

Developing a follow-up survey focused on participation of children and youth with acquired brain injuries after discharge from inpatient rehabilitation

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Abstract. *Objective:* To describe the development and content of a follow-up survey designed to monitor needs and outcomes of children and youth with acquired brain injuries (ABI) and their families after discharge from inpatient rehabilitation. Preliminary findings pertaining to the core measure of the survey that focused on participation in home, school and community life will be presented as well.

Methods: The follow-up survey was completed by sixty caregivers of children with ABI discharged from one pediatric inpatient rehabilitation program in the Northeast, USA. Time since discharge ranged from 4 months to 6.5 years. Children's ages at discharge ranged from 4 months to 21 years and at follow-up ranged from 3 to 27 years.

Results: Preliminary evidence of reliability, internal consistency and criterion-related validity was demonstrated for the participation measure. Results from exploratory factor analyses and Rasch analyses suggest that the participation measure may be measuring essentially one construct that may encompass two dimensions: Participation in movement-related activities and participation in communication and school-based social activities. Age, activity performance and child and environmental factors were associated with children's overall extent of participation.

Conclusions: The results presented are preliminary yet promising. The follow-up survey is being further developed and tested. Future research also will investigate clinical utility, differences in scores among children and youth with different diagnostic conditions, and feasibility of creating separate versions of the participation measure for different age groups.

Keywords: Pediatric rehabilitation, outcome measurement, International Classification of Functioning

1. Introduction

Children and youth with traumatic and other acquired brain injuries (ABI) frequently experience restrictions in their participation in home, school and community life [1,2]. *Participation*, as defined in the International Classification of Functioning, Disability and Health (ICF), is the nature and extent of involve-

ment in life situations and events [3]. Participation is differentiated from *Activity*, another ICF term which pertains to the execution of tasks and actions, by its focus on either being or doing with others in a social context. Children learn how to interact, work and live with others through their participation in real-life situations and activities [1,2,4–13].

There is evidence that suggests that the extent of participation is associated with the quality of life of children and youth with and without disabilities [4–7]. In Werner's longitudinal study that followed high-risk children into young adulthood, it was found that the resilient children and youth often had at least one but usually several close friends, and participated in a num-

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ber of extra-curricular activities [4]. Participation was reported to be an important part of the resilient children's lives, especially activities that involved cooperation with others. Based on data from Canada's National Longitudinal Survey of Children and Youth, Law reported that youth who had previously participated in organized activities and stopped were 3 times more likely to have lower self-esteem, have difficulty making friends, smoke, and have poor reading and math skills than children who continued to participate in these activities [5]. Newacheck and Halfon conducted a cross-sectional analysis of data on children younger than 18 years in the USA from the National Health Interview Survey ($n = 99,513$) and reported that 6.5% of the children had some type of disability that was associated with long-term reductions in their social role activities such as school and play [6]. They estimated that childhood disability resulted in 66 million restricted activity days annually which included 24 million days lost from school. Other research has shown that children and youth with disabilities including ABI are often most restricted in their involvement in education, active recreation, and social and productive activities in the community [1,2,5–13].

There are a number of environmental and child-related factors that may have an impact on the nature and extent of participation of children and youth with ABI and other disabilities. The reader is also referred to King and colleagues for an extensive literature review of the child and environmental factors that may influence the participation of children with a variety of disabilities [7].

Environmental factors, as conceptualized in the ICF [3], are aspects of the physical, social and attitudinal environment in which people live their everyday lives. Environmental factors that may influence participation include the availability and quality of services, equipment, social support, assistance from others, as well as institutional policies and discrimination [7,8,14,15]. For example, Law and colleagues found that parents of children with physical disabilities living in Ontario, Canada more frequently reported social or attitudinal environmental barriers, such as problems associated with institutional policies and attitudes of others, than physical environmental problems [8]. Edwards and colleagues found that adolescents with disabilities reported lower quality of life than adolescents without disabilities and that social and attitudinal environmental factors had an influence on their quality of life [9]. Forty-six percent of the adolescents with disabilities reported missing out on desired activities compared with 16% of those without disabilities.

Family functioning and resources are examples of environmental factors that have been associated with long-term rehabilitation outcomes of children and youth with ABI and their families [16–18]. Rivara and colleagues found pre-injury family functioning and injury severity to be predictive of academic performance and behavioral outcomes in children with TBI one-year post-injury [16]. Family functioning was a strong predictor of behavioral outcomes and a somewhat weaker predictor of academic performance. Yeates and colleagues also found pre-injury family functioning and severity of injury to be highly predictive of the cognitive and behavioral functioning of children with TBI at 6 and 12 months post-injury [17]. Taylor and colleagues reported on the bidirectional influences of family functioning on outcomes for the child with TBI and of the child's functioning on family outcomes [18]. Higher family distress at 6 months post-injury predicted more child behavioral problems at one year and more child behavioral problems at 6 months predicted poorer family functioning at 1 year.

Child-related factors, are a combination of personal factors, health-related factors and body functions internal to the child and youth. Personal factors are characteristics about individuals, such as their age, gender, preferences, or beliefs that are not part of their primary health condition [3]. Health-related factors are symptoms associated with the child's primary health condition such as headaches, seizures or other condition-related symptoms or medical complications. Body functions are defined within the ICF as physiological functions of body systems such as cognitive, psychological and sensory motor functions and impairments are problems with body functions [3].

Age, development, type and severity of the brain injury, and neurobehavioral functions and symptoms are examples of child-related factors that have been associated with long-term rehabilitation outcomes in children and youth with ABI [1,19–21]. With respect to age and development, Taylor and Alden's synthesis of the literature suggest that development and acquisition of knowledge and skills may be affected more in children who acquired their brain injuries at younger ages [19]. Differences in the effects of age on outcome were reportedly most evident in studies that compared children who were younger than 7 years to older children and youth. Jaffe and colleagues found no significant differences between children and youth with mild brain injuries and age-matched peers without disabilities on neurobehavioral, intellectual, daily living and school outcomes [20]. On the other hand, they

found that children and youth with moderate to severe brain injuries demonstrated significant deficits in these same areas with greater severity associated with poorer outcomes. Barry and colleagues examined whether a checklist which included a number of neurobehavioral functions and symptoms would be predictive of neuropsychological functioning of children with TBI and family functioning at 6 months post-injury [21]. Results showed that the total number of neurobehavioral functions and symptoms predicted lower cognitive and academic performance, general adjustment problems, decreased adaptive functioning and poorer family functioning.

Mancini and colleagues examined predictors of school participation in children with a variety of disabilities and found that scores from measures of activity performance (physical and cognitive-behavioral functional abilities) were highly predictive of school participation and were better predictors than the type or severity of the child's impairment [10]. Bedell and colleagues also found that scores from activity performance measures (social behavioral, mobility and self-care abilities) of children and youth with ABI were the strongest predictors of their reported readiness to participate in the community at discharge from inpatient rehabilitation [2]. Although a number of studies suggest that many child factors are associated with outcomes related to participation, results from these last two studies suggest that activity performance may be more directly linked to participation [2,10]. One possible explanation for this is that children participate in activities and that measures of participation may, in part, incorporate an activity component.

Promoting participation in social and productive activities by children and adults with disabilities and reducing the impact of factors that hinder their active participation are targeted outcomes of Healthy People 2010, the current health agenda in the USA [23]. Other aims of Healthy People 2010 of particular importance to rehabilitation professionals are preventing secondary conditions – medical, social, emotional, mental, family or community problems that persons with disabilities may experience – and eliminating health disparities between people with and without disabilities. To monitor whether the objectives set forth in Healthy People 2010 are being addressed and achieved for children and youth with ABI and their families in the community, programs will need to collect data in a systematic way that reflects their long-term rehabilitation needs and outcomes.

Currently, there are no follow-up surveys or outcome-monitoring systems being used on a large-scale basis

to systematically collect data on the long-term rehabilitation needs and outcomes of children and youth with ABI and their families in the USA. The National Pediatric Trauma Registry (NPTR) has collected data on children and youth from birth to 19 years of age admitted to pediatric trauma centers or hospitals related to an acute trauma-related injury such as Traumatic Brain Injury, but has not collected data on long-term outcomes focused on participation in home, school and community life [24]. The Traumatic Brain Injury (TBI) Model Systems National Database [25–27] collects data on long-term outcomes of individuals sixteen years and older with TBI with 28% of these data related to the youngest age category aged 16 to 24 years (S. Millis, personal communication, May 5, 2004). However, specific data related to youth (16 to 18 years old) are not distinguished from young adults in the youngest age category when data are reported from the TBI Model Systems National Database [26]. This lack of differentiation makes it difficult to examine outcomes related to participation of youth with TBI who have different developmental and life challenges than young adults with TBI. Furthermore, existing measures such as the Craig Hospital Assessment Reporting Technique (CHART) and Community Integration Questionnaire (CIQ) that have been used extensively to monitor long-term outcomes related to participation of adults with TBI and other disabilities may not be appropriate for use with children and youth due to the wide range of developmental and experiential differences between these age groups [28,29].

An outcome monitoring instrument designed to collect information about participation of children and youth with TBI and other acquired brain injuries in home, school and community activities would be particularly useful since this is a targeted goal of Healthy People 2010 and the ultimate aim of rehabilitation [23]. This information could provide insights to assist with ongoing program improvements and to help consumers compare the performance of different programs on achieving these long-term rehabilitation outcomes [30]. Understanding the environmental and child-related factors that may affect participation could provide additional insights to assist with intervention efforts to promote children's participation in home, school and community life.

The purpose of this article is to describe the development and content of a follow-up survey designed to monitor needs and outcomes of children and youth with ABI and their families after discharge from inpatient rehabilitation. A description of the core measure of

the survey that focuses on participation in home school and community life and a detailed summary of preliminary psychometric findings pertaining to this measure will be presented. The survey measures that address environment and child-related factors that may affect participation will be briefly described as well.

2. Child and Family Follow-up Survey (CFFS): Development and recruitment procedures

The CFFS was developed to monitor the rehabilitation and education needs and outcomes of children and youth with ABI and their families who were discharged from Franciscan Children's Hospital and Rehabilitation Center (FCH) in Boston, Massachusetts, USA. The key focus of the survey was to monitor participation in home, school and community life of children and youth with ABI after discharge and other factors that may have an impact on their participation. It was hoped that the information obtained from the CFFS would provide insights that could assist with making ongoing improvements focused on inpatient rehabilitation services and community discharge planning and follow-up.

The ICF [3] and targeted rehabilitation outcomes from Healthy People 2010 [23] were used to guide survey design along with feedback from program stakeholders such as rehabilitation service providers and administrators, and family caregivers of children with ABI who previously received services at the program. Existing measures and literature were reviewed that covered a broad range of needs and outcomes associated with children and youth with ABI and their families and the factors that may be associated with these needs and outcomes over time. This review increased the likelihood that the survey included items and content domains that were relevant to the long-term health and functioning of children and youth with ABI from a wide-range of age groups and socio-cultural contexts [27,31]. Literature and items pertinent to young adulthood were included as well since pediatric inpatient rehabilitation programs often vary in their admission criteria and include young adults with ABI. For example, admission criteria at FCH include young adults up to 22. Furthermore, there is a lack of follow-up information on young adults who acquire their brain injury during childhood or youth or who are admitted to pediatric inpatient rehabilitation units [32,33].

Development of the CFFS initially focused on how to design a follow-up survey that would best fit the needs of this one program, and then how other pro-

grams may be able to use or adapt the survey for their own needs and purposes. For example, inpatient or community programs could use the information from individual items or summary scores from the measures within the CFFS to monitor the needs and outcomes of current or past recipients of their services and this information could provide insights for ongoing program improvements.

Phase 1 of the development of the CFFS involved review of the existing inpatient rehabilitation program database at FCH and generating a list of 194 names of children and youth with ABI and their caregivers discharged between September 1994 and March 2001. Postal addresses were available for 168 families. From this list of 168 families, a random list of 50 names of families was produced, and these families were sent the phase 1 version of the CFFS along with an informed consent form and a cover letter describing the project. Twenty-one of the 50 caregivers volunteered to participate and were administered the initial version over the telephone by one of three interviewers. Survey administration time was roughly 45 minutes, yet ranged from 30 to 60 minutes. Caregivers were also asked about the clarity and importance of the individual questions on the CFFS and for additional topics that should be included. In addition, eight interdisciplinary rehabilitation and education service providers and administrators at FCH were interviewed about important topics to be addressed after discharge from inpatient rehabilitation pertaining to community integration and participation [34]. The survey was revised based on data collected from the phase 1 CFFS, feedback from providers and consumers from FCH, and advice from two individuals with combined expertise in measurement development and pediatric rehabilitation.

In phase 2, the revised (phase 2) version of the CFFS was sent to the same list of 168 families with available postal addresses, accompanied by an informed consent form and a cover letter describing the project. The 50 families who were asked to participate in phase 1 were asked to participate in phase 2 as well. A second letter with the same materials was sent within 3 to 4 weeks to families who did not respond to the initial letter requesting their participation. Thirty-nine (23%) of the 168 phase 2 surveys were returned as undeliverable. Sixty (47%) of the remaining 129 surveys were completed by caregivers – 59 surveys were completed and returned by mail and one survey was conducted over the phone since this was the preferred method of administration for this particular caregiver. Sixty-nine (53%) surveys were not returned.

Based on analyses of the available data on all 168 prospective participants obtained from the database at FCH, there were no statistically significant differences on selected characteristics between the children from the caregivers who responded to the survey ($n = 60$) and the children from caregivers who did not respond to the survey ($n = 69$). Selected characteristics that were examined included type of brain injury, gender, race, ethnicity, age at discharge, time since discharge, length of inpatient rehabilitation stay, discharge living setting and discharge scores from the Pediatric Evaluation of Disability Inventory (PEDI) [35]. These data are presented elsewhere [1].

Phase 3 involved obtaining additional feedback from content and measurement experts and making revisions to the survey based on this feedback and psychometric testing. The newest (phase 3) version of the CFFS, available upon request from the author, has minor revisions and is currently being tested with caregivers of children with ABI and other conditions between the ages of 3 and 21. The sample, instrument content description, and summary of preliminary results presented in this article are based on the phase 2 development and version of the CFFS.

3. Child and Family Follow-up Survey (CFFS): Content description

The CFFS consists of five sections with closed and open-ended questions. Family caregivers can complete the postal mail survey on their own or be administered the survey in person or over the phone. A web-based survey also has been designed, but has not yet been implemented. Section 1 asks six questions about the child's physical and emotional health and well-being, primary way of moving around and communicating, and medical problems or hospitalizations within the last year or since leaving the program. Section 2 includes the Child and Adolescent Scale of Participation (CASP) (described later) and three subsequent open-ended questions about equipment, modifications or strategies that are used to promote the child's participation. Section 3 includes the Child and Adolescent Factors Inventory (CAFI) and Child and Adolescent Scale of Environment (CASE) (both described later) and a question about health or medical restrictions on the child's daily activities. Section 4 asks three questions about the child's current educational placement, rehabilitation and health services, and satisfaction with services. Three additional questions are asked in Sec-

tion 4 about the family's quality of life, and current services and needs. Finally, Section 5 has two questions that ask for suggestions to improve services at the program from where the child was discharged to better address the needs of the child and family and for additional information that was not addressed in the CFFS.

The only demographic information that is asked on the CFFS is the child's name and current living situation, caregiver respondent's name and relationship to the child, and date the caregiver completed the CFFS. Since the CFFS was designed as a follow-up survey, it was assumed that programs would have existing demographic data in medical charts or program – specific databases. Programs that did not have easy access to this information would need to create a supplemental demographic form with information that would suit their particular needs. Available data obtained from the database at FCH included admission and discharge dates, length of stay, and admission and discharge scores from the Pediatric Evaluation of Disability Inventory (PEDI) [35]. The PEDI is used frequently in pediatric rehabilitation to measure functional activity in three sub-domains (self-care, mobility and social function) and has well documented evidence of reliability and validity [35,26,37]. The PEDI Functional Skills Subscales measure children's capability to perform activities, consistent with the general definition of Activity in the ICF [3].

3.1. The Child and Adolescent Scale of Participation (CASP)

The CASP consists of 20 items that were developed from life domains identified in the literature, the ICF, and by consumers and professionals at FCH. Items pertain to activities or events that children are involved in at home, school or in the community such as social, play, self-care, mobility, communication, educational, independent living and work activities. A full list of the items is included in Appendix A. Family caregivers are asked: "Compared to other children your child's age, what is your child's current level of participation in the following activities?" Each item is rated on a 4-point rating scale: Age-expected (4), somewhat limited (3), very limited (2), or unable (1). Caregivers are provided with the following rating criteria for each response option:

- *Age-expected*: 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 (may also need occasional supervision and assistance)
- *Very limited*: Your child participates in much less than other children his or her age (may also need a lot of supervision or assistance)
- *Unable*: Your child does not participate in the activities, although other children his or her age do.

In addition, a “not applicable” response option is provided for each item that caregivers would select if they believed that other children of their child’s age would not be expected to participate in the activities identified.

CASP summary scores are calculated by summing the scores from each applicable item, dividing this number by the maximum possible score (based on the number of applicable items rated), and multiplying this number by 100 to conform to a 100-point scale. Higher scores indicate a greater extent of age-expected participation.

3.2. *The Child and Adolescent Factors Inventory (CAFI)*

The CAFI items are presented in Appendix B along with a description of the items that were modified or added in the phase 3 version. The phase 2 version of the CAFI consisted of 10 items that pertain to cognitive, psychological and sensory motor functions with which children with ABI may experience difficulty as well as health-related problems. The CAFI and the CASE (described next) are both included in the same section of the larger survey (CFFS) entitled, “Problems experienced in daily life”. Family caregivers are given a list of possible problems that their child may be experiencing as a result of his or her diagnosis or condition. Each item or problem is rated on a 3-point scale: No problem (1), little problem (2), and big problem (3). CAFI summary scores can be calculated by summing the scores from each item, dividing this number by the maximum possible score, and multiplying this number by 100 to conform to a 100-point scale. Higher scores indicate a greater number of child-related problems, a greater impact of child-related problems or a combination of the two.

3.3. *Child and Adolescent Scale of Environment (CASE)*

The CASE was developed based on the items and conceptualization of the Craig Hospital Inventory of Environmental Factors (CHIEF) [14], a measure used to monitor the frequency and intensity of physical, social and attitudinal environment problems experienced by adults with disabilities. With permission from the primary author, the CHIEF was modified so that a measure could be administered to family caregivers of children and adolescents with disabilities. Some items from the CHIEF were modified or deleted and some new items were developed to create the CASE. The CASE only examines intensity of the problem, unlike the CHIEF which examines both frequency and intensity. The CASE items are presented in Appendix C along with a description of the items that were modified or added in the phase 3 version.

The phase 2 version of the CASE consisted of 15 items of physical, social and attitudinal environmental problems that children may experience at home, school or in the community. In the larger survey (CFFS) the CASE is presented in the same section as and immediately after the CAFI. Family caregivers are given a list of possible problems that their child may experience in relation to the physical or social aspects of the home and other places in the community and the quality or availability of services, support or assistance from others. Each item or problem is rated on a 3-point scale: No problem (1), little problem (2), and big problem (3). CASE summary scores can be calculated by summing the scores from each item, dividing this number by the maximum possible score, and multiplying this number by 100 to conform to a 100 point scale. Higher scores indicate a greater number of environmental problems, a greater impact of environmental problems or a combination of the two.

4. Results

4.1. *Sample*

Sixty family caregivers responded to the survey. The respondents were mothers ($n = 51$), fathers ($n = 4$) or other legal guardians ($n = 5$). The time since their children were discharged from inpatient rehabilitation was approximately 4 months to 6.5 years ($\bar{X} = 3.5$, $SD = 1.85$ years). The ages of the children at discharge ranged from 4 months to 21 years ($\bar{X} = 9.7$,

Table 1
Selected sample characteristics ($n = 60$)

Characteristic	Frequency	Percentage
<i>Type of acquired brain injury</i>		
Traumatic brain injury	38	63.3%
Brain tumor	7	11.7%
Stroke	7	11.7%
Seizure disorder	4	6.6%
Brain infection	3	5.0%
Anoxia	1	1.7%
<i>Age at follow-up (years)</i>		
6 or younger	5	8.3%
6.01–12	20	33.3%
12.01–15	10	16.7%
15.01–18	11	18.3%
18.01–21	13	21.7%
21.01 or older (27 years)	1	1.7%
<i>Race/Ethnicity</i>		
Caucasian	46	76.6%
African american	7	11.7%
Hispanic	5	8.3%
Asian	1	1.7%
Other/unreported	1	1.7%
<i>Gender</i>		
Female	31	51.7%
Male	29	48.3%

SD = 4.7 years) and at follow-up ranged from 3 to 27 years ($\bar{X} = 13.2$, SD = 5.2 years). At the time of the follow-up interview, data were collected on 60 children, youth and young adults. Table 1 presents descriptive statistics (frequencies/percentages) related to type of acquired brain injury, specific age category at follow-up, race/ethnicity and gender. No information about the severity of brain injury was available from the existing database, however children were admitted to the program with moderate to severe activity limitations as measured by the PEDI [3,35]. Data pertaining to prior medical history, co-morbidities, and pre-injury functioning and education were not examined since these data were not systematically recorded in the database.

4.2. Summary of preliminary psychometric findings

Descriptive data on the items from the CASP, CAFI and CASE and additional psychometric data based on the responses from this sample have been described elsewhere [1,38,39]. Preliminary evidence of test-retest reliability was demonstrated for all three measures in the CFFS based on the intra-class correlation coefficient ($n = 33$; CASP = 0.94; CAFI = 0.67; CASE = 0.75; $p < 0.001$). The summary to follow will present and discuss selected preliminary findings

pertaining to the core measure of the CFFS, the Child and Adolescent Scale of Participation (CASP).

The CASP summary scores ranged from 0 to 100 ($\bar{X} = 79$; SD = 19). On average, children younger than 6 years of age ($n = 5$; $\bar{X} = 65$, SD = 14) had the lowest CASP summary scores and youth between ages 15 and 18 had the highest scores ($n = 11$; $\bar{X} = 92$, SD = 4.8) followed by children between the ages of 12 and 15 ($n = 10$; $\bar{X} = 84$, SD = 10). Exploration of ceiling and floor effects indicated that seven (12%) persons scored at the ceiling and one person (1.5%) scored at the floor. As expected, a number of items were not applicable to the younger children, especially those items related to Home and Community Living Activity (HCLA). The one HCLA item pertaining to work was applicable to only 35% of the sample ($n = 21$) and the other four HCLA items were applicable only for approximately half ($n = 26 - 31$) of the sample (see Appendix A).

The CASP summary scores were positively correlated with discharge scores from the Pediatric Evaluation of Disability Inventory (PEDI) Functional Skills Subscales [35] obtained from the existing database at the inpatient rehabilitation program. On average, children with higher ability in functional activity as reflected by higher PEDI scores had a greater extent of age-expected participation as indicated by higher CASP summary scores ($r = 0.72$, self-care; $r = 0.65$, social function; $r = 0.51$, mobility, $p < 0.01$).

CASP summary scores also were negatively correlated with summary scores from the CASE ($r = -0.57$, $p < 0.01$) and CAFI ($r = -0.58$, $p < 0.01$). Children with more or a greater impact of environmental and child-related problems as reflected by higher CASE and CAFI summary scores had a lesser extent of age-expected participation as indicated by lower CASP summary scores.

The internal consistency and structure of the CASP was investigated to assess whether it was measuring essentially one construct, "Extent of Age-expected Participation". High internal consistency was demonstrated for the items on the CASP based on data from participants who responded to all 20 items as applicable ($n = 21$; Cronbach's alpha = 0.98) and based on data from all participants with non-applicable item scores replaced with their respective mean scores ($n = 60$; Cronbach's alpha = 0.95). In addition, each item was moderately to highly correlated with the total test score as reflected by point biserial correlations ranging from 0.67 to 0.81.

Exploratory factor analysis and Rasch analysis were used to examine the internal structure or dimensional-

ity of the CASP. Factor analysis identifies patterns of items that are linearly correlated with each other with the assumption that these patterns or factors are measuring the same construct or the same dimension of a construct. Principal components analysis was used for the initial extraction of the patterns of correlated items or components. Varimax rotation was used to ease in the interpretation of these patterns by shifting the items so that they were more likely to load or correlate more strongly onto one pattern or factor instead of more than one factor [40].

Table 2 presents the results from the exploratory factor analysis. Two factors were identified with eigen values greater than one that together contributed approximately 78% of the total variance explained. Most items loaded on both factors. Sixteen of the 20 items had factor loadings above 0.4 on the first and second factor. Items with higher or more distinct factor loadings on the first factor involved participation in movement-related activities like mobility, using educational materials, self-care and some of the home and community living activities. Items with higher or more distinct factor loadings on the second factor involved participation in communication at home, school and the community and social-based school activities.

Rasch analysis is a probabilistic measurement model often used to examine the properties of scales designed to measure essentially one unidimensional construct [41,42]. The Rasch model is based on the premise that data pertaining to items and persons from any unidimensional scale must adhere to some reasonable hierarchy or order of “less than” and “more than” on a single continuum or metric [42]. Item difficulty (the extent to which children are likely to experience participation restrictions on each item) and the child’s summary scores (overall extent of age-expected participation) are estimated on the same metric. The logit, the natural log of an odds ratio, is the basic unit of measurement.

According to the Rasch model, children with a greater extent of age-expected participation would be expected to participate in more difficult CASP items than children with a lesser extent of age-expected participation, and more children would be expected to participate in less difficult items than more difficult items. Fit statistics can be generated to identify how well the items or children fit with this expected pattern of responses [43].

Table 3 presents selected results pertaining to the CASP items based on Rasch analyses conducted with the WINSTEPS software program [43]. Other Rasch-

based findings have been presented elsewhere [38]. The first column identifies the items in the order of item difficulty – items that are most to least difficult to participate or most to least likely to be restricted in when compared to same age peers. The second column provides the logit values which reflect average item difficulty level. Higher positive logit values indicate greater item difficulty and lower values indicate lesser item difficulty. The third column provides the standard error associated with each item’s logit value, an indicator of measurement precision. The fourth and fifth column are the fit statistics presented as mean squares. The infit statistic is an indicator of unexpected responses from children whose extent of age expected participation are close to the difficulty level of the item. The outfit statistic is outlier sensitive and an indicator of unexpected responses from children whose extent of age expected participation are far from the difficulty level of the item. Mean square fit statistics above 1.3 may indicate misfit or deviation from the expected pattern. Mean square fit statistics below 0.6 may indicate redundancy in the items or a more rigid deterministic ordering of the items [41,42].

The item difficulty levels and order presented in Table 3 (column 1 and 2) indicate that activities that involved more simple actions or skills acquired at a younger age such as mobility, communication, self-care and use of school materials and activities that occurred at home and with family members generally were less difficult to participate in (or less likely to be reportedly restricted in) when compared to children of the same age. Activities or situations that involved more complex actions or skills acquired at an older age such as the home and community living activities, that involved more social interaction with friends or classmates and that occurred at school or in the community, generally, were more difficult to participate in (or more likely to be reportedly restricted in) when compared to children of the same age.

The results in column 3 of Table 2 indicate somewhat large standard errors associated with each item’s difficulty level (logit value) which may reflect some measurement imprecision. The results in column 4 and 5 also suggest that three CASP items (work, shopping – managing money, and educational activities with others) may be misfitting or deviating somewhat from the expected pattern based on their fit statistics greater than 1.3.

Table 2
Child and Adolescent Scale of Participation (CASP): Factors and factor loadings

Participation items	Factor 1	Factor 2
1. Home: Social/play (family)	0.570	0.696
2. Home: Social/play (friends)	0.749	0.580
3. Home: Chores/responsibilities	0.588	0.568
4. Home: Self-care	0.873*	0.393
5. Home: Mobility	0.648	0.578
6. Home: Communication	0.347	0.869*
7. Community: Social/play (friends)	0.664	0.543
8. Community: Structured activities	0.598	0.451
9. Community: Mobility	0.892*	0.239
10. Community: Communication	0.547	0.664
11. School: Educational activities	0.209	0.795*
12. School: Social/play (students)	0.377	0.770*
13. School: Mobility	0.809*	0.441
14. School: Using materials	0.659	0.390
15. School: Communication	0.280	0.920*
16. HCLA: Household activities	0.933*	0.267
17. HCLA: Shopping/managing money	0.615	0.568
18. HCLA: Managing daily schedule	0.658	0.561
19. HCLA: Using transportation	0.851*	0.319
20. HCLA: Work activities	0.703*	0.279
<i>Total variance explained</i>	<i>Variance explained</i>	<i>Variance explained</i>
76.87 =	43.42%	33.45%

HCLA = Home and Community Living Activities.

*Higher or more distinct factor loadings.

5. Discussion

This article described the development and content of the Child and Family Follow-up Survey (CFFS) which was designed to monitor needs and outcomes of children and youth with ABI and their families after discharge from inpatient rehabilitation. A more detailed description was provided for the core measure of the survey, the Child and Adolescent Scale of Participation (CASP), and the two measures that address child-related and environment factors that may affect participation, the Child and Adolescent Factors Inventory (CAFI) and Child and Adolescent Scale of Environment (CASE). A summary of preliminary psychometric data pertaining to the CASP was presented as well.

Preliminary psychometric testing of the CASP demonstrated evidence of criterion-related validity reflected by significant correlations between the CASP summary scores and selected variables in directions and with general magnitudes that were expected. It was expected that there would be significant positive associations found between participation (CASP scores) and activity (discharge PEDI scores) since a similar relationship was found in a prior study conducted by the author and colleagues [2]. In this prior study a new measure of community participation readiness at discharge from inpatient rehabilitation was highly correlated with

new measures of activity performance at discharge in children and youth with ABI who received inpatient rehabilitation in eight programs throughout the USA. Furthermore, it was expected that child and environmental factors, as measured by the CAFI and CASE, would be negatively associated with the extent of the children's participation given that the items included in the CAFI and CASE reflect problems identified in the literature that reportedly can have a negative impact on participation. Other preliminary evidence of criterion-related validity has been presented elsewhere [1,38].

The high internal consistency and the results from factor analysis (Table 2) suggest that the CASP may be measuring essentially one construct but may encompass two dimensions: Participation in movement-related activities and participation in communication and school-based social activities. Future research will need to further examine the factor structure of the CASP to know whether it is more valid to use total summary scores, factor-specific scores or both types of scores. Both types of scores are computed when using the CHART and CIQ which measure participation in adults with disabilities [28,29].

The Rasch-based item difficulty levels reported in Table 3 (column 1 and 2) closely matched the a priori conceptualization of the hierarchical order of item difficulty for the construct "Extent of Age-expected

Table 3
Rasch analyses: Item difficulty order, standard errors and fit statistics

Item description (item difficulty order)	Logit	Error	Infit	Outfit
<i>[Most difficult to participate in]</i>				
HCLA: Manage daily schedule	1.46	0.29	1.18	1.14
HCLA: Work*	0.92	0.36	2.02*	1.88
Community:structured events	0.87	0.23	0.84	1.10
HCLA: Shopping – manage money*	0.66	0.33	1.59*	1.44*
HCLA: Household activities	0.65	0.29	0.96	0.85
Community: Leisure with friends	0.41	0.24	0.77	1.04
Home: Family chores	0.26	0.23	0.85	0.90
Home: Play with friends	0.22	0.24	0.75	0.69
School: Educational activities with others*	0.20	0.24	1.50*	1.34*
School: Social – leisure	0.20	0.24	0.96	0.93
HCLA: Using transportation	0.11	0.31	1.09	0.96
Community: Communication	0.04	0.23	0.89	0.79
School: Communication	-0.30	0.25	0.84	0.75
Home: Self-care	-0.35	0.24	0.79	1.07
Home: Social-leisure with family	-0.55	0.25	0.80	0.72
Community: Mobility	-0.66	0.25	1.15	1.27
School: Using materials	-0.76	0.27	1.10	1.03
School: Mobility	-0.90	0.27	0.98	0.79
Home: Communication	-0.97	0.27	0.80	0.77
Home: Mobility	-1.51	0.29	0.81	0.56
<i>[Least difficult to participate in]</i>				

* Possible misfitting items.

HCLA = Home and Community Living Activities.

Participation”, a further indication that the CASP may be measuring basically one unidimensional construct. The order or extent of item difficulty seemed to correspond with the degree of complexity, familiarity and predictability associated with each item’s specified activity and context. Age-expected participation was least likely to be restricted in for activities that involved simpler and more routine actions or skills acquired at younger ages, and that occurred at home with family members. Age-expected participation was more likely to be restricted in for activities that involved more complex actions or skills acquired at an older age, that involved social interaction with peers and that occurred at school or in the community. Similar item domain difficulty trajectories have been identified in relation to activity performance, community readiness skills and school function in children and youth with ABI and other disabilities [2,24,35,44,45].

The somewhat large standard errors (Table 2, column 3) associated with each item’s difficulty level (logit value) suggest that the CASP may not have been able to fully measure item difficulty, although some measurement imprecision was expected given the small size and heterogeneity of this particular sample. Other Rasch-based findings reported elsewhere that pertained to the child’s summary scores (overall extent of age-expected participation) indicated some measurement imprecision as well [27]. Until additional research is

done, all that can be said at this point is that the CASP may provide an approximate estimate of the children’s extent of age-expected participation.

The fact that children six years and younger had the lowest CASP scores also may indicate that the CASP could not fully assess this groups’ extent of age-expected participation, especially since there are a number of items on the CASP that are not applicable for younger children. However, the lower scores may be reflective of the evidence that suggests that poorer outcomes have been associated with younger children with brain injury, especially between children younger than 7 years and older children and youth [16].

Three items on the CASP appeared to deviate somewhat from the expected pattern of responses that was estimated by the Rasch analyses (Table 3, column 4 and 5). The work and shopping - manage money items may have misfit because these items were applicable for the least number of children in the sample (work, $n = 21$; shopping/manage money, $n = 26$). It is unclear why the item, “Educational activities with others”, may have misfit. Family caregivers may have focused more on the child’s academic performance (reading, math), more in line with the ICF construct “activity”, when rating the child on this item rather than focusing on the child’s involvement in educational activities with classmates, more in line with the intended construct “participation” [3]. In fact, this may have been true

for all items on the CASP. Although family caregivers were asked to rate the child's participation in activities associated with each item, caregivers may have based their ratings, in part, on the child's actual performance of these activities. Although the constructs activity and participation are provided with distinct albeit general definitions within the ICF, both constructs pertain to the same domains of functioning which creates a challenge for those developing instruments to measure participation [3].

Family caregivers may have had particular difficulty rating the item "educational activities with others" because they may not have direct knowledge (through observation) or may have varying degrees of direct knowledge of their children's participation in the classroom and school in general. Caregivers may have had similar difficulty rating the other school participation items but may have rated their children's participation on these items based on similar types of activities that they observed their children doing or participating in at home or in the community.

The link between the constructs activity and participation and the child and environmental factors that may affect activity and participation has been discussed in findings presented in this article and previous research. It is possible that the activities in which children and youth with ABI perform and participate follow a similar trajectory based on environment and child-related factors, developmental challenges, and the demands and skill requirements of the activity, situation or setting [31]. One plausible trajectory was demonstrated for this particular sample as reflected by the hierarchical ordering of CASP item difficulty presented in this article. This information along with the other research findings cited may potentially provide insights to rehabilitation and education professionals and families about the timing or sequencing of efforts to promote participation of children and youth with ABI in home, school and community life [45]. However, future investigation is needed since other samples of children and youth with ABI and other diagnoses may demonstrate different participation trajectories.

6. Conclusion

These preliminary findings, although promising in many ways, indicate that further development and testing of the Child and Adolescent Scale of Participation (CASP) and larger Child and Family Follow-up Survey (CFFS) are needed. The findings can not be general-

ized to other children and youth with ABI due to the small sample size and the fact that the sample was recruited from one inpatient rehabilitation program with the majority being Caucasian and having sustained a Traumatic Brain Injury. The findings only reflect the perspectives of the family caregivers who responded to the CFFS who may be different in a number of ways from caregivers who did not respond to the survey. Furthermore, the perspectives of children and youth with ABI were not examined. The CFFS was not designed to be administered to or completed by children, however, it is likely that children would rate themselves somewhat differently from their caregivers on items from the CASP and other CFFS measures (CAFI, CASE) [27].

The CFFS has the potential to be used by programs to monitor rehabilitation outcomes and needs to provide insights that may assist with program improvement. One study has been conducted using the sample described in this study to demonstrate how the information obtained from the CFFS particularly in relation to monitoring participation and child-related and environmental factors can be used for this purpose [1].

In addition to being used as a tool for monitoring program outcomes and needs, the CFFS may have the potential to assist with collaborative intervention planning and service provision decisions for individual children and families. For example, scores on particular items and measures might provide insights about the extent of an individual child's participation restrictions and environment and child-related problems and this information could be discussed during team meetings for making decisions about intervention and service provision [46–48]. In addition, family caregivers and school professionals could be encouraged to complete and discuss the items on the CFFS, particularly the CASP, with which they are most familiar to increase the likelihood that the information is relevant to efforts to promote the children's participation in home, school and community life.

If the CFFS is to be used in the future for individualized service planning, it would be important to seek out the perspectives of the children and youth as well. Although the CFFS was not designed to be administered to or completed by children, family caregivers could be encouraged to seek out their children's perspectives in relation to specific items before they complete the CFFS themselves.

Other data collection methods such as a child-focused interview could be conducted to gain the child's perspective. Measures completed by school professionals such as the School Function Assessment [44]

could be administered to obtain information specifically about school participation. The recent report from the Centers for Disease Control and Prevention (CDC) on assessing long-term outcomes in children and youth with TBI also provides a review of related instruments, many of which can be administered to or completed by children and youth and school professionals [27].

The CFFS and particularly the CASP are being further developed and tested with samples of children and youth with ABI and other conditions. Differences in scores on the items and measures will be examined in relation to diagnostic condition, age and severity of condition. Future research also will investigate how programs use the information gathered from the measures and larger follow-up survey (e.g., for program or individualized intervention planning) and the feasibility of creating separate versions of the CASP for different age groups. The ultimate aim is to have reliable, valid and useful measures to guide efforts to address meaningful participation of children and youth with ABI and other conditions and the environment and child factors that have an impact on their participation – the ultimate aim of rehabilitation.

Acknowledgements

The author would like to thank Ms. Helene Dumas, Project Co-director and Manager, Research Center for Children With Special Health Care Needs, Franciscan Children's Hospital (FCH), the caregivers and providers from FCH who participated in this study; Wendy Coster, Ph.D., OTR and Steve Haley, Ph.D., PT, from Boston University – Sargent College of Health and Rehabilitation Sciences, who provided feedback about content and psychometrics; Gale Whiteneck, Ph.D. who gave permission to modify the Craig Hospital Inventory of Environmental Factors (CHIEF) to be used in the follow-up survey. I also thank Fleet Boston Financial, Trustee of the Deborah Munroe Noonan Memorial Fund, Boston, MA for providing funding for this research and the National Institute on Disability and Rehabilitation Research for funding my post-doctoral research fellowship (Grant # H133P99004) at Boston University – Sargent College to further support this work.

Appendix A: Item content from the Child and Adolescent Scale of Participation (CASP) [phase 2 version]

Home participation

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 (For younger children this may be getting things or putting things away when asked, or helping with small parts of household chores; for older children 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

Neighborhood and community participation

7. Social, play, or leisure activities with friends in the neighborhood and community (e.g., casual games, “hanging out”, going to public places such as 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) – please consider your child's primary way of moving around, NOT his or her use of transportation
10. Communicating with other children and adults in the neighborhood and community

School participation

11. Educational (academic) activities with other children in the classroom
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., getting to and using the bathroom, playground, cafeteria, library, or other rooms and services that are available to other children his or her age)
14. Using educational materials and equipment available to other children in his or her classroom, or using materials and equipment that have been modified for your child (e.g., books,

computers, chairs, and desks)

15. Communicating with other children and adults at school

Home and community living activities

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). Driving vehicle or using public transportation are both applicable.
20. Work activities and responsibilities (e.g., task completion, punctuality, attendance, and getting along with supervisors and co-workers)

Appendix B: List of problem areas on the Child and Adolescent Factors Inventory (CAFI) [phase 2 version]

1. Attention / Memory
2. Problem solving – Judgment/Understanding or learning new things
3. Controlling behaviors, moods or activity level
4. Motivation (lacks interest or initiative)
5. Psychological (e.g., depression or anxiety)
6. Speech
7. Vision
8. Hearing
9. Movement/Strength – Endurance
10. Other health and medical conditions

Note: The newest (phase 3) version has a total of 15 items. Selected items above with more than one problem identified (items #1, 2 and 9) were made into two separate items and the two following items or problem areas were added:

1. Reacting to sensation or stimulation (over- or under-reacting to sound, light, touch, movement)
2. Physical symptoms (e.g., headaches, dizziness, pain)

Appendix C: List of problems on the Child and Adolescent Scale of Environment (CASE) [phase 2 version]

1. Problem with physical design of home

2. Problem with physical design of community or neighborhood
3. Problem with physical design of school or work
4. Lack of support in the community or neighborhood
5. Lack of support at school or work
6. Problem with people's attitudes in the community or neighborhood
7. Problem with people's attitudes at school or work
8. Inadequate or lack of assistance or equipment at home
9. Inadequate or lack of assistance or equipment in the community
10. Inadequate or lack of assistance or equipment at school or work
11. Inadequate or lack of transportation
12. Inadequate or lack of programs and services at school
13. Inadequate or lack of programs and services in the community
14. Problems with government agencies and policies
15. Inadequate or lack of information about your child's diagnosis or condition or intervention approaches (e.g., educational, rehabilitation, or medical)

Note: The newest (phase 3) version has a total of 18 items. Modifications in wording were made to some of the items above and the following three items or problems were added:

1. Inadequate or lack of family finances
2. Family stress
3. Crime or violence in the community or neighborhood

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