Appendix A

Overview of Outcome Assessments Available for Use with Children and Youth with TBI

Quality of Life

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used in child / youth TBI studies?	Ref.	Strengths	Weaknesses
CHIP (Child Health & Illness Profile)	Assess physical & mental health	11-17	Child / youth	Self-administered	153	30-45	Yes	Yes	-----	12, 15, 22	Can be used to assess change over time	Utilization questions within the health status scale; requires professional interpretation
CHQ (Child Health Question-naire)	Assess physical, emotional & social well-being	5-17 10/12 & older 5 & younger	Parent Child Parent	Self-administered	28 or 50 87 87	-----	Yes	Yes	Yes	6, J. Landgraf	Specifically developed for children/youth; well normed; used in other pediatric populations; allows parallel child & parent reports; telephone interview scripted	Limited data on sensitivity to change; under 5 version not yet normed; may not be as sensitive as condition-specific instrument; paper-&-pencil version normed but telephone interview not normed
COOP Charts (Dartmouth Primary Care Cooperative Info. Project)	Assess functioning and health-related quality of life	8-12 13-18	Child Youth	Self-administered	9 14	-----	Yes	Yes	-----	12		Floor and ceiling effects; relies on sample size for power
PedsQL (Pediatric Quality of Life Inventory)	Assess health-related quality of life	8-18	Child/ youth Parent	Child: interview Youth & parent: self-administered	15 core, 30 disease-specific	-----	Yes	Yes	-----	25		
QWB (Quality of Well-Being)	Assess quality of life	12 and older	Youth	Structured interview	-----	15	For adults	Yes	-----	3, 8		Weighted based on population preferences; adapted from adult measure; low parent/ youth correlation; not designed for a neurological population

--- Information was not found. * Measure was discussed during the meeting. ** General topic was discussed during the meeting.

Epidemiology

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used in child / youth TBI studies?	Ref.	Strengths	Weaknesses
NHIS (National Health Interview Survey)	Assess prevalence of certain health-related conditions in the US	1988 Child Supp: 0-18 1994 Disability Supp: 0-18	Parent Parent	Structured telephone interview Structured telephone interview	65 -----	----- -----	----- -----	----- -----	yes -----	12, 21		
OCHS (Ontario Child Health Survey)	Assess prevalence of emotional & behavioral disorders	4-16 12-16	Parent Youth	Interview & self-administered	304 169	----- -----	Yes	Yes	-----	12		

Behavioral / Cognitive

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used in child / youth TBI studies?	Ref.	Strengths	Weaknesses
*BASC (Behavior Assessment System for Children)	Measure anxiety, depression, aggression, coping, social relationships	2.5-18 8-18	Parent/ teacher Child/ youth	Self-administered Self-administered	130 152 child 186 youth	10-20 30-45	Yes	Yes	-----	14	Normed; relatively brief	
*BRIEF (Behavior Rating Inventory of Executive Function)	Assess executive functioning including self-monitoring, organizational control, & individual planning	5-18 2.5-5 11-22	Parent & teacher Parent Youth	Self-administered Self-administered Self-administered	86	10	Yes	Yes	Yes	10	5-18 year parent version normed; more specific than some other measures	2.5-5 year parent and 11-22 year youth versions still being normed; rather long
*CBCL (Child Behavior Checklist)	Assess children's competencies & behavioral/ emotional problems	1.5-5 4-18	Parent Parent	Self-administered Self-administered	99 118	-----	Yes	Yes	Yes	1, 20		Designed to assess psychopathology; may not be appropriate for brain injured population; quite long; can give inconsistent results

--- Information was not found. * Measure was discussed during the meeting. ** General topic was discussed during the meeting.

Behavioral / Cognitive continued												
*FS-II(R) (Functional Status II(R))	Assess behavioral response to illness that interferes with normal social roles	0-16	Parent	Structured interview	long: 43 short: 14	----- -----	Yes	Yes	----- -----	12, 15, 23	Can be used repeatedly to document change	Designed for lower end of the functional continuum; permission must be obtained from authors

Functional

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used in child / youth TBI studies?	Ref.	Strengths	Weaknesses
*PEDI (Pediatric Evaluation of Disability Inventory)	Measure capability & performance of functional activities	0.5-7.5	Parents and/or physicians	Interview or direct observation	41	45	Yes	Yes	Yes	2, 9 S. Haley	Incorporates more cognitive, behavioral, & safety components than WeeFIM	Primarily a rehab instrument; limited age range
*PEDI II (Pediatric Evaluation of Disability Inventory, Version II)	Measure ADLs, social/ behavioral activities & community participation	0-18	Clinical staff Parent	Self-administered	44	45	Planned	Planned	Designed for TBI	S. Haley	Focuses more on community participation than PEDI; some questions may be useful for TBI surveillance	Still in development; questionable inter-rater reliability; too detailed for surveillance; focuses on rehab, more severe injuries, people who receive services
*SIB (Scales of Independent Behavior)	Assess adaptive & maladaptive behavior	0-80+	Parent	Structured interview or checklist	long: 259 short: 40	45-60 15-20	Yes	Yes	-----	11, 18, 19	Global index of independence; considers initiation of activity	
*VABS (Vineland Adaptive Behavior Scales)	Survey activities the child/youth habitually demonstrates in the environment	0-18	Parent	Semi-structured interview	297	30-60	Yes	Yes	Yes	11, 16	Short form has global index of independence	Complicated interview process
*WeeFIM (Functional Independence Measure for Children)	Assess functional independence by focusing on dependence	0.5-7	Parent	Interview or direct observation	18	15-20	Yes	Yes	Yes	9, 15, 24	Can be used repeatedly to document change	Difficult to teach to interviewers with no rehab experience; designed for inpt assessment of kids with serious injury; ceiling effect; underrepresents cognitive defects

--- Information was not found. * Measure was discussed during the meeting. ** General topic was discussed during the meeting.

Educational/Vocational/Recreation

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used in child / youth TBI studies?	Ref.	Strengths	Weaknesses
*PPSC (Play Performance Scale for Children)	Assess play performance	0.5-16	Parent or clinician	Self-administered	Single scale	2	Yes	Yes	-----	13, 15	Assessment can be done by non-professionals; easy to administer, analyze & interpret	Used primarily in oncology studies
*PSO (Post-Secondary Outcomes)	Assess educational & vocational status	post-high school	Youth & parent	Structured interview	-----	-----	-----	-----	Designed for TBI	Bonnie Todis		
*SFA (School Function Assessment)	Assess ability to perform functional tasks necessary for the academic & social aspects of education	K-6th grade	-----	Interview / evaluation	-----	-----	-----	Yes	-----	7	May have useful elements	Long

Family Functioning

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used in child / youth TBI studies?	Ref.	Strengths	Weaknesses
*FAD (McMaster Family Assessment Device)	Assess global family functioning	na	Parents / family members	Self-administered	53	15-20	Yes	Yes	Yes	9, 27		Not designed to measure impact on family; not sensitive to change over time
*FBII (Family Burden of Injury Interview)	Assess burden of pediatric TBI on families	na	Parent	Interview	27	-----	Yes	Yes	Yes	4, 27	Sensitive to change over time	May not be applicable to non-TBI groups; rather long
*IOF-G (Impact on the Family Scale, Version G)	Measure impact of pediatric disability on family	na	Parent	Interview	34	-----	-----	Yes	Yes	15, 27	Brief, useful; designed to be more sensitive to change	Difficult to get; may not be as useful as FBII

--- Information was not found. * Measure was discussed during the meeting. ** General topic was discussed during the meeting.

**Depression

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used in child / youth TBI studies?	Ref.	Strengths	Weaknesses
BDI (Beck Depression Inventory)	Evaluate depressive symptoms	Youth	Youth	Self-administered	21	5-10	Yes	Yes	-----	17, 20		Measuring depression may not be as important in children/ youth as in adults
CDI (Child Depression Inventory)	Assess frequency of depressive symptoms	8-17	Child / youth	Self-administered	27	-----	-----	Yes	-----	26		Measuring depression may not be as important in children/ youth as in adults
CES-D (Center for Epidemiological Studies Depression Scale)	Measure current depressive symptoms	Youth	Youth	Self-administered	20	-----	Yes	Yes	-----	9		Measuring depression may not be as important in children/ youth as in adults

**PTSD

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used in child / youth TBI studies?	Ref.	Strengths	Weaknesses
CAPS-CA (Clinician Administered PTSD Scale, Child/ Adolescent version)	Measure PTSD-related symptoms	7-18	Child/ youth	Structured interview	33	30-120	-----	-----	Yes	5	Can assess impact of symptoms on functioning; extremely detailed and thorough	Requires a longer time period than other assessments; requires administration by a trained professional
CPTS-RI (Child Posttraumatic Stress Reaction Index)	Measure PTSD-related symptoms	6-17	Child/ youth Parent	Semi-structured interview	20	20-45	Yes	Yes	Yes	5, 28	Relatively brief and easy to administer	Does not inquire about all DSM-IV symptoms; parent version not yet validated
TESI (Traumatic Events Screening Inventory)	Assess trauma history	4-18	Child/ youth Parent	Semi-structured interview Interview or self-administered	15 19	10-30 10-30	Yes	Yes	Yes	5		Requires administration by a trained professional

--- Information was not found. * Measure was discussed during the meeting. ** General topic was discussed during the meeting.

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