Your child's housing/future living arrangements in adulthood	◯	◯	◯	◯	◯
Your child's future education (such as college, trade school)	◯	◯	◯	◯	◯

Your child's ability to live alone as an adult	○	○	○	○	○
Your child's ability to find a career	○	○	○	○	○
Your child's ability to take care of a family in the future	○	○	○	○	○

80% Complete

YOU'RE ALMOST THERE!

BUT IF YOU WANT TO TAKE A BREAK, SAVE NOW AND COME BACK WITHIN THE NEXT 30 DAYS.

NEXT SURVEYS - AGE LIMIT

Respond to the next surveys ONLY if your child is age 5 - 17.

If your child is younger than age 5, leave the questions blank and click "SUBMIT" at the end of each questionnaire.