



# **The Child and Family Follow-up Survey (CFFS)<sup>©</sup>**

Administration and  
Scoring Guidelines

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## **TABLE OF CONTENTS:**

|                                                             |       |
|-------------------------------------------------------------|-------|
| About the author.....                                       | 3     |
| Introduction.....                                           | 3-4   |
| CFFS: Description.....                                      | 4-5   |
| CFFS: Administration.....                                   | 6-7   |
| The Child and Adolescent Scale of Participation (CASP)..... | 8-12  |
| The Child and Adolescent Factors Inventory (CAFI).....      | 13-15 |
| The Child and Adolescent Scale of Environment (CASE).....   | 16-19 |
| Acknowledgements.....                                       | 20-21 |
| References.....                                             | 22-25 |
| Appendix: The CFFS protocol.....                            | 26    |

## ABOUT THE AUTHOR

Gary Bedell, Ph.D., OTR, FAOTA is the primary author of the *Child and Family Follow-up Survey (CFFS)* which consists of the *Child and Adolescent Scale of Participation (CASP)*, *Child and Adolescent Factors Inventory (CAFI)*, *Child and Adolescent Scale of Environment (CASE)* and other questions about children and youth with disabilities, their families and the services they receive. Dr. Bedell is an Associate Professor at Tufts University, Department of Occupational Therapy, Medford, MA, USA. His research involves measurement development and investigating effective strategies to promote participation of children and youth in home, school and community activities. Most of his recent work has focused on children and youth with acquired brain injuries and their families.

## INTRODUCTION

*The Child and Family Follow-up Survey (CFFS)* was initially designed to monitor outcomes and needs of children with traumatic and other acquired brain injuries (ABI) (Bedell, 2004; Bedell & Dumas, 2004, Galvin, Froude, & McAleer, 2010; Wells, Minnes, & Phillips, 2009) The content and methods used in the CFFS were informed by the International Classification of Functioning (ICF, WHO, 2001), research addressing participation of children and youth with a range of disabilities and factors related to the child, family and physical and social environment that support and/or hinder participation. As well, feedback was obtained by parents of children/youth with ABI and clinical and measurement experts (Bedell, 2004; Bedell, Cohn, & Dumas, 2005; Dumas, Bedell, & Hamill, 2004).

The CFFS as well as the CASP, CAFI, and CASE (all which can be used separately from the CFFS) have been used to assess children with other diagnoses (Bedell, 2009; McDougall, Wright, Schmidt, Miller, & Lowry, 2011; Robertson, et al., 2011; Voll, 2009, Weintraub, Rot, Shoshani, Pe'er, & Weintraub, 2011). The CASP and CASE also have been reviewed and described by others as key measures for children and youth with acquired brain injuries and other disabling conditions (Badge, Hancock, & Waugh, 2009; Bedell, in press; Bedell & Coster, 2009; Bedell, Khetani, Coster, Law, & Cousins, in press; Khetani, Bedell, Coster, Law, & Cousins, in press; MacCauley et al., in press; Haley, Graham, & Dumas, 2004; McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006; Sherwin, et al., 2006; Ziviani, Desha, Feeney, & Boyd, 2010).

## **CFFS: DESCRIPTION**

The CFFS consists of five sections with closed and open-ended questions. It can be completed by or administered to the child's family caregiver (parents or primary guardians). For further description of the content and format of the CFFS please refer to the appendix which includes the full CFFS protocol.

**Section I:** Includes six questions about the child's physical and emotional health and well-being, primary way of moving around and communicating, and medical problems or hospitalization within the last year or at follow-up after leaving a particular program.

**Section II:** Includes the *Child and Adolescent Scale of Participation (CASP)* and three additional open-ended questions about equipment, modifications and strategies that are used to promote the child's participation.

**Section III:** Includes two subsections: A) The *Child and Adolescent Factors Inventory (CAFI)* and a question about health or medical restrictions on the child's daily activities; and B) The *Child and Adolescent Scale of Environment (CASE)*.

**Section IV:** Includes two subsections: A) Three questions about the child's: 1. Special education or early intervention services, 2. Rehabilitation and health services, and 3. Satisfaction with services; and B) Three questions about the 1. Family's quality of life, and 2. Current services and 3. Additional services and needs.

**Section V:** Includes two questions. One question asks for suggestions to improve services at the program where the child *was* or *is* receiving services, i.e., to better address the needs of the child and family. A final question asks parents or guardians to provide additional information that was not adequately addressed in the CFFS.

The CFFS can be used for individualized intervention planning, program evaluation, and multi-site and population-based research. The CFFS does not include a demographic section, so additional demographic information (e.g., age, gender, type of disability, facility, geographic location, time since diagnosis) will need to be asked or data from the CFFS will need to be linked to databases that include demographic information that is relevant to the clinical, research and/or policy questions being asked.

## **CFFS: ADMINISTRATION**

The CFFS takes about 30 minutes to complete. The CASP, CAFI, and CASE each can be administered in 5 to 10 minutes when completed separately from CFFS. There is no specific

training to administer the CFFS (or the CASP, CAFI or CASE). Those using the CFFS measures should be knowledgeable about the content and rating scales used, the key concepts being measured (particularly, “participation,” and “environmental factors”) as defined in the International Classification of Functioning (WHO, 2001; 2007) and the conceptual, methodological and psychometric information reported in two published articles and summarized in these guidelines (Bedell, 2004; 2009).

There are two ways to administer the parent/guardian - report version of the CFFS or separate measures. Consistency between the two modes of administration has not been examined.

***Self-Administered (in person or mail survey):*** The parent or guardian is provided with the CFFS in person or via postal mail (or e-mail attachment) and asked to complete it on his or her own and then return it to the specific contact person responsible for data coordination (in person or via postal mail). Parents/guardians should be provided with a description of the specific purposes of the project or research being conducted in person or via a cover letter if the CFFS is sent via postal mail or e-mail. Each institution is responsible for adhering to guidelines for research ethics with human participants (e.g., informed consent procedures) if the CFFS is used for research purposes.

***Interviewer administered (in-person or by telephone):*** The parent or guardian would be administered the CFFS in person or by phone using the same version used for self-administration. The interviewer essentially asks the same questions along with the examples provided as they are described in the order in which they are asked on the CFFS protocol.

Respondents and interviewers are allowed to ask for and provide clarification or further explanation, if needed.

The next sections will describe the scoring and the psychometric results pertaining to the three specific measures that are included in and can be used separately from the CFFS:

Section II. The Child and Adolescent Scale of Participation (CASP)

Section III.A. The Child and Adolescent Factors Inventory (CAFI)

Section III.B. The Child and Adolescent Scale of Environment (CASE)

## The Child and Adolescent Scale of Participation (CASP): Section II

The CASP consists of 20 ordinal-scaled items and four subsections: 1) Home Participation (6 items), 2) Community Participation (4 items), 3) School Participation (5 items), and 4) Home and Community Living Activities (5 items). The 20 items are rated on a four-point scale: “Age Expected (*Full participation*),” “Somewhat Restricted,” “Very Restricted,” “Unable.” A “Not Applicable” response is selected when the item reflects an activity in which the child would not be expected to participate due to age (e.g., work). Most items are applicable to children who are five and older and thus it is suggested that the CASP is used for school-aged children (5 years and older) so that most items and subsections can be completed.

Each CASP item examines a broad type of activity or life situation. Most items include examples of activities that fall within the broad life situation. Item, subsection, and total summary scores can be examined for use in research and practice. Higher scores reflect greater age-expected participation. The CASP also includes three additional open-ended questions about equipment, modifications and strategies that are used to promote the child’s participation. When the CASP is used separately from the CFFS, parents/guardians also are asked to identify child or environmental factors that hinder their child’s participation.

### **CASP: Scoring**

There are a number of ways to score the CASP depending on the purpose of the project or research being conducted:

**CASP Total Summary Scores:** This score is the sum of all “Applicable” items divided by the maximum possible score of applicable items. The maximum possible score if all items were applicable would be: 20 items X 4 = **80**. This score then should be multiplied by 100 to



conform to a 100-point scale. For example, let's say the sum of all 20 items was 66. This sum (66) would be divided by 80 (which would equal 0.825) and then multiplied by 100 to obtain a total summary score of 82.5.

**CASP Subsection Summary Scores:** Subsection summary scores can be used for all four or selected subsections depending on the specific aims of the research or project. Computation of subsection summary scores is essentially the same as for computation of the total summary score. This score is the sum of all "Applicable" items in each subsection divided by the maximum possible score of applicable items in each subsection. The maximum possible score if all items in each subsection were applicable would be: 1) Home Participation, 6 items  $\times 4 = 24$ ; 2) Community Participation, 4 items  $\times 4 = 16$ ; 3) School Participation, 5 items  $\times 4 = 20$ ; and 4) Home and Community Living, 5 items  $\times 4 = 20$ . This score then should be multiplied by 100 to conform to a 100-point scale. For example, let's say the sum of all six Home Participation items was 18. This sum (18) would be divided by 24 (which would equal 0.75) and then multiplied by 100 to obtain a Home participation subsection summary score of 75.

**CASP Item-level Scores:** Item-level scores can be used if interested in responses to or change in specific items (i.e., specific types of life situations or activities) or for comparing item-level responses or change among all or selected CASP items. This score is the rating provided for each item (e.g., 1=Unable to participate, 2=Very limited, 3=Somewhat limited, 4=Age expected /Full participation).

How to address "Not Applicable" responses in the computation of CASP scores is still in development and will be further explored as the next wave of data have been received and analyzed. Currently, there are two ways to address "Not Applicable" responses in the scoring.

Most investigators have used the aforementioned guidelines, i.e., they do not include the not applicable item in the scoring. Another option is to first take the average of all items and/or specific subsections and use this as the score for the non applicable item, and then use the aforementioned guidelines for computation of total summary and subsection summary scores. Item and or subsection scores should be the primary scores used when there are many non-applicable items responses, i.e., when the CASP is used with younger children.

The open-ended questions at the end of the CASP can provide useful information to understand factors that might support or hinder the child's participation and elaborate on information that was not obtained from the ordinal-scaled items. This information along with the responses to the ordinal-level responses specific to each child/youth is useful for individualized family-centered planning. As well, information provided to from open-ended questions from a larger group of participants involved in programs or research projects can be content analyzed and summarized to inform program, research or policy-related decisions. Responses from each ordinal-scaled item can be aggregated using descriptive statistics to inform similar decisions.

### **CASP: Overview of Psychometric Findings**

Bedell (2004; 2009) has reported the main results of psychometric testing of the CASP based on two studies. Data for the first study was conducted with 60 parents/guardians of children and youth with acquired brain injury discharged from Franciscan Hospital for Children, Boston, MA, USA (Bedell, 2004; Bedell & Dumas, 2004). Psychometric findings related to the initial version of the CASP and the larger Child and Family Follow-up Survey (CFFS) were reported (Bedell, 2004) as were descriptive and exploratory results (Bedell & Dumas, 2004).

The second study focused specifically on further validation of the CASP (Bedell, 2009). Data for this study were collected from 313 parents or primary guardians of children/youth with a range of disabling conditions (83%) and children/youth without disabilities (17%). Data were collected in the USA (74%), Canada (15%), Australia (6%), and Israel (5%).

The CASP has reported evidence of test re-test reliability (Intraclass Correlation Coefficient = 0.94), internal consistency ( $\alpha \geq 0.96$ ) and construct and discriminant validity. Moderate correlations were found between the CASP scores and scores from measures of functional activity performance ( $r=0.51$  to  $0.75$ ; Pediatric Evaluation of Disability Index [PEDI], Haley, Coster, Ludlow, Haltiwanger, & Andrellos, 1998), extent of child impairment ( $r=-0.58$  to  $-0.66$ ; Child and Adolescent Factors Inventory [CAFI], Bedell, 2004; 2009) and problems in the physical and social environment ( $r= -0.43$  to  $-0.57$ ; Child and Adolescent Scale of Environment [CASE], Bedell, 2004; 2009). Significant differences in CASP scores were found related to type of disability (Bedell, 2009). As expected, children without disabilities, on average, had significantly higher CASP scores than children with disabilities. No significant differences were found related to age category

Recent results from factor analyses showed three factors contributing 63% of the variance explained: 1) Participation in social, leisure, communication items (50%); 2) Participation in advanced daily living items (7%); 3) Participation in basic daily living and mobility items (6%) (Bedell, 2009). Recent results from Rasch analyses demonstrated that the CASP appears to be measuring essentially a uni-dimensional construct. An expected pattern of life situations for which children would find more or less challenging to participate was found. Greater limitations were found in school and community activities requiring more complex cognitive and social skills and lesser limitations were found in more basic and routine home and school activities

such as mobility, communication and personal-care. Two of the 20 CASP items (Shopping/Managing Money; Using Transportation) showed minor misfit to the Rasch measurement model (i.e., the actual responses for these two items deviated somewhat from the expected pattern of responses predicted). Thus, further examination of these items is a future area of inquiry.

It is important to note, that additional psychometric testing of the CASP with a larger and more diverse sample is currently underway. Additional and more detailed findings will be reported once data have been obtained and analyzed from colleagues. Also, the responsiveness of the CASP in detecting change over time or due to intervention has not been examined and will be a focus of future inquiry.

The CASP has been translated in Spanish, French, German, Hebrew, and Mandarin. An English and Spanish youth-report version was also designed for a large population-based longitudinal study of children and youth with Traumatic Brain Injury in the USA. Psychometric testing has yet to be conducted for these versions and will be a focus of future inquiry.

## The Child and Adolescent Factors Inventory (CAFI): Section III.A

The CAFI consists of a list of 15 potential problems that the child may be experiencing as a result of his or her diagnosis or condition related to health and cognitive, psychological, physical and sensory functioning. Each item or problem is rated on a 3-point ordinal scale: 1) No problem; 2) Little problem; 3) Big problem. There is one additional question that asks whether the child has any health or medical restrictions on his or her daily activities, and if so, to describe the specific restrictions. When the CAFI is used separately from the CFFS, parents/guardians also are asked to identify characteristics about their child that are strengths or helpful to him or her in daily life.

### **CAFI: Scoring**

There are a number of ways to score the CAFI depending on the purpose of the project or research being conducted:

***CAFI Total Summary Scores:*** This score is the sum of all CAFI item ratings divided by the maximum possible score (i.e., 15 items X 3 = **45**). This score then should be multiplied by 100 to conform to a 100-point scale. For example, let's say the sum of all 15 CAFI item ratings was 30. This sum (30) would be divided by 45 (which would equal 0.666) and then multiplied by 100 to obtain a total summary score of 66.6. Higher scores indicate a greater extent of problem.

**CAFI Composite (Domain) Scores:** Composite scores can be created by summing ratings of individual items that fall within a specific domain of functioning (e.g., cognitive). Computation of composite scores is essentially the same as for computation of the total summary score. This score is the sum of all items that fall within the domain of interest divided by the maximum possible score. For example, if you want to create a composite Cognitive Domain Score you might want to sum the first four CAFI item ratings (1. Paying attention or concentrating, 2. Remembering people places, or directions, 3. Problem solving or judgement, and 4. Understanding or learning new the things) and divide this sum from the maximum possible score ( $4 \times 3 = 12$ ). If the sum of the four item ratings is 10, this sum (10) would be divided by 12 (which would equal 0.833) and then multiplied by 100 to obtain a composite Cognitive Domain score of 83.3.

**CAFI Item-level Scores:** Item-level scores can be used if interested in responses to or change in specific items (i.e., specific types of problems) or for comparing item-level responses or change among all or selected CAFI items. This score is the rating provided for each item (e.g., 1=No problem; 2=Little problem; 3=Big problem).

### **CAFI: Overview of Psychometric Findings**

The CAFI has reported evidence of test re-test reliability (Intraclass Correlation Coefficient = 0.68) and internal consistency ( $\alpha = 0.86$ ) and construct / discriminant validity (Bedell, 2004). Higher CAFI scores (greater extent of impairment) significantly associated with lower scores on the Child Adolescent Scale of Participation (CASP, more restricted participation,  $r = -0.58$ ,

Bedell & Dumas, 2004;  $r = -0.66$ , Bedell, 2009) and Pediatric Evaluation of Disability Index (PEDI, Haley, et al., 1992; more limited functional skills) self-care ( $r = -0.26$ ) and social function ( $r = -0.31$ ) subscales, and higher scores on the Child Adolescent Scale of Environment (CASE, greater impact of environmental problem,  $r = -0.36$ , Bedell & Dumas, 2004;  $r = 0.55$ , recent analyses) Recent analyses (unpublished data) demonstrated that as a group, children with disabilities had significantly ( $p < 0.001$ ) higher CAFI scores (greater extent of impairment) than children without disabilities.

## **The Child and Adolescent Scale of Environment (CASE): Section III.B**

The CASE is a modification of the *Craig Hospital Inventory of Environmental Factors* (CHIEF, Whiteneck, et al., 2004), an existing instrument designed to assess the frequency (how often) and impact (how much of a problem) of environmental barriers experienced by adults with disabilities. To develop the CASE, items from the CHIEF were modified and additional items were created based on review of existing literature and feedback from families and clinical and measurement experts.

The CASE consists of 18 items that ask parents/guardians only about the impact (*not frequency*) of problems experienced with physical, social and attitudinal environment features of the child's home, school and community and problems related to the quality or availability of services or assistance that the child receives or might need. Each CASE item or problem is rated on a 3-point ordinal scale: 1) No problem; 2) Little problem; 3) Big problem. There is a "non applicable" response as well. For example, the items referring to school or work would not be applicable for those not attending school, or a structured program or work setting). When the CASE is used separately from the CFFS, parents/guardians also are asked to identify the physical or social aspects of the environment or qualities about the services that their child receives that are supportive or helpful to their child.

### **CASE: Scoring**

There are a number of ways to score the CASE depending on the purpose of the project or research being conducted:



**CASE Total Summary Scores:** This score is created by summing the item responses for applicable items, dividing this number by the maximum possible score, and multiplying this number by 100 to conform to a 100-point scale. The maximum possible score if all CASE items were applicable would be: 18 items X 3 = **54**. For example, let's say the sum of all 18 item ratings was 40. This sum (40) would be divided by 54 (which would equal 0.741) and then multiplied by 100 to obtain a CASE total summary score of 74.1. Higher scores indicate a greater extent of environment problem.

NOTE: Most CASE items are applicable for school-age children (ages 5-17). The current method of handling not applicable items is to not consider them in the scoring of the CASE total summary score. For example, if a child was not attending school or a structured program or work setting, items related to school/work would not be scored (3, 5, 6, 10, 12) and scoring would only include the remaining 13 applicable item ratings. In this instance, the maximum possible score would be 13 items x 3 = **39**. If the sum of these 13 applicable item ratings was 20. This sum (20) would be divided by 39 (which would equal 0.513) and then multiplied by 100 to obtain a modified CASE total summary score of 51.3. Because this score is based on a substantially reduced number of items, it would be imprecise to compare these scores with CASE total summary scores that included the full 18-item set.

Also, for four CASE items (3, 5, 6, 10) that pertain to either school or work, parents/guardians are asked to circle the primary setting where the child spends most of his time. As a general rule, these items should always refer to school when the child is in primary school or when the younger child attends some type of structured school or program (e.g., pre-school, day care). Parents/guardians only need to select school or work for the older youth transitioning to adulthood and young adult (18 years and older) who both attends school (i.e.,

college or a vocational program) AND works. It is important for all four of these items to pertain to the same setting. Again, it would be imprecise to compare CASE Total scores if the ratings to these items refer to different settings (i.e., school or work).

To address these two issues (when scoring non-applicable items and when items refer to school or work), it is recommended that item-level scores (described below) are used or composite (or subsection) scores are created so that the same scores can be used when comparing different children/youth OR when comparing scores over time for the same children/youth. For example, one composite / subsection could be created for the four or five school/work items and another composite score could be created for the 13 remaining items that were applicable for all children. Scores on the 13-item set could be compared among all children and over time for the same children. Scores on the 5-item set (3, 5, 6, 10, 12) could be used only for the children attending school and scores on the 4-item set (3, 5, 6, 10) could be used only for youth transitioning to adulthood who attend work.

These issues related to CASE scoring will require future inquiry as additional data are analyzed. Additional factor analyses will determine whether CASE factor subscores can be created and used in research and/or practice.

***CASE Item-level Scores:*** Item-level scores can be used if interested in responses to or change in specific items (i.e., specific types of environment problems) or for comparing item-level responses or change among all or selected CASE items. This score is the rating provided for each item (e.g., 1=No problem; 2=Little problem; 3=Big problem).

## **CASE: Overview of Psychometric Findings**

The CASE has reported evidence of test re-test reliability (Intraclass Correlation Coefficient = .75) and internal consistency ( $\alpha = 0.91$ ; Bedell, 2004;  $\alpha = 0.82$ , recent analyses) and construct / discriminant validity (Bedell, 2004). Higher CASE scores (greater extent of environmental problem) were significantly associated with lower scores on the Child Adolescent Scale of Participation (CASP, more restricted participation,  $r = -0.57$ , Bedell & Dumas, 2004;  $r = -0.43$ , Bedell, 2009) and Pediatric Evaluation of Disability Index (PEDI, Haley, et al., 1992, more limited functional skills) mobility ( $r = -0.28$ ) and social function ( $r = -0.31$ ) subscales, and higher scores on the Child Adolescent Factors Inventory (CAFI, greater extent of impairment,  $r = 0.36$ , Bedell & Dumas, 2004;  $r = 0.55$ , recent analyses). Recent analyses (unpublished data) demonstrated that as a group, children with disabilities had significantly ( $p < 0.02$ ) higher CASE scores (greater extent of environment problems) than children without disabilities.

Results from initial factor analyses and Rasch analyses suggest that the CASE is best viewed as an inventory of environmental factors or multidimensional scale rather than a unidimensional scale (Bedell, 2004). Recent factor analyses identified four main factors explaining 58% of the variance: 1) Problems associated with home / community (includes inadequate information, problems with government policies); 2) Problems related to school (support, assistance, services, equipment, attitudes); 3) Problems with physical design of school, home and community; 5) Other family / neighborhood problems (family stress, problems with finances, inadequate transportation, and neighborhood crime / violence (Khetani, et al., in press).

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## **APPENDIX: Child & Family Follow-up Survey (CFFS)**

**Child's name** \_\_\_\_\_

## **Child & Family Follow-up Survey (CFFS)**

### **Instructions**

1. This five-section survey asks questions about your child's current activities, needs, and services, and includes questions related to your family's needs and services.

You are also asked to provide information and suggestions that we can use to continue to improve services at our program.

2. There are no right or wrong answers. You will have to choose—and in some cases write—the answer that best describes your child and family. If you are not sure how to answer a question, give your best guess.

*Thank you*

**Your name** \_\_\_\_\_

**Your relationship to child** \_\_\_\_\_

**Date you completed survey** \_\_\_\_\_

*(Month / Day / Year)*

## Section I. General Information

The following questions ask how your child is overall and how he or she gets around and communicates with others. *Please put an X in the box next to one answer. If you are not sure, please give your best guess.*

**1. In general, how would you describe your child's physical health?**

☐ Poor      ☐ Fair      ☐ Good      ☐ Very good      ☐ Excellent

**2. In general, how would you describe your child's emotional health and well-being?**

*(i.e., the way he or she feels about himself or herself and his or her life)*

☐ Poor      ☐ Fair      ☐ Good      ☐ Very good      ☐ Excellent

**3. Has your child had any serious medical or health problems that required medical attention or hospitalization this year or since leaving our program?**

☐ Yes      ☐ No

**If Yes, please describe.**

**4. What is your child's primary way of moving around? (select one answer)**

☐ Walking      ☐ A manual wheelchair  
☐ Walking using an assistive device (e.g., walker, crutches, braces)      ☐ A powered wheelchair  
☐ Creeping or crawling      ☐ Other: \_\_\_\_\_

**5. What is your child's primary way of communicating? (select one answer)**

☐ Verbal speech: full sentences      ☐ Sign Language  
☐ Verbal speech: 1–2 word phrases      ☐ Writing  
☐ Nonverbal gestures (e.g., pointing or body language)      ☐ Typing  
☐ Communication device: \_\_\_\_\_  
☐ Other: \_\_\_\_\_

**6. Do you and your child live in the same home?** ☐ Yes      ☐ No

**If No, where does your child live?**

## Section II. Home and Community Participation

We are interested in finding out about the activities that your child participates in at home, school and in the community.

You will be asked about your child's current level of participation with activities as compared to other children his or her age. For each item, choose one of the following responses:

- **Age expected (Full participation)**, your child participates in the activities the same as or more than other children his or her age. [*With or without assistive devices or equipment*]
- **Somewhat limited**, your child participates in the activities somewhat less than other children his or her age [*Your child may also need occasional supervision or assistance*]
- **Very limited**, your child participates in the activities much less than other children his or her age. [*Your child may also need a lot of supervision or assistance*]
- **Unable**, your child can not participate in the activities, although other children his or her age do participate.
- **Not applicable**, other children your child's age would not be expected to participate in the activities.

Please select one answer by placing an X in one of the columns next to each item. If you are not sure, choose your best guess.

| Compared to other children your child's age, what is your child's current level of participation in the following activities?                                                                                                                                                                                                    | Age expected | Somewhat limited | Very limited | Unable | Not applicable |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|------------------|--------------|--------|----------------|
| <b>HOME PARTICIPATION</b>                                                                                                                                                                                                                                                                                                        |              |                  |              |        |                |
| 1) Social, play or leisure activities with family members at home (e.g., games, hobbies, "hanging out")                                                                                                                                                                                                                          |              |                  |              |        |                |
| 2) Social, play or leisure activities with friends at home (can include conversations on the phone or internet)                                                                                                                                                                                                                  |              |                  |              |        |                |
| 3) Family chores, responsibilities and decisions at home ( <i>For younger children</i> this may be getting things or putting things away when asked or helping with small parts of household chores; <i>For older children</i> this may be more involvement in household chores and decisions about family activities and plans) |              |                  |              |        |                |
| 4) Self-care activities (e.g., eating, dressing, bathing, combing or brushing hair, using the toilet)                                                                                                                                                                                                                            |              |                  |              |        |                |
| 5) Moving about in and around the home                                                                                                                                                                                                                                                                                           |              |                  |              |        |                |
| 6) Communicating with other children and adults at home                                                                                                                                                                                                                                                                          |              |                  |              |        |                |

| Compared to other children your child's age, what is your child's current level of participation in the following activities?                                                                                   | Age expected | Somewhat limited | Very limited | Unable | Not applicable |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|------------------|--------------|--------|----------------|
| <b>NEIGHBORHOOD AND COMMUNITY PARTICIPATION</b>                                                                                                                                                                 |              |                  |              |        |                |
| 7) Social, play, or leisure activities with friends in the neighborhood and community (e.g., casual games, "hanging out," going to public places like a movie theater, park or restaurant)                      |              |                  |              |        |                |
| 8) Structured events and activities in the neighborhood and community (e.g., team sports, clubs, holiday or religious events, concerts, parades and fairs)                                                      |              |                  |              |        |                |
| 9) Moving around the neighborhood and community (e.g., public buildings, parks, restaurants, movies) [ <i>Please consider your child's primary way of moving around, NOT his or her use of transportation</i> ] |              |                  |              |        |                |
| 10) Communicating with other children and adults in the neighborhood and community                                                                                                                              |              |                  |              |        |                |

| Answer the following 5 questions if your child attends school or another structured educational program such as an early intervention program or day care center. <u>Please specify</u> the type of program your child is attending here: |              |                  |              |        |                |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|------------------|--------------|--------|----------------|
| Compared to other children your child's age, what is your child's current level of participation in the following activities?                                                                                                             | Age expected | Somewhat limited | Very limited | Unable | Not applicable |
| <b>SCHOOL PARTICIPATION</b>                                                                                                                                                                                                               |              |                  |              |        |                |
| 11) Educational (academic) activities with other children in his or her classroom at school                                                                                                                                               |              |                  |              |        |                |
| 12) Social, play and recreational activities with other children at school (e.g., "hanging out," sports, clubs, hobbies, creative arts, lunchtime or recess activities)                                                                   |              |                  |              |        |                |
| 13) Moving around at school (e.g., to get to and use bathroom, playground, cafeteria, library or other rooms and things that are available to other children his or her age)                                                              |              |                  |              |        |                |
| 14) Using educational materials and equipment that are available to other children in his or her classroom/s or that have been modified for your child (e.g., books, computers, chairs and desks)                                         |              |                  |              |        |                |
| 15) Communicating with other children and adults at school                                                                                                                                                                                |              |                  |              |        |                |

| Compared to other children your child's age, what is your child's current level of participation in the following activities?                                                    | Age expected | Somewhat limited | Very limited | Unable | Not applicable |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|------------------|--------------|--------|----------------|
| <b>HOME AND COMMUNITY LIVING ACTIVITIES</b>                                                                                                                                      |              |                  |              |        |                |
| 16) Household activities (e.g., preparing some meals, doing laundry, washing dishes)                                                                                             |              |                  |              |        |                |
| 17) Shopping and managing money (e.g., shopping at stores, figuring out correct change)                                                                                          |              |                  |              |        |                |
| 18) Managing daily schedule (e.g., doing and completing daily activities on time; organizing and adjusting time and schedule when needed)                                        |              |                  |              |        |                |
| 19) Using transportation to get around in the community (e.g., to and from school, work, social or leisure activities) [ <i>Driving vehicle or using public transportation</i> ] |              |                  |              |        |                |
| 20) Work activities and responsibilities (e.g., completion of work tasks, punctuality, attendance and getting along with supervisors and co-workers)                             |              |                  |              |        |                |

**21. Please describe things that help your child participate in the above-mentioned activities (e.g., things that your child does, or that family, friends, or education and rehabilitation professionals do to help your child). Please write clearly.**

**22. Does your child currently use any assistive devices or equipment to help him or her participate? (e.g., adapted eating utensils, shower chair, note-taker for school, daily planner, computer)**

☐ Yes    ☐ No

**If Yes, please describe:**

**23. Have you made any changes to your home, community, school, or work setting to help your child participate? (e.g., rearranging furniture and materials; adjusting lighting or noise levels; building a ramp or other physical structures)**

☐ Yes    ☐ No

**If Yes, please describe:**

### Section III. Problems Experienced in Daily Life

The following is a list of possible problems that your child may be experiencing as a result of his or her diagnosis or condition. Please put an ☒ in the box under the appropriate column indicating whether each area listed is “No Problem,” a “Little Problem” or a “Big Problem” for your child.

| A. Child-Related                                                                                         | No Problem               | Little Problem           | Big Problem              |
|----------------------------------------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|
| 1. Paying attention or concentrating                                                                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Remembering people, places or directions                                                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Problem solving or judgment                                                                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Understanding or learning new things                                                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Controlling behavior, moods or activity level                                                         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Motivation (lacks interest or initiative)                                                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. Psychological (e.g., depression or anxiety)                                                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Speech                                                                                                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. Vision                                                                                                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. Hearing                                                                                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. Movement (balance, coordination, muscle tone)                                                        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. Strength or energy level (e.g., weakness or fatigue)                                                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. Reacting to sensation or stimulation (e.g., over- or under- reacts to sound, light, touch, movement) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. Physical symptoms (e.g., headaches, dizziness, pain)                                                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Specify → _____                                                                                          |                          |                          |                          |
| 15. Other health and medical <u>conditions</u>                                                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Please list specific conditions: \_\_\_\_\_

Does your child have any health or medical restrictions on his or her daily life activities (e.g., physical contact sports)?

☐ Yes ☐ No

**If Yes**, please identify:



The following is a list of possible problems your child may be experiencing with the physical or social aspects of the home and other places in the community OR with the quality or availability of services or assistance that he or she needs. Please put an ☒ in the box under the appropriate column next to each problem listed below.

| B. Environment-Related                                                                                                               | No Problem               | Little Problem           | Big Problem              | Not Applicable           |
|--------------------------------------------------------------------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. Problem with design and layout of <u>home</u><br>(Hard to get to places and things, or hard to see or hear important information) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Problem with design and layout of buildings and places your child uses in the <u>community or neighborhood</u>                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Problem with design and layout of <u>school or work setting</u> (Circle <u>school</u> or <u>work</u> )                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Lack of support and encouragement for your child in the <u>community or neighborhood</u>                                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Lack of support and encouragement for your child at <u>school or work</u> (Circle <u>school</u> or <u>work</u> )                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Problems with people's attitudes toward your child at <u>school or work</u> (Circle <u>school</u> or <u>work</u> )                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. Problems with people's attitudes toward your child in the <u>community or neighborhood</u>                                        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Inadequate or lack of assistive devices or equipment                                                                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. Inadequate or lack of assistance from people at <u>home</u> or in the <u>community or neighborhood</u>                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. Inadequate or lack of assistance from people at <u>school or work</u> (Circle <u>school</u> or <u>work</u> )                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. Inadequate or lack of transportation                                                                                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. Inadequate or lack of programs and services at <u>school</u>                                                                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. Inadequate or lack of programs and services in the <u>community or neighborhood</u>                                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**B. Environment-related  
(continued)**

|                                                                                                                                                                     | No<br>Problem            | Little<br>Problem        | Big<br>Problem           | Not<br>Applicable        |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 14. Inadequate or lack of family finances                                                                                                                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. Family stress                                                                                                                                                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. Crime or violence in the <u>community or</u><br>neighborhood                                                                                                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. Problems with government agencies and<br>programs                                                                                                               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 18. Inadequate or lack of information about your<br>child's diagnosis or condition and/or intervention<br>approaches (e.g., educational, rehabilitation or medical) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**Other problems or comments:**

## Section IV A. Child's Current Services

**1. Does your child receive special education or early intervention services?** ☐ Yes ☐ No

**If yes, where? (select one answer)**

- |                                                                                |                                                           |
|--------------------------------------------------------------------------------|-----------------------------------------------------------|
| <input type="checkbox"/> Regular classroom                                     | <input type="checkbox"/> Resource room in regular school  |
| <input type="checkbox"/> Regular class and resource room                       | <input type="checkbox"/> Separate class in regular school |
| <input type="checkbox"/> Separate class and regular class<br>in regular school | <input type="checkbox"/> Special day school               |
| <input type="checkbox"/> Residential school                                    | <input type="checkbox"/> Home                             |

Other: \_\_\_\_\_

**2. Please identify whether your child is receiving any of the following services:**

- |                           |                                                          |                             |                                                          |
|---------------------------|----------------------------------------------------------|-----------------------------|----------------------------------------------------------|
| Occupational Therapy      | <input type="checkbox"/> Yes <input type="checkbox"/> No | Physical Therapy            | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Speech & Language Therapy | <input type="checkbox"/> Yes <input type="checkbox"/> No | Audiology                   | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Psychology/Counseling     | <input type="checkbox"/> Yes <input type="checkbox"/> No | Independent Living Services | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Vocational Rehabilitation | <input type="checkbox"/> Yes <input type="checkbox"/> No | Home Health/Nursing         | <input type="checkbox"/> Yes <input type="checkbox"/> No |
- Others: \_\_\_\_\_

**3. In general, how satisfied or dissatisfied are you with your child's current services?**

☐ Very Satisfied    ☐ Somewhat Satisfied    ☐ Somewhat Dissatisfied    ☐ Very Dissatisfied

**If you are dissatisfied in any way, please describe why:**

## **Section IV B. Family Services**

**1. In general, how would you rate your family's quality of life?**

☐ Poor      ☐ Fair      ☐ Good      ☐ Very Good      ☐ Excellent

**2. Do you or other family members currently receive services related to your child's diagnosis or condition?**

☐ Yes      ☐ No

**If Yes, please describe:**

**3. Are there any services, assistance, or information that you or other family members need in relation to your child's diagnosis or condition, that are not being provided?**

☐ Yes      ☐ No

**If Yes, please describe:**

## **Section V. Suggestions and Additional Information**

**1. Do you have any suggestions to improve services at our program to better address the needs of your child and family?** ☐ Yes      ☐ No

**If Yes, please describe:**

**2. Is there anything else you would like to tell us that was not addressed in our survey?**

☐ Yes      ☐ No

**If Yes, please describe:**

**Thank you for completing this survey!**

*The Child & Family Follow-up Survey (CFFS) was originally developed by*

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