St. Jude Children's Research Hospital
ALSAC • Danny Thomas, Founder
Finding cures. Saving children.

SJLIFE

Behavior Survey
5-10 Years of Age Parent Report

Finding cures. Saving children.

The questions in this booklet relate to:

Name

Person completing this questionnaire is:

percomp text

Your relationship:

2 ☐ Parent 3 ☐ Other: percode coded

relation

Today's date: ☐☐ / ☐☐ / ☐☐☐☐
m m d d y y y y
datecomp

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SJLIFEID STUDYNAME Please! Do not mark below this line MRN

Survey #311

2640297178

11/01/2021 09:41:05 AM

SCHOOL HISTORY

A1. Is your child currently in school? schoolyn

1 ☐ Yes — *If yes, what grade is he/she in?* ☐☐ schoolgr

2 ☐ No — *If no, please explain.* noschool text

A2. What is the highest grade or level of schooling that your child's mother has completed? gradem

1 ☐ 1 - 8 years (grade school)
2 ☐ 9 - 12 years (high school), but did not graduate
3 ☐ Completed high school/GED
4 ☐ Training after high school, other than college
5 ☐ Some college
6 ☐ College graduate
7 ☐ Post-graduate level
9 ☐ Not Applicable
10 ☐ Unknown
8 ☐ Other — *Specify.* grdmspe text

A3. What is the highest grade or level of schooling that your child's father has completed? gradef

1 ☐ 1 - 8 years (grade school)
2 ☐ 9 - 12 years (high school), but did not graduate
3 ☐ Completed high school/GED
4 ☐ Training after high school, other than college
5 ☐ Some college
6 ☐ College graduate
7 ☐ Post-graduate level
9 ☐ Not Applicable
10 ☐ Unknown
8 ☐ Other — *Specify.* grdfspe text

Continue on next page.

Please! Do not mark below this line

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A4. In school was your child ever in any of the following programs? *(Mark all that apply)*

	2 No	1 Yes	3 Not sure
Advanced placement or talented program? adplc	☐	☐	☐
Homebound education (instruction at home by a school teacher) for at least one school year? homed	☐	☐	☐
Learning disabled or special education program? speced	☐	☐	☐

If no, skip to A6.

If yes, was he/she in the program because of. . .

a. Missed school. speced_a	☐	☐	☐
b. Low scores on tests. speced_b	☐	☐	☐
c. Problems learning or concentrating. speced_c	☐	☐	☐
speced_read i. In Reading?	☐	☐	☐
speced_math ii. In Math?	☐	☐	☐
speced_write iii. In Writing?	☐	☐	☐
d. Emotional or behavioral problems speced_d	☐	☐	☐

A5. If your child was in a learning disabled or special education program, what grades was he/she in at that time? *(Mark all that apply)* specprog

- ☐ Pre-K specprog_prek
- ☐ K specprog_k
- ☐ 1st specprog_1
- ☐ 2nd specprog_2
- ☐ 3rd specprog_3
- ☐ 4th specprog_4
- ☐ 5th specprog_5
- ☐ 6th specprog_6

A6. Has your child ever . . .

	2 No	1 Yes	3 Not sure
a. Attended summer school? smrsch	☐	☐	☐
b. Repeated a grade? repgrd	☐	☐	☐
c. Skipped a grade? skpgrd	☐	☐	☐
d. Taken adaptive physical education? adappe	☐	☐	☐
e. Been suspended from school? suspend	☐	☐	☐
f. Been expelled from school? expelled	☐	☐	☐
g. Been physically bullied? phybully	☐	☐	☐
h. Been emotionally bullied? emotbully	☐	☐	☐
i. Bullied others? bully	☐	☐	☐
j. Been socially isolated by classmates? socisol	☐	☐	☐
k. Engaged in self harm? selfharm	☐	☐	☐
l. Engaged in dangerous or risky internet behavior? riskyint	☐	☐	☐

A7. Is your child currently receiving . . .

	2 No	1 Yes	3 Not sure
a. Physical therapy? phythrp	☐	☐	☐
b. Occupational therapy? occthrp	☐	☐	☐
c. Speech therapy? sphthrp	☐	☐	☐
d. Counseling? counseling	☐	☐	☐
e. Services via 504 plan? srvc504	☐	☐	☐
f. Services via IEP? srvciep	☐	☐	☐
g. Services for sensory impairment (vision/hearing)? srvcsnsry	☐	☐	☐

A8. Has your child ever received neuropsychological/ psychoeducational assessment (also known as "testing")? npsytst

- 2 ☐ No → *Go to Question B1 on next page.*
- 3 ☐ Not sure
- 1 ☐ Yes

A8a. Where did he/she get tested?

npsytst_loc text

A8b. How many years has it been since your child's last testing took place? ☐☐ years

npsytst_yrs

Please! Do not mark below this line

INSURANCE

Health Insurance

B1. Have you ever had difficulty obtaining health insurance for your child because of his/her health history? hltins

2 ☐ No

1 ☐ Yes

B2. Does your child currently have health insurance coverage? hltcov

3 ☐ Non U. S. resident → *Go to C1.*

2 ☐ No → *Go to C1.*

1 ☐ Yes

B3. How is this insurance provided? insprv
(Mark all that apply)

☐ Through parent's place of employment insprv_emp

☐ Through parent's policy insprv_par

☐ Through a policy you have purchased for your child insprv_sel

☐ Affordable Care Act (Obama Care) insprv_aca

☐ Medicaid or other public assistance program insprv_pub

☐ Medicare insprv_med

☐ Military dependent/Veteran's benefits (CHAMPUS) insprv_mil

☐ Other insprv_oth

If other, please specify.

insspe text

B3a. Does this health insurance plan have any exclusions or restrictions because of your child's health history? insexc

3 ☐ Don't know

2 ☐ No

1 ☐ Yes

If yes, please specify.

insexcsp text

B3b. Is there an extra premium charge on your health insurance policy because of your child's health history? insext

3 ☐ Don't know

2 ☐ No

1 ☐ Yes

LIVING ARRANGEMENT

C1. What is your child's current living arrangement? curliv
(Mark all that apply)

☐ Lives with parent(s) curliv_par

☐ Lives with adult brother(s) and/or sister(s) curliv_sib

☐ Lives with other adult relative(s) curliv_rel

☐ Other curliv_oth

If Other, please specify.

msspec

text

INCOME

C2. Over the last year, what was the total income of the household your child lived in? homeinc

1 ☐ Less than $20,000

2 ☐ $20,000 - $39,999

3 ☐ $40,000 - $59,999

4 ☐ $60,000 - $79,999

5 ☐ $80,000 - $99,999

6 ☐ Over $100,000

9 ☐ Don't know

C3. During the past year, how many people in this household were supported on this income? incsupn

1 ☐ 1

2 ☐ 2

3 ☐ 3

4 ☐ 4

5 ☐ 5

6 ☐ 6

7 ☐ 7

8 ☐ 8

9 ☐ 9 or more

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PHYSICAL FUNCTIONING

D1. Would you rate your child as being: disable

1 ☐ Completely disabled

2 ☐ Severely disabled

3 ☐ Moderately disabled

4 ☐ Mildly disabled

5 ☐ Not at all disabled

D2. In general, would you say your child's health is:

health

1 ☐ Excellent

2 ☐ Very good

3 ☐ Good

4 ☐ Fair

5 ☐ Poor

D3. Compared to one year ago, how would you rate your child's health in general now? hlthcomp

1 ☐ Much better now than one year ago

2 ☐ Somewhat better now than one year ago

3 ☐ About the same as one year ago

4 ☐ Somewhat worse now than one year ago

5 ☐ Much worse now than one year ago

D4. Please respond to each item by marking one box per row.

In the past 7 days. . . .

	0 Not able to do	1 With a lot of trouble	2 With some trouble	3 With a little trouble	4 With no trouble
a. My child could do sports and exercise that other kids his/her age could do . . . . . trbsport	☐	☐	☐	☐	☐
b. My child could get up from the floor. . trbgetup	☐	☐	☐	☐	☐
c. My child could keep up when he/she played with other kids . . . . . trbkeepup	☐	☐	☐	☐	☐
d. My child could move his/her legs . . . trbmvleg	☐	☐	☐	☐	☐
e. My child could stand up without help . . . . . trbstand	☐	☐	☐	☐	☐
f. My child could stand up on his/her tiptoes . . . . . trbtiptoe	☐	☐	☐	☐	☐
g. My child could walk up stairs without holding on to anything . . . . . trbstair	☐	☐	☐	☐	☐
h. My child has been physically able to do the activities he/she enjoys most . trbactv	☐	☐	☐	☐	☐

Continue on next page.

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SOCIAL FUNCTIONING

E1. About how many close friends does your child have? friendsn

0 ☐ 0 → *Go to Question E3.*
1 ☐ 1
2 ☐ 2 or 3
3 ☐ 4 or more

E2. About how many times a week does your child do things with close friends? friendswk

0 ☐ Less than 1
1 ☐ 1 or 2
2 ☐ 3 or more

E3. Compared to other children of his/her age, how well does your child . . .

	1 Worse	2 About Same	3 Better
a. Get along with his/her brothers and sisters? sfsibs	☐	☐	☐
b. Get along with other children? sfkids	☐	☐	☐
c. Behave with his/her parents? sfprnt	☐	☐	☐
d. Play and work by himself/herself? sfself	☐	☐	☐

E4. How well do the following statements describe your child's behavior?

	1 Often True	2 Sometimes True	3 Not True
a. Has sudden changes in mood or feelings moody	☐	☐	☐
b. Feels or complains that no one loves him/her unloved	☐	☐	☐
c. Is rather high strung, tense, or nervous highstrung	☐	☐	☐
d. Cheats or tells lies lies	☐	☐	☐
e. Is too fearful or anxious fearful	☐	☐	☐
f. Argues too much argues	☐	☐	☐
g. Has difficulty concentrating, cannot pay attention for long attention	☐	☐	☐
h. Is easily confused, seems to be in a fog fog	☐	☐	☐
i. Bullies, or is cruel or mean to others cruel	☐	☐	☐
j. Is disobedient at home disobhm	☐	☐	☐
k. Is disobedient at school disobsch	☐	☐	☐
l. Does not seem to feel sorry after he/she misbehaves remorse	☐	☐	☐

E4. (Cont.) How well do the following statements describe your child's behavior?

	1 Often True	2 Sometimes True	3 Not True
m. Has trouble getting along with other children peers	☐	☐	☐
n. Has trouble getting along with teachers teachers	☐	☐	☐
o. Is impulsive, or acts without thinking impulse	☐	☐	☐
p. Feels worthless or inferior inferior	☐	☐	☐
q. Is not liked by other children disliked	☐	☐	☐
r. Has a lot of difficulty getting his/her mind off certain thoughts, has obsessions obsess	☐	☐	☐
s. Is restless or overly active, cannot sit still active	☐	☐	☐
t. Is stubborn, sullen, or irritable stubborn	☐	☐	☐
u. Has a very strong temper and loses it easily temper	☐	☐	☐
v. Is unhappy, sad or depressed unhappy	☐	☐	☐
w. Is withdrawn, does not get involved with others alone	☐	☐	☐

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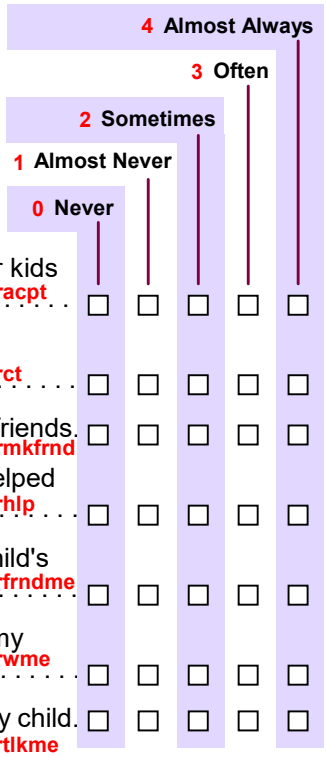
E5. Please respond to each item by marking one box per row.

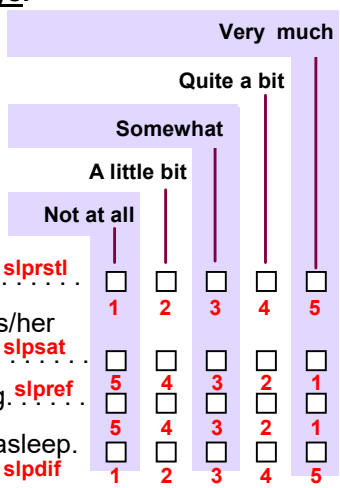


In the past 7 days. . . .

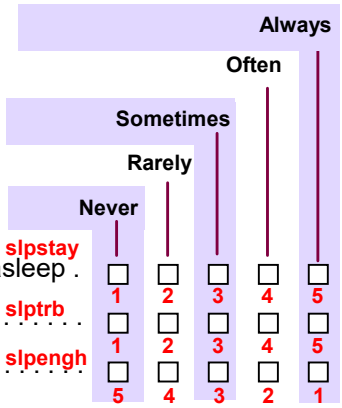
a. My child felt accepted by other kids his/her age . . . . . peeracpt
b. My child was able to count on his/her friends . . . . . peerct
c. My child was good at making friends. peermkfrnd
d. My child and his/her friends helped each other out . . . . . peerhlp
e. Other kids wanted to be my child's friend . . . . . peerfrndme
f. Other kids wanted to be with my child . . . . . peerwme
g. Other kids wanted to talk to my child. peertlkme

SLEEP

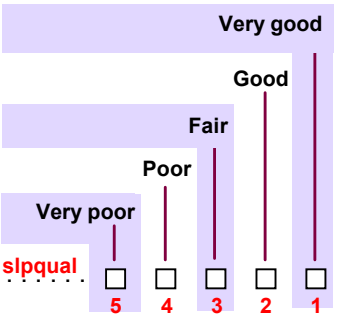
F1 to F8 relate to the past 7 days.



F1. His/her sleep was restless . . . . . slprstl 1 2 3 4 5
F2. He/she was satisfied with his/her sleep . . . . . slpsat 5 4 3 2 1
F3. His/her sleep was refreshing. . . . . slpref 5 4 3 2 1
F4. He/she had difficulty falling asleep. slpdif 1 2 3 4 5



F5. He/she had trouble staying asleep . slpstay 1 2 3 4 5
F6. He/she had trouble sleeping . . . . . slptrb 1 2 3 4 5
F7. He/she got enough sleep. . . . . slpengh 5 4 3 2 1



F8. His/her sleep quality was . . . . . slpqual 5 4 3 2 1

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PAIN

G1. Does your child <u>currently</u> have pain as a result of his/her cancer or similar illness, or its treatment? capain

1 ☐ No pain
2 ☐ Small amount of pain
3 ☐ Medium amount of pain
4 ☐ A lot of pain
5 ☐ Very bad, excruciating pain

G2. For pain that your child has had during the <u>past 4 weeks</u>, where has this pain been located? painloct
(Mark all that apply)

☐ My child did not have pain in the past 4 weeks. painloct_none
☐ Head painloct_head
☐ Neck painloct_neck
☐ Chest painloct_chst
☐ Hands/Arms painloct_arm
☐ Abdomen painloct_abd
☐ Back painloct_back
☐ Pelvis painloct_pel
☐ Legs/Feet painloct_leg
☐ Other painloct_oth

If other, please specify.
painspe1-4 coded

G3. How much <u>bodily</u> pain has your child had during the <u>past 4 weeks</u>? painmuch

1 ☐ None
2 ☐ Very mild
3 ☐ Mild
4 ☐ Moderate
5 ☐ Severe
6 ☐ Very severe

G4. Please respond to each item by marking one box per row.

In the <u>past 7 days</u>. . . .

	0 Never	1 Almost Never	2 Sometimes	3 Often	4 Almost Always
a. My child had trouble sleeping when he/she had pain painslp	☐	☐	☐	☐	☐
b. My child felt angry when he/she had pain painang	☐	☐	☐	☐	☐
c. My child had trouble doing schoolwork when he/she had pain painwk	☐	☐	☐	☐	☐
d. It was hard for my child to pay attention when he/she had pain painatn	☐	☐	☐	☐	☐
e. It was hard for my child to run when he/she had pain painrun	☐	☐	☐	☐	☐
f. It was hard for my child to walk one block when he/she had pain painwlk	☐	☐	☐	☐	☐
g. It was hard for my child to have fun when he/she had pain painfun	☐	☐	☐	☐	☐
h. It was hard for my child to stay standing when he/she had pain painstnd	☐	☐	☐	☐	☐

Continue on next page.

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WORRY/CONCERNS

H1. Does your child <u>currently</u> have anxieties/fears as a result of his/her cancer or similar illness, or its treatment? caanx

1 ☐ No anxiety/fears

2 ☐ Small amount of anxiety/fears

3 ☐ Medium amount of anxiety/fears

4 ☐ A lot of anxiety/fears

5 ☐ Very many, extreme anxiety/fears

MOOD

H2. Please respond to each item by marking one box per row.

In the <u>past 7 days</u>. . . .

	0 Never	1 Almost Never	2 Sometimes	3 Often	4 Almost Always
a. My child could not stop feeling sad . . . mdfsad	☐	☐	☐	☐	☐
b. My child felt everything in his/her life went wrong . . . . . mdwrng	☐	☐	☐	☐	☐
c. My child felt like he/she couldn't do anything right . . . . . mdrght	☐	☐	☐	☐	☐
d. My child felt lonely . . . . . mdlonely	☐	☐	☐	☐	☐
e. My child felt sad . . . . . mdsad	☐	☐	☐	☐	☐
f. My child thought that his/her life was bad . . . . . mdbad	☐	☐	☐	☐	☐

Please respond to each item by marking one box per row.

In the <u>past 7 days</u>. . . .

	0 Never	1 Almost Never	2 Sometimes	3 Often	4 Almost Always
H3. My child felt nervous . . . . . anxnrv	☐	☐	☐	☐	☐
H4. My child felt scared . . . . . anxscrd	☐	☐	☐	☐	☐
H5. My child felt worried . . . . . anxwor	☐	☐	☐	☐	☐
H6. My child felt like something awful might happen . . . . . anxbad	☐	☐	☐	☐	☐
H7. My child thought about scary things . . . . . anxscary	☐	☐	☐	☐	☐
H8. My child was afraid that he/she would make mistakes . . . . . anxmis	☐	☐	☐	☐	☐
H9. My child worried about what could happen to him/her . . . . . anxhap	☐	☐	☐	☐	☐
H10. My child worried when he/she went to bed at night . . . . . anxbed	☐	☐	☐	☐	☐

ATTENTION/CONCENTRATION

Please read each item carefully and tell us how true it is about your child in the <u>past month</u>.

	1 Never or seldom	2 Occasionally	3 Often	4 Very often
I1. It is hard for my child to pay attention to details . . . . . atndetail	☐	☐	☐	☐
I2. My child can't pay attention for long . . atnlength	☐	☐	☐	☐
I3. My child loses track of what he/she is supposed to do . . . . . atntrack	☐	☐	☐	☐
I4. My child gets distracted by things that are going on around him/her . . . . atndistr	☐	☐	☐	☐
I5. My child has trouble finishing things . . atnfin	☐	☐	☐	☐
I6. My child has trouble concentrating . . . atnconc	☐	☐	☐	☐

Please! Do not mark below this line

IMPACT ON FAMILY

These questions ask about the impact cancer or a similar illness has had on your family. For each item, please indicate whether or not the statement describes your family.

		0 Strongly Agree	1 Agree	2 Disagree	3 Strongly Disagree	4 Don't Know	5 Prefer Not to Answer
J1.	Because of the illness, we are not able to travel out of the city	fitravel	☐	☐	☐	☐	☐	☐
J2.	People in the neighborhood treat us special because of my child's illness	fispecial	☐	☐	☐	☐	☐	☐
J3.	We have little desire to go out because of my child's illness	fiisolated	☐	☐	☐	☐	☐	☐
J4.	It is hard to find a reliable person to take care of my child	ficare	☐	☐	☐	☐	☐	☐
J5.	Sometimes, we have to change plans about going out at the last minute because of my child's condition	fiflexible	☐	☐	☐	☐	☐	☐
J6.	We see family and friends less because of the illness.	fisocial	☐	☐	☐	☐	☐	☐
J7.	Sometimes I wonder whether my child should be treated "special" or the same as a normal child	fiwonder	☐	☐	☐	☐	☐	☐
J8.	I think about not having more children because of the illness.	fikids	☐	☐	☐	☐	☐	☐
J9.	I don't have much time left over for other family members after caring for my child	fitime	☐	☐	☐	☐	☐	☐
J10.	Our family gives up things because of my child's illness.	fisacrifice	☐	☐	☐	☐	☐	☐
J11.	Fatigue is a problem for me because of my child's illness.	fifatigue	☐	☐	☐	☐	☐	☐
J12.	I live from day to day and don't plan for the future	fifuture	☐	☐	☐	☐	☐	☐
J13.	Nobody understands the burden I carry	fiburden	☐	☐	☐	☐	☐	☐
J14.	Traveling to the hospital is a strain on me	fistrain	☐	☐	☐	☐	☐	☐
J15.	Sometimes I feel like we live on a rollercoaster: in crisis when my child is acutely ill, OK when things are stable	fistability	☐	☐	☐	☐	☐	☐

Please! Do not mark below this line

DAILY STRESS

These questions ask about your child's feelings and thoughts during the last month. For each item, please indicate with a mark how often your child felt or thought a certain way.

	1 Never	2 Almost Never	3 Sometimes	4 Fairly Often	5 Very Often
K1. How often did your child appear frustrated by being unable to control or do something . . . . . dscntrl	☐	☐	☐	☐	☐
K2. How often did your child appear confident about his or her ability to handle personal problems. . . . . dsconf	☐	☐	☐	☐	☐
K3. How often did your child seem to feel things were going well . . . . . dswell	☐	☐	☐	☐	☐
K4. How often did difficulties pile up so high that your child did not seem able to overcome them . . . . . dspile	☐	☐	☐	☐	☐

OTHER ISSUES

Please rate how concerned you are about the following:

	1 Very concerned	2 Somewhat concerned	3 Concerned	4 Not very concerned	5 Not at all concerned
L1. Your child's future health . . . confhlth	☐	☐	☐	☐	☐
L2. Your child's ability to have children . . . . . conkids	☐	☐	☐	☐	☐
L3. Your child developing another cancer . . . . . conca	☐	☐	☐	☐	☐
L4. Your ability to get health insurance for your child . . . . conhins	☐	☐	☐	☐	☐
L5. Your ability to get life insurance for your child . . . . conlins	☐	☐	☐	☐	☐
L6. Your ability to cover expenses for health care for your child . . . . . conhcexp	☐	☐	☐	☐	☐
L7. Your ability to cover expenses for prescribed medicine for your child . . . . . conrxexp	☐	☐	☐	☐	☐
L8. Any other issues . . . . . conoth	☐	☐	☐	☐	☐

Please specify.

conspe

text

Please! Do not mark below this line

Has your child been diagnosed with any of the following medical problems?

M1. Depression depdx 1☐ Yes 2☐ No

If yes, did your child ever receive treatment? deptrt

1☐ Yes, in the past 2☐ Yes, currently 3☐ No

If yes, what type of treatment? ***(Mark all that apply)*** ydeptrt

☐ Behavior/talk therapy/counseling ydeptrt_talk

☐ Hospitalization ydeptrt_hosp

☐ Medication ydeptrt_med

List medications:

depmed1-4 coded

M2. Anxiety anxdx 1☐ Yes 2☐ No

If yes, did your child ever receive treatment? anxtrt

1☐ Yes, in the past 2☐ Yes, currently 3☐ No

If yes, what type of treatment? ***(Mark all that apply)*** yanxtrt

☐ Behavior/talk therapy/counseling yanxtrt_talk

☐ Hospitalization yanxtrt_hosp

☐ Medication yanxtrt_med

List medications:

anxmed1-4 coded

M3. Attention Deficit Disorder (with or without hyperactivity) 1☐ Yes 2☐ No adddx

If yes, did your child ever receive treatment? addtrt

1☐ Yes, in the past 2☐ Yes, currently 3☐ No

If yes, what type of treatment? ***(Mark all that apply)*** yaddtrt

☐ Behavior/talk therapy/counseling yaddtrt_talk

☐ Hospitalization yaddtrt_hosp

☐ Medication yaddtrt_med

List medications:

addmed1-4 coded

M4. Bipolar Disorder biplrdx 1☐ Yes 2☐ No

If yes, did your child ever receive treatment? biplrtrt

1☐ Yes, in the past 2☐ Yes, currently 3☐ No

If yes, what type of treatment? ***(Mark all that apply)*** ybiplrtrt

☐ Behavior/talk therapy/counseling ybiplrtrt_talk

☐ Hospitalization ybiplrtrt_hosp

☐ Medication ybiplrtrt_med

List medications:

biplrmed1-4 coded

M5. Oppositional Defiant/Conduct Disorder odddx 1☐ Yes 2☐ No

If yes, did your child ever receive treatment? oddtrt

1☐ Yes, in the past 2☐ Yes, currently 3☐ No

If yes, what type of treatment? ***(Mark all that apply)*** yoddtrt

☐ Behavior/talk therapy/counseling yoddtrt_talk

☐ Hospitalization yoddtrt_hosp

☐ Medication yoddtrt_med

List medications:

oddmed1-4 coded

M6. Other psychiatric disorder (e.g. obsessive-compulsive disorder) 1☐ Yes 2☐ No opsydx

If yes, please specify the disorder:

psydxsp1-2 coded

If yes, did you ever receive treatment? opsytrt

1☐ Yes, in the past 2☐ Yes, currently 3☐ No

If yes, what type of treatment? ***(Mark all that apply)*** yopsytrt

☐ Behavior/talk therapy/counseling yopsytrt_talk

☐ Hospitalization yopsytrt_hosp

☐ Medication yopsytrt_med

List medications:

opsymed1-4 coded

Do any of these medical conditions prevent your child from attending school or engaging in extracurricular activities on a regular basis (more days than not)? psyint

1☐ Yes 2☐ No

If yes, which condition(s):

psyintsp1-4 coded

Please! Do not mark below this line