

## SUPPLEMENTARY MATERIALS

**Table S1.** A preliminary pool of items and mean scores for each item from the modified Delphi approach

Domain	Item	Mean score
Mobility	Running	4.9
	Can run many circuits	3.3
	Can run 15 feet, stop and run back	3.7
	Can jump forward 21 inches with both feet simultaneously	3.7
	Stair climbing (up and down stairs)	4.9
	Climbs stairs without assistance	4.9
	Climbs stair with aid of railing	4.3
	Climbs stairs slowly with aid of railing (over 25 seconds for 8 standard steps)	2.7
	Cannot climb stairs	5.0
	Walking	5.0
	Walk as far as possible on their heels	3.6
	Turn and walk back	3.1
	Walks without assistance	4.6
	Walks with aid of railing	3.9
	Walks slowly with aid of railing (over 25 seconds for 8 standard steps)	3.0
	Walks unassisted and rises from chair	4.3
	Walks unassisted but cannot rise from chair	4.3
	Walks only with assistance or long leg braces	1.3
	Walks in long leg braces but requires assistance for balance	1.1
	Unable to walk even with assistance	4.3
	Outdoor mobility	3.6
	Distance/speed outdoors	2.1
	Indoor mobility (school attendance)	3.7
	Distance/speed indoors	1.7
	Transferring from bed to chair or wheelchair	4.3
	Transferring from wheelchair to toilet	4.4
	Transferring from wheelchair to bathtub or shower	2.7
	Transferring from wheelchair to car	2.9
	Wheelchair manipulation (manual)	3.7
	Standing from a floor	5.0
	Standing	4.6
	Holding on with one hand	3.7
	Independently	4.3
Sitting from lying through side lying	4.3	

**Table S1.** Continued 1

<b>Domain</b>	<b>Item</b>	<b>Mean score</b>
	Sitting	5.0
	Frog (floor)/chair sitting no hand support	4.4
	Long sitting, no hands	4.1
	Raises one hand to ear level (R/L)	2.9
	Raises 2 hands to ear level	3.3
	Gets to lying from sitting (safely, not accidentally)	4.1
	Rolling (changing body position in bed)	4.9
	Bed mobility (transfer)	4.7
	Lifts head from surface in supine	3.4
	1/2; Roll from supine, both ways	3.9
	Rolls prone to supine over R	2.6
	Rolls prone to supine over L	2.6
	Rolls supine to prone over R	2.6
	Rolls supine to prone over L	2.6
	Lifts head from prone (arms down by sides)	3.6
	Achieves prop on forearms-head up	3.1
	Achieves prop on extended arms-head up	3.0
	Achieves four point kneeling	3.3
	Crawls on hands and knees	3.9
Activities of daily living	Eating	5.0
	Drooling	1.4
	Feeding	4.7
	Swallowing	4.4
	Drinking	4.3
	Use of drinking containers	3.6
	Cutting food	2.4
	Grooming	5.0
	Washing face and hands	4.4
	Combing hair (hairbrushing)	4.4
	Brushing teeth (toothbrushing)	4.4
	Cutting fingernail	3.0
	Cutting toenail	2.4
	Shaving	2.1
	Nose care	2.0
	Bathing	4.7
	Washing body	4.4
	Toileting (getting on and off toilet)	4.9
	Handling clothes	4.1
	Wiping or flushing	4.1

**Table S1.** Continued 2

<b>Domain</b>	<b>Item</b>	<b>Mean score</b>
	Dressing	4.9
	Bracing	2.7
	Put on/take off formal dresses	3.4
	Dressing upper part of body	4.4
	Dressing lower part of body (pants)	4.4
	Shoes/socks	3.9
	Bladder control	4.1
	Bladder incontinence	3.7
	Care of perineum	4.1
	Handling utensils	2.9
	Bowel control	4.3
	Bowel incontinence	3.3
	Speech	3.9
	Writing	4.0
	Turning books	3.3
	Card turning	2.3
	Cleaning table	2.7
	Pullover/front - opening garments	2.1
	Fasteners	2.3
	Food preparation	2.9
	Washing clothes	2.1
	Household chores	2.0
	Managing objects over head	3.1
	Picking up small, common objects	3.6
	Manipulating small, common objects	3.0
	Carrying large, light objects	3.4
	Carrying large, heavy objects	3.3
	Heavy home maintenance tasks	2.0
	Bilateral lifting	2.1
	Using personal computer	4.7
	Using personal computer with adaptive devices	4.3
<b>Muscle power</b>	Gower's sign	4.6
	Strength of neck	3.1
	Strength of trunk	3.1
	Strength of knee extensor	3.6
	Strength of shoulder abductor	3.3
	Starting with arms at the sides, the patient can abduct the arms in a full circle until they touch above the head	4.4
	Can raise arms above head only by flexing the elbow (shortening the circumference of the movement) or using accessory muscles	4.3
	Cannot raise hands above head, but can raise an 8-oz glass of water to the mouth	4.3
	Can raise hands to the mouth, but cannot raise an 8-oz glass of water to the mouth	4.1

**Table S1.** Continued 3

<b>Domain</b>	<b>Item</b>	<b>Mean score</b>
	Cannot raise hands to the mouth, but can use hands to hold a pen or pick up pennies from the table	4.0
	Cannot raise hands to the mouth and has no useful function of hands	4.4
Joint contracture (range of motion, ROM)	Severity of neck contracture	2.6
	Severity of trunk contracture	3.1
	Number of contracted joints in the upper limbs	4.0
	Number of contracted joints in the lower limbs	4.1
	Severity of upper limb joint contractures	4.3
	Finger	3.6
	Wrist	4.0
	Elbow	4.1
	Shoulder	4.3
	Severity of lower limb joint contractures	4.4
	Toe	2.6
	Ankle	4.4
	Knee	4.6
	Hip	4.6
Pulmonary function	Respiratory insufficiency (ventilator assisted)	4.7
	Orthopnea	4.4
	Dyspnea in stable condition	4.6
	Dyspnea after activity	4.6
	Sputum clearance	4.4
	Peak cough flow	5.0
	Pulmonary function test	4.4
	Forced vital capacity (FVC, L)	4.0
	Maximum voluntary ventilation (L/min)	3.9
	Maximal expiratory pressure (cmH <sub>2</sub> O)	3.6
	Maximal inspiratory pressure (cmH <sub>2</sub> O)	4.1
Cardiac function	Dyspnea after activity	4.7
	Electrocardiogram (ECG)	4.0
	Arrhythmia	3.7
	Left ventricular dysfunction	4.3
	Using drug for heart disease	4.7
	Echocardiogram (EchoCG)	4.4
	Fractional shortening	3.9
	Ejection fraction	4.4
	Dilated cardiomyopathy (DCMP); left ventricular dysfunction	4.3
	Brain natriuretic peptide (BNP)	3.7
Scoliosis	Scoliosis	4.9
	Cobb angle (none/mild/moderate/severe)	4.7
	Degree or severity	3.7

**Table S1.** Continued 4

<b>Domain</b>	<b>Item</b>	<b>Mean score</b>
Pain	Number of pain areas	3.1
	Frequency of pain	3.1
	Intensity of pain	3.1
	Pain-inducing activities	3.4
Cognition and social function	Mental retardation (KEDI-WISC, none/mild/mod/severe)	5.0
	Comprehension	3.7
	Comprehension of word meanings	3.7
	Comprehension of sentence complexity	4.0
	Expression	3.7
	Functional expressive communication	3.9
	Complexity expressive communication	3.6
	Social Interaction	4.6
	Social interactive play	3.7
	Peer interactions	4.4
	Community function	4.1
	Play with objects	2.9
	Problem solving	3.3
	Memory	3.6
	Time orientation	3.3
	Self-information	3.0
Self-protection	3.3	