

Appendix F. Final Survey for Caregivers

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Since you last saw [ds_firstname]'s primary care provider for an annual wellness visit, has [ds_firstname] been recommended to have and, if so, completed, any of the following....

	Yes, test or consult completed	Test or consult recommended, but not completed	No, not recommended nor completed	Not sure
Blood test for anemia?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
thyroid blood work (TSH and/or T4)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
cholesterol bloodwork?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
blood work to test for celiac disease?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
seen an audiologist for a formal hearing exam?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
seen a nutritionist for a formal consult?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
seen an ophthalmologist for a formal eye exam?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
seen an orthopedic doctor for a formal consult?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
had a sleep study performed to test for obstructive sleep apnea?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
had an EEG?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
had a brain MRI?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
had an echocardiogram (heart scan)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If a thyroid test was recommended, but not completed, please explain why _____

If an audiogram was recommended, but not completed, please explain why _____

If an eye exam by an ophthalmologist was recommended, but not completed, please explain why _____

If a sleep study was recommended, but not completed, please explain why _____

If a blood test for celiac disease was recommended, but not completed, please explain why _____

Was [ds_firstname] found to have a thyroid disease as a result of this test?

- Yes
 No
 Not sure

Was [ds_firstname] found to have a hearing impairment as a result of this test?

Yes
 No
 Not sure

Was [ds_firstname] found to have obstructive sleep apnea or other sleep disorder as a result of this test?

Yes
 No
 Not sure

Was [ds_firstname] found to have celiac disease as a result of this test?

Yes
 No
 Not sure

Was [ds_firstname] found to have a vision impairment as a result of this test?

Yes
 No
 Not sure

Using any number from 0 to 10, where 0 is the LEAST HELPFUL information possible and 10 is the MOST HELPFUL information possible, what number would you use to rate the CAREGIVER CHECKLIST?

- 0, least helpful information possible
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10, most helpful information possible

Would you recommend the DSC2U INTAKE FORM and CAREGIVER CHECKLIST to another caregiver of someone with Down syndrome?

- Yes, Definitely
- Yes, Somewhat
- No

Since enrolling in DSC2U and getting the CAREGIVER CHECKLIST, approximately how much has your family spent out of your pocket on health care costs for [ds_firstname] as a result of any health consultations, tests, copayments, deductibles, medical help or equipment?

- Less than \$250
- \$250-499
- \$500-999
- \$1000-1999
- \$2000-2999
- \$3000+

Now that you have completed the DSC2U intake form and viewed the CAREGIVER CHECKLIST, if you could access DSC2U whenever you want in the coming year at no cost, how often would you want to do each of the following:

	More than 5 times per year	2-5 times per year	Once per year	Never
Go back and re-read and re-use the links in the CAREGIVER CHECKLIST.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Complete the intake form to update [ds_firstname]'s medical information and obtain a new CAREGIVER CHECKLIST.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

As you know, DSC2U was developed for a research project. You have been paid to participate in this study. Would you have participated in this study, including completing all forms, if we had not paid you?

- Definitely would
 Probably would
 Probably would not
 Definitely would not

And if we continue DSC2U, but charged a fee for you to access the intake form and update your CAREGIVER CHECKLIST, would you be willing to pay out of your pocket for the service?

- Yes
 No
 Not sure

What if the price were \$300 per use to complete DSC2U and get the CAREGIVER CHECKLIST would you be willing to pay?

- Yes
 No
 Not sure

What if the price were \$200 per use to complete DSC2U and get the CAREGIVER CHECKLIST would you be willing to pay?

- Yes
 No
 Not sure

What if the price were \$100 per use to complete DSC2U and get the CAREGIVER CHECKLIST would you be willing to pay?

- Yes
 No
 Not sure

What if the price were \$50 per use to complete DSC2U and get the CAREGIVER CHECKLIST would you be willing to pay?

- Yes
 No
 Not sure

Any other amount?

What is your annual household income?

- Less than \$25,000
 \$25,000-49,999
 \$50,000-99,999
 \$100,000-149,999
 \$150,000 or more

In this study you received a CAREGIVER CHECKLIST for your own use and a PRIMARY CARE PROVIDER PLAN for the PCP.

Do you have any suggestions for improving the CAREGIVER CHECKLIST?

Do you have any suggestions for improving the PCP PLAN?

Did a doctor ever tell you that [ds_firstname] had obstructive sleep apnea prior to [pcp_date]?

- Yes
- No

Since the appointment with the primary care provider on [pcp_date], has [ds_firstname] been diagnosed by any health care professional with any of the following NEW diagnoses? (Check all that apply.)

Ear, Nose, and Throat	<input type="checkbox"/> seasonal allergies
Lungs	<input type="checkbox"/> obstructive sleep apnea
Stomach and Intestines	<input type="checkbox"/> celiac disease <input type="checkbox"/> chronic constipation <input type="checkbox"/> gastroesophageal reflux disease
Urinary system	<input type="checkbox"/> undescended testicles
Brain and Nervous System	<input type="checkbox"/> autism spectrum disorder <input type="checkbox"/> moyo moyo disease <input type="checkbox"/> infantile spasms <input type="checkbox"/> dementia (Alzheimer's disease)
Skin	<input type="checkbox"/> eczema <input type="checkbox"/> dry skin <input type="checkbox"/> hidradenitis suppurative (skin boils) <input type="checkbox"/> alopecia areata <input type="checkbox"/> acne <input type="checkbox"/> vitiligo <input type="checkbox"/> toenail fungus
Musculoskeletal	<input type="checkbox"/> atlantoaxial instability <input type="checkbox"/> arthropathy/arthritis
Endocrine	<input type="checkbox"/> thyroid disease <input type="checkbox"/> diabetes <input type="checkbox"/> growth hormone deficiency
Cancer (blood disorders)	<input type="checkbox"/> leukemia
Mental Health	<input type="checkbox"/> depression <input type="checkbox"/> obsessive-compulsive disorder <input type="checkbox"/> anxiety <input type="checkbox"/> attention deficit hyperactivity disorder (ADHD)

PedsQL: Quality of Life Inventory**Version 4.0 Short Form (SF15)****PARENT REPORT****Used with permission. Copyright (c) 1998 JW Varni, PhD. All rights reserved.**

On the following page is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past ONE month by checking:

- if it is never a problem
- if it is almost never a problem
- if it is sometimes a problem
- if it is often a problem
- if it is almost always a problem

There are no right or wrong answers.

In the past ONE month, how much of a problem has your child had with...**PHYSICAL FUNCTIONING (problems with...)**

	Never	Almost never	Sometimes	Often	Almost always
Walking more than one block	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Running	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participating in sports activity or exercise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participating in active play or exercise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lifting something heavy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing chores around the house	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing chores, like picking up his or her toys	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helping to pick up his or her toys	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past ONE month, how much of a problem has your child had with...**EMOTIONAL FUNCTIONING (problems with...)**

	Never	Almost never	Sometimes	Often	Almost always
Feeling afraid or scared	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling sad or blue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling angry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble sleeping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worrying about what will happen to him or her	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worrying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past ONE month, how much of a problem has your child had with...**SOCIAL FUNCTIONING (problems with...)**

	Never	Almost never	Sometimes	Often	Almost always
Playing with other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting along with other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting along with other teens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting along with other young adults	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting along with other adults	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other kids not wanting to play with him or her	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other kids not wanting to be his or her friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other teens not wanting to be his or her friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other young adults not wanting to be his or her friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other adults not wanting to be his or her friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting teased by other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting teased by other teens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting teased by other young adults	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting teased by other adults	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past ONE month, how much of a problem has your child had with...**WORK/STUDIES FUNCTIONING (problems with...)**

	Never	Almost never	Sometimes	Often	Almost always
Paying attention at work or school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Forgetting things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keeping up with work or studies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past ONE month, how much of a problem has your child had with...**SCHOOL FUNCTIONING (problems with...)**

	Never	Almost never	Sometimes	Often	Almost always
Doing the same school activities as peers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paying attention in class	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Forgetting things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keeping up with school activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Missing school/daycare because of not feeling well	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keeping up with schoolwork	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Missing school/daycare to go to the doctor or hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

PedsQL Family Impact Module**Version 2.0****PARENT REPORT****Used with permission. Copyright (c) 1998 JW Varni, Ph.D. All rights reserved.**

Families of children sometimes have special concerns or difficulties because of the child's health. On the following page is a list of things that might be a problem for you. Please tell us how much of a problem each one has been for you during the past ONE month by checking:

- if it is never a problem
- if it is almost never a problem
- if it is sometimes a problem
- if it is often a problem
- if it is almost always a problem

There are no right or wrong answers.

In the past ONE month, as a result of your child's health, how much of a problem have you had with...

PHYSICAL FUNCTIONING (problems with...)

	Never	Almost never	Sometimes	Often	Always
I feel tired during the day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel tired when I wake up in the morning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel too tired to do the things I like to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get headaches	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel physically weak	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel sick to my stomach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past ONE month, as a result of your child's health, how much of a problem have you had with...

EMOTIONAL FUNCTIONING (problems with...)

	Never	Almost never	Sometimes	Often	Almost always
I feel anxious	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel sad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel angry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel frustrated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel helpless or hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past ONE month, as a result of your child's health, how much of a problem have you had with...

SOCIAL FUNCTIONING (problems with...)

	Never	Almost never	Sometimes	Often	Almost always
I feel isolated from others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have trouble getting support from others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is hard to find time for social activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do not have enough energy for social activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past ONE month, as a result of your child's health, how much of a problem have you had with...

COGNITIVE FUNCTIONING (problems with...)

	Never	Almost never	Sometimes	Often	Almost always
It is hard for me to keep my attention on things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is hard for me to remember what people tell me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is hard for me to remember what I just heard	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is hard for me to think quickly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have trouble remembering what I was just thinking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past ONE month, as a result of your child's health, how much of a problem have you had with...

COMMUNICATION (problems with...)

	Never	Almost never	Sometimes	Often	Almost always
I feel that others do not understand my family's situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is hard for me to talk about my child's health with others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is hard for me to tell doctors and nurses how I feel	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past ONE month, as a result of your child's health, how much of a problem have you had with...**WORRY (problems with...)**

	Never	Almost never	Sometimes	Often	Almost always
I worry about whether or not my child's medical treatments are working	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry about the side effects of my child's medications/medical treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry about how others will react to my child's condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry about how my child's illness is affecting other family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry about my child's future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Below is a list of things that might be a problem for your family. Please tell us how much of a problem each one has been for your family during the past ONE month.

In the past ONE month, as a result of your child's health, how much of a problem has your family had with...

DAILY ACTIVITIES (problems with...)

	Never	Almost never	Sometimes	Often	Almost always
Family activities taking more time and effort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty finding time to finish household tasks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling too tired to finish household tasks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past ONE month, as a result of your child's health, how much of a problem has your family had with...

FAMILY RELATIONSHIPS (problems with...)

	Never	Almost never	Sometimes	Often	Almost always
Lack of communication between family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Conflicts between family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty making decisions together as a family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty solving family problems together	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stress or tension between family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

This study will be ending in the coming months. In the future...

Would you like your name and e-mail to be added to our list to receive notices of other Mass General Hospital studies about Down syndrome? Yes
 No

Would you like your name and e-mail to be shared with researchers outside of the Mass General who may be doing other studies about Down syndrome? Yes
 No

Would you be willing to be added to a list of study participants who are willing to speak to people in the media about your experience of having a child with Down syndrome? Yes
 No