Appendix E. Health Care Outcome Survey for Caregivers

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Survey Instructions

Please answer each question by marking the circle to the right of your answer. Please answer the questions as they pertain to [ds_firstname].

Our records show that [ds_firstname] had a wellness visit with [pcpfirstname] [pcplastname] about 2 weeks ago, is that right?	◯ Yes ◯ No
Did [ds_firstname] have a recent wellness visit with a different provider about 2 weeks ago?	◯ Yes ◯ No

Please e-mail dsc2u@mgh.harvard.edu with the date of [ds_firstname]'s upcoming wellness visit with a primary care provider. We will update our records with this new date and re-send you this survey after that time.

You may STOP completing this survey at this time.

What is the name of the provider that [ds_firstname] recently saw for a wellness visit?	_____
Is this recent provider the one that [ds_firstname] usually sees for a check-up, health problems, or sick visits?	◯ Yes ◯ No
How long has [ds_firstname] been going to this provider?	◯ Less than 6 months ◯ At least 6 months but less than 1 year ◯ At least 1 year but less than 3 years ◯ At least 3 years but less than 5 years ◯ 5 years or more
In general, how would you rate the quality of your communication with this provider?	◯ Excellent ◯ Very Good ◯ Good ◯ Fair ◯ Poor
In the last 12 months, how many times did [ds_firstname] visit a primary care provider for care?	◯ None ◯ 1 time ◯ 2 times ◯ 3 times ◯ 4 times ◯ 5 to 9 times ◯ 10 or more times

[ds_firstname]'s Care During Most Recent Wellness Visit

Did the primary care provider tell you that you needed to do anything to follow up on the care [ds_firstname] got during the visit?
- ◯ Yes, definitely
- ◯ Yes, somewhat
- ◯ No

Did the primary care provider give you enough information about what you needed to do to follow up on [ds_firstname]'s care?
- ◯ Yes, definitely
- ◯ Yes, somewhat
- ◯ No

During [ds_firstname]'s most recent visit, did the primary care provider listen carefully to you?
- ◯ Yes, definitely
- ◯ Yes, somewhat
- ◯ No

During [ds_firstname]'s most recent visit, did you talk with the primary care provider about any questions or concerns you had about [ds_firstname]'s health?
- ◯ Yes, definitely
- ◯ Yes, somewhat
- ◯ No

During [ds_firstname]'s most recent visit, did the primary care provider give you easy to understand information about these health questions or concerns?
- ◯ Yes, definitely
- ◯ Yes, somewhat
- ◯ No

During [ds_firstname]'s most recent visit, did the primary care provider seem to know the important information about [ds_firstname]'s medical history?
- ◯ Yes, definitely
- ◯ Yes, somewhat
- ◯ No

During [ds_firstname]'s most recent visit, did the primary care provider show respect for what you had to say?
- ◯ Yes, definitely
- ◯ Yes, somewhat
- ◯ No

During [ds_firstname]'s most recent visit, did the primary care provider spend enough time with [ds_firstname]?
- ◯ Yes, definitely
- ◯ Yes, somewhat
- ◯ No

During [ds_firstname]'s most recent visit, did the primary care provider seem knowledgeable about medical issues related to Down syndrome?
- ◯ Yes, definitely
- ◯ Yes, somewhat
- ◯ No

Using any number from 0 to 10, where 0 is the worst WELLNESS VISIT possible and 10 is the best WELLNESS VISIT possible, what number would you use to rate this WELLNESS VISIT?
- ◯ 0 Worst wellness visit possible
- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4
- ◯ 5
- ◯ 6
- ◯ 7
- ◯ 8
- ◯ 9
- ◯ 10 Best wellness visit possible

Using any number from 0 to 10, where 0 is the worst PROVIDER possible and 10 is the best PROVIDER possible, what number would you use to rate this primary care provider?	◯ 0 Worst provider possible ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 Best provider possible
Have you viewed, downloaded, or printed a copy of the CAREGIVER CHECKLIST? (Choose all that apply.) (The Caregiver Checklist is the personalized list of recommendations that were generated for [ds_firstname].)	☐ I viewed the Caregiver Checklist on a computer or tablet or smartphone ☐ I downloaded the Caregiver Checklist to my computer, tablet or smartphone ☐ I printed the Caregiver Checklist

For this study, you completed a DSC2U INTAKE FORM online, answering questions about [ds_firstname]'s health.

We used that information to create a CAREGIVER CHECKLIST of information and resources for you.

We also created a PRIMARY CARE PLAN for you to give to your child's primary care provider.

Did you have any problems viewing, downloading, or printing the CAREGIVER CHECKLIST?

- ◯ Yes, definitely
- ◯ Yes, somewhat
- ◯ No

Please describe any difficulties that you had viewing, downloading or printing the CAREGIVER CHECKLIST.

_____

Which of the following best describes what happened after you had problems with the CAREGIVER CHECKLIST?

- ◯ My problems were fully resolved after I reached out to the DSC2U research team for assistance.
- ◯ I figured out how to fully resolve the problems on my own.
- ◯ My problems were never fully resolved.

Did the CAREGIVER CHECKLIST explain the recommendations in a way that was easy for you to understand?

- ◯ Yes, definitely
- ◯ Yes, somewhat
- ◯ No

Did you use the links to information that were included in the CAREGIVER CHECKLIST?

- ◯ Yes, definitely
- ◯ Yes, somewhat
- ◯ No

Please describe any difficulties or concerns that you had with the CAREGIVER CHECKLIST.

_____

Did you discuss the CAREGIVER CHECKLIST or any of the recommendations with [ds_firstname]?

- ◯ Yes, definitely
- ◯ Yes, somewhat
- ◯ No

Please describe what sorts of issues or questions you discussed with your son or daughter about any of the information in the CAREGIVER CHECKLIST.

_____

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

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, 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	◯	◯	◯	◯
Complete the intake form again to update [ds_firstname]'s medical information and obtain a new CAREGIVER CHECKLIST	◯	◯	◯	◯

Were you able to view or download the PRIMARY CARE PLAN that was created for your primary care provider?
◯ Yes
◯ No

Please share why you were NOT able to view or download the PRIMARY CARE PLAN?
_____

Did you give a copy of the PRIMARY CARE PLAN to [ds_firstname]'s primary care provider before or during the wellness visit?
◯ Yes, before the visit
◯ Yes, at the visit
◯ Yes, before the visit AND at the visit
◯ No

Did you give a copy of the PRIMARY CARE PLAN to the primary care provider AFTER the wellness visit?
◯ Yes
◯ No

Why did you NOT give a copy of the PRIMARY CARE PLAN before or during the visit?
◯ I chose not to.
◯ I forgot to.
◯ I experienced technical difficulties in downloading the plan.
◯ I didn't feel comfortable sharing.
◯ Other

Please describe why you did not give a copy of the PRIMARY CARE PLAN before or during the visit.
_____

Did your primary care provider review the PRIMARY CARE PLAN and discuss it with you at [ds_firstname]'s visit?
◯ Yes, definitely
◯ Yes, somewhat
◯ No

Did your primary care provider seem interested in the information in the PRIMARY CARE PLAN?
◯ Yes, definitely
◯ Yes, somewhat
◯ No

Did your primary care provider seem to agree with the recommendations in the PRIMARY CARE PLAN?
◯ Yes, definitely
◯ Yes, somewhat
◯ No
◯ Not sure

In the past year, how much has your family spent out of your pocket on health care costs for all members of your household, including [ds_firstname]? This includes your insurance premiums, copayments, deductibles, medical help or equipment.	◯ Less than $250 ◯ $250-499 ◯ $500-999 ◯ $1000-1999 ◯ $2000-2999 ◯ $3000+
Now that you have seen the CAREGIVER CHECKLIST, do you have suggestions for improving the content or the layout?	_____

PedsQL: Quality of Life Inventory
Version 4.0 Short Form (SF15)
PARENT REPORT

DIRECTIONS

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 one of the following on each row:

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	○	○	○	○	○
Walking	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activity or exercise	○	○	○	○	○
Participating in active play or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Doing chores around the house	○	○	○	○	○
Doing chores, like picking up his or her toys	○	○	○	○	○
Helping to pick up his or her toys	○	○	○	○	○

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	○	○	○	○	○
Feeling sad or blue	○	○	○	○	○
Feeling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying about what will happen to him or her	○	○	○	○	○
Worrying	○	○	○	○	○

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	○	○	○	○	○
Getting along with other children	○	○	○	○	○
Getting along with other teens	○	○	○	○	○
Getting along with other young adults	○	○	○	○	○
Getting along with other adults	○	○	○	○	○
Other kids not wanting to play with him or her	○	○	○	○	○
Other kids not wanting to be his or her friend	○	○	○	○	○
Other teens not wanting to be his or her friend	○	○	○	○	○
Other young adults not wanting to be his or her friend	○	○	○	○	○
Other adults not wanting to be his or her friend	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Getting teased by other teens	○	○	○	○	○
Getting teased by other young adults	○	○	○	○	○
Getting teased by other adults	○	○	○	○	○

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	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with work or studies	○	○	○	○	○

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	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with school activities	○	○	○	○	○
Missing school/daycare because of not feeling well	○	○	○	○	○
Keeping up with schoolwork	○	○	○	○	○
Missing school/daycare to go to the doctor or hospital	○	○	○	○	○

PedsQL: Family Impact Module

Version 2.0

PARENT REPORT

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	Almost always
I feel tired during the day	○	○	○	○	○
I feel tired when I wake up in the morning	○	○	○	○	○
I feel too tired to do the things I like to do	○	○	○	○	○
I get headaches	○	○	○	○	○
I feel physically weak	○	○	○	○	○
I feel sick to my stomach	○	○	○	○	○

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	◯	◯	◯	◯	◯
I feel sad	◯	◯	◯	◯	◯
I feel angry	◯	◯	◯	◯	◯
I feel frustrated	◯	◯	◯	◯	◯
I feel helpless or hopeless	◯	◯	◯	◯	◯

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	○	○	○	○	○
I have trouble getting support from others	○	○	○	○	○
It is hard to find time for social activities	○	○	○	○	○
I do not have enough energy for social activities	○	○	○	○	○

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	○	○	○	○	○
It is hard for me to remember what people tell me	○	○	○	○	○
It is hard for me to remember what I just heard	○	○	○	○	○
It is hard for me to think quickly	○	○	○	○	○
I have trouble remembering what I was just thinking	○	○	○	○	○

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	○	○	○	○	○
It is hard for me to talk about my child's health with others	○	○	○	○	○
It is hard for me to tell doctors and nurses how I feel	○	○	○	○	○

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	○	○	○	○	○
I worry about the side effects of my child's medications/medical treatments	○	○	○	○	○
I worry about how others will react to my child's condition	○	○	○	○	○
I worry about how my child's illness is affecting other family members	○	○	○	○	○
I worry about my child's future	○	○	○	○	○

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	○	○	○	○	○
Difficulty finding time to finish household tasks	○	○	○	○	○
Feeling too tired to finish household tasks	○	○	○	○	○

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	○	○	○	○	○
Conflicts between family members	○	○	○	○	○
Difficulty making decisions together as a family	○	○	○	○	○
Difficulty solving family problems together	○	○	○	○	○
Stress or tension between family members	○	○	○	○	○

Thank you. Please submit your survey now.

Consumer Assessment of Healthcare Providers and Systems (CAHPS) program" is a program of the U.S. Agency for Healthcare Research and Quality.