INTERNATIONAL SPINAL CORD INJURY DATA SET

**PEDIATRIC EDUCATION BASIC DATA SET**

Version 1.0, March 2018

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 **Introduction**

Through the support of the International Spinal Cord Society, American Spinal Injury Association, and Canadian Institutes of Health Research International, an effort to develop International Spinal Cord Injury Data Sets is underway. These data sets are being developed to provide comparable data elements internationally for the examination and treatment of spinal cord injuries and disorders (SCI/D)1. Following development of a series of data sets for adults with SCI/D workgroups have set out to develop datasets applicable to children and adolescents2. For most children and adolescents, participation in educational programing represents a significant portion of daily life. Although primarily medical in nature, professionals treating pediatric patients with SCI/D deemed participation in education an important construct to include in data being collected. This is the first version of the International Spinal Cord Injury Education Basic Data Set. It is intended to collect meaningful data on children and adolescents with SCI/D in the context of a student’s education program.

**Uses**

The Education Basic Data Set was designed to standardize the collection and reporting of a minimal amount of data useful to evaluate and compare results across research and clinical programs treating pediatric patients with SCI/D. Additionally it may allow improved understanding of the international status of education for students with SCI/D. Educational agencies and caregivers may find it a useful tool in the development of educational programs and supports for individual students with SCI/D. It may also serve to examine the system-wide status of education supports and related services for the population with physical impairments. The educational program of the student with SCI/D typically is guided by cognitive and physical needs and facilitated by the appropriate educational agency. For children and adolescents with SCI/D, especially in the case of recent onset of injury, educational programming also may be influenced by family or student preference. As educational programming also varies internationally, it is invaluable to include descriptors of the educational program of the student with SCI/D in a global measure such as this basic data set.

**Development**

Driving forces behind the development of the Education Basic Data Set include both the rights of children and adolescents with impairments related to SCI/D and the long term international challenge to expand basic access to education for all learners. International leadership continues to promote this equality. For example, Article 24 of the United Nations *Convention of Rights of Persons with Disabilities* *(CPRD*) emphasizes the need for governments to ensure equal access to an ‘inclusive education systems at all levels’ and to provide reasonable accommodation and individual support services to facilitate education3. Participation in educational programming represents a major component of the lives of school-aged children and adolescents and students with chronic impairments who are at risk for failing to meet their educational potential4-7. In addition to the degree of physical and neurological impairment, educational achievement is an important factor in subsequent employability and potential for independent living8-11. Low education impacts upon the ability to gain knowledge and new skills after SCI/D12. Education can be seen further as a proxy for socio-economic status, with higher education levels being associated with a healthier lifestyle, having better living conditions, easier access to care, and a number of outcomes of SCI/D rehabilitation including fewer secondary health conditions, greater participation and better quality of life13-16.

The interdisciplinary working group for the Education Basic Data Set consisted of an international representation of expert educators, therapists and physicians who treat and follow school-aged individuals with SCI/D. Educational expertise was enlisted from individuals with specific experience in educational program planning for children with disabilities from the perspectives of both a large varied school system and specifically, re-entry from rehabilitation to educational programming following injury or medical care. Its development attempted to follow closely the process other International SCI Basic Data Sets have used since 2002. All of these International SCI Data Sets may be seen and downloaded for free from the International Spinal Cord Society’s website: http://www.iscos.org.uk/international-sci-data-sets.

**Administration**

To facilitate both the responses and the reading of the items to students who may need assistance, the data set is designed to be administered by interview (clinician, researcher, and/or educator) and recommended for use at least 3 months following discharge from initial acute rehabilitation so that the child has had adequate time to participate in the school setting. Data points describing the educational program, starting with years of formal education completed, through the item that asks about number of school days missed, should be obtained from the caregiver. Physical impairments of the child with SCI/D present potential environmental barriers in the educational setting, barriers to full participation in school activities, and can affect accessibility, attitude, comfort and safety17-22. Educational programming for the student with SCI/D-related impairments also can be complicated by the student’s pre-injury cognitive profile or a co-occurring traumatic brain injury23-28. Therefore, the remaining items, starting with the student’s current academic performance and through the remainder of the data set, assess the status of many of these constructs. Although assistance can be given in reading and explaining the items, ratings of these items should be provided by self-report of the child/adolescent him or herself.

Upon consensus of the workgroup, items specific to participation in school or with classmates were adapted from the Pediatric Measure of Participation (PMoP) 29. Items seeking information about access and other potential barriers were adapted from the Nottwil Environmental Factors Inventory-Short Form30. Student feelings toward school in general are sought by an item from the Health Behavior in School-Aged Children31-33.

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**International Spinal Cord Injury Data Set**

**Pediatric Education Basic Data Set**

Version 1.0 March 2018

VARIABLE NAME: Date of Data Collection

DESCRIPTION: This variable documents the date of data collection

FORMAT: Numeric

CODES: yyyy/mm/dd

 9999/99/99 Unknown

COMMENTS: The collection of data on education may be conducted at any time following SCI/D, however it is recommended for use at least 3 months following discharge from initial acute rehabilitation so that the child has had adequate time to participate in the school setting. The date of data collection is imperative to compute the length of time since the spinal cord lesion occurred and to identify data collected in relation to other data collected on the same individual at various time points.

VARIABLE NAME: Years of Formal Education Completed

DESCRIPTION: This variable documents the number of years of school starting at 6 years of age

FORMAT: Numeric

CODES: \_\_\_\_\_ Years

99 Unknown

COMMENTS: Start counting formal education at the age of 6. For an incomplete year, round up to the next year, if it is more than 6 months.

The question is taken from the International Spinal Cord Injury Socio-Demographic Basic Data Set (Version 1.0; 2016.0210)

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VARIABLE NAME: Educational Setting

DESCRIPTION: This variable documents the current educational setting

FORMAT: Numeric

CODES: 1 regular education

2 integrated education

1. special education
2. home schooling and/or hospital schooling
3. other education (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
4. Not Applicable/Unknown

COMMENTS: These codes are meant to document current educational setting.

 **Regular Education**: defined as an inclusive educational setting where students with SCI/D are provided with additional resources and support according to need with age-appropriate peers

 **Integrated Education** offers separate classes and additional resources for

 students with SCI/D within mainstream schools

 **Special Education**: defined as a segregated educational setting for students with special needs. These schools provide specialized services in separate settings from mainstream educational institutions.

 **Home Schooling and/or Hospital Schooling**: Check this code if the child is receiving education in the home and/or hospital setting. May include online instruction in those settings.

 **Other education**: Specify any other educational setting including, virtual school, or combinations of learning environments

 **Not Applicable/Unknown**: Check this code if the child is not in school for any reason such as: medical instability, dropped out of school,

 too young to be in school, or aged out of school or setting not known

VARIABLE NAME: Therapeutic Services

DESCRIPTION: This variable documents therapeutic services being utilized in the most recent school year in the educational setting

FORMAT: Numeric

CODES: 1 Medical care attendant (related to SCI/D injury)

 2 Physical Therapy

 3 Occupational therapy

4 Speech/language therapy

5 Counselling/mental health

1. Social work/case management
2. Adapted physical education
3. Vocational services
4. Other, if so specify\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
5. Not Applicable

99 Unknown

COMMENTS: Reports on the utilization of therapeutic services while at school.

 **Medical care attendant** (related to your SCI/D injury): defined as a licensed/skilled care provider such as a nurse, nurse’s aide, etc.

 **Physical therapy:** uses therapeutic exercise, training, and patient education for the preservation, enhancement or restoration of movement and physical function. Prevention of further disability is a desired outcome.

 **Occupational therapy**: a form of therapy that encourages rehabilitation through the performance of activities required in daily life

**Speech/language therapy:** therapy to help individuals learn to produce speech sounds correctly or fluently, to swallow safely, or to acquire, understand, or express language concepts

**Counselling/mental health:** the provision of assistance and guidance in resolving personal, social and/or psychological problems and difficulties by a professional

 **Social work/case management:** work carried out by trained personnel with the aim to alleviate the conditions of those needing help or welfare

 **Adapted physical education:** instruction in physical education and games

 provided in school adapted to the abilities of those with SCI/D

 **Vocational services**: services relating to an occupation or employment

**Other, if so specify** *\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_*

**Not Applicable**

 **Unknown**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

VARIABLE NAME: School Days Missed Due To Spinal Cord Injury/Disorder

DESCRIPTION: This variable documents if the student has missed **5 or more days** of school during the past 4 weeks due to health related issues

 Injury/Disorder

CODES: 1 Yes

 2 No

 99 Unknown

COMMENTS: Missing more than 5 days of school in a 4-week period may indicate serious health issues and/or issues specific to willingness or ability to attend school regularly. In rare cases, number of days not in school could also indicate the availability of the education program/services.

VARIABLE NAME: Student’s Current Academic Performance

DESCRIPTION: This variable documents the student’s academic performance in all subjects in comparison to classmates

CODES: 1 Doing at least as well as classmates ***in all*** academic or course subjects 2 Not doing as well as classmates in ***some*** academic or course subjects

 3 Not doing as well as classmates ***in all*** academic or course subject

 99 Unknown

COMMENTS: This code is meant to document the student with SCI/D’s academic performance in academic or course subjects compared to his fellow classmates.

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

VARIABLE NAME: Eating With Friends/Classmates

DESCRIPTION: This variable documents whether or not the individual eats lunch with friends/classmates during school, and the degree to which they do it based on what they want to do

FORMAT: Numeric

CODES: 0         I don’t do it

 1         I do it a lot less than I want

 2         I do it a little less than I want

 3         I do it as much as I want

 99   N/A

COMMENTS: Provides social, play and recreational information about the child’s function within the education setting. Adapted from the PMoP CAT Response Scale and Items.

Note that a response of *I don’t do it* may not necessarily mean physical limitation. It could mean the child is not being allowed to participate by a parent for example, or not having access to participate.

Source: Mulcahey MJ, Slavin MD, Ni P, Vogel LC, Thielen CC, Coster WJ, Jette AM. The Pediatric Measure of Participation (PMoP) short forms. Spinal Cord 2016; 54(12):1183 - 1187.

VARIABLE NAME: Participation in School Trips

DESCRIPTION: This variable documents participation in school trips with friends/classmates and the degree to which they do it based on what they want to do

FORMAT: Numeric

CODES: 0         I don’t do it

 1         I do it a lot less than I want

 2         I do it a little less than I want

 3         I do it as much as I want

 99   N/A

COMMENTS: Based on self-reporting, the variable provides social, play and recreational information about the child’s function within the education setting. Adapted from the PMoP CAT Response Scale and Items.

Note that a response of *I don’t do it* may not necessarily mean physical limitation. It could mean the child is not being allowed to participate by a parent for example, or not having access to participate.

 Sourced in the first PMoP item above.

VARIABLE NAME: Participation in Physical Education Activities

DESCRIPTION: This variable documents participation in gym class (Physical Education or formal school-arranged sporting activities) and the degree to which they do it based on what they want to do

FORMAT: Numeric

CODES: 0         I don’t do it

 1         I do it a lot less than I want

 2         I do it a little less than I want

 3         I do it as much as I want

 99   N/A

COMMENTS: Based on self-reporting, the variable provides social, play and recreational information about the child’s function within the education setting. Adapted from the PMoP CAT Response Scale and Items.

Note that a response of *I don’t do it* may not necessarily mean physical limitation. It could mean the child is not being allowed to participate by a parent for example, or not having access to participate.

 Sourced in the first PMoP item above.

VARIABLE NAME: Participation in Recess

DESCRIPTION: This variable documents participation in recess or time allocated for recreational play with friends/classmates during the school day and the degree to which they do it based on what they want to do

FORMAT: Numeric

CODES: 0         I don’t do it

 1         I do it a lot less than I want

 2         I do it a little less than I want

 3         I do it as much as I want

 99   N/A

COMMENTS: Based on self-reporting, the variable provides social, play and recreational information about the child’s function within the education setting. Adapted from the PMoP CAT Response Scale and Items.

Note that a response of *I don’t do it* may not necessarily mean physical limitation. It could mean the child is not being allowed to participate by a parent for example, or not having access to participate.

 Sourced in the first PMoP item above.

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VARIABLE NAME: Barriers to School Access

DESCRIPTION: This variable document accessibility within the school building

FORMAT: Numeric

CODES: 1 Has no influence

2 Makes school a little harder

3 Makes school a lot harder

99 Unknown

COMMENTS: Adapted from the Nottwil Environmental Factors Inventory- Short Form. NEFI Source: Ballert CS, Post MW, Brinkhof MW, Reinhardt JD; SwiSCI Study Group. [Psychometric Properties of the Nottwil Environmental Factors Inventory Short Form.](https://www.ncbi.nlm.nih.gov/pubmed/25264112) Arch Phys Med Rehabil. 2015 Feb;96(2):233-40.

VARIABLE NAME: Barriers to Transportation to and from School

DESCRIPTION: This variable documents adequate transportation to and from school

FORMAT: Numeric

CODES: 1 Has no influence

2 Makes school a little harder

 3 Makes school a lot harder

 99 Unknown

COMMENTS: Adapted from the Nottwil Environmental Factors Inventory- Short Form. NEFI. Source is cited in the first NEFI item above.

VARIABLE NAME: Barriers to Communication Devices at School

DESCRIPTION: This variable documents accessibility to adequate communication devices such as writing devices, voice recognition software, and other assistive or computer devices

FORMAT: Numeric

CODES: 1 Has no influence

2 Makes school a little harder

 3 Makes school a lot harder

99 Unknown

COMMENTS: Adapted from the Nottwil Environmental Factors Inventory- Short Form. NEFI. Source is cited in the first NEFI item above.

VARIABLE NAME: Barriers to Other Educational Supports at School

DESCRIPTION: This variable documents accessibility to education supports such as personal assistant, and changes to the individual with the SCI/D school curriculum

FORMAT: Numeric

CODES: 1 Has no influence

2 Makes school a little harder

 3 Makes school a lot harder

 99 Unknown

COMMENTS: Adapted from the Nottwil Environmental Factors Inventory- Short Form. NEFI. Source is cited in the first NEFI item above.

VARIABLE NAME: Attitudes of Educational Professionals

DESCRIPTION: This variable documents the individual’s perception of possible negative attitudes of school staff

FORMAT: Numeric

CODES: 1 Has no influence

2 Makes school a little harder

 3 Makes school a lot harder

99 Unknown

COMMENTS: Adapted from the Nottwil Environmental Factors Inventory- Short Form. NEFI. Source is cited in the first NEFI item above.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

VARIABLE NAME: Perception of School

FORMAT: Numeric

DESCRIPTION: This variable documents the individual’s feelings toward school in general

CODES: 1 I like it a lot

 2 I like it a bit

 3 I don’t like it very much

 4 I don’t like it at all

COMMENTS: Adapted from the HBSC: **Health Behavior in School-Aged**

 **Children (World Health Organization)** Curie C, van der Sluijs W, Whitehead R, Currie D, Rhodes G, Neville F, Inchley J. *. HBSC 2014 Survey in Scotland National Report*. Child and Adolescent Health. Research Unit (CAHRU), University of St Andrews. 2015 September.

INTERNATIONAL SPINAL CORD INJURY DATA SET

**PEDIATRIC EDUCATION BASIC DATA SET COLLECTION FORM**

Version 1.0 March 2018

**Date performed: YYYY/MM/DD \_\_\_\_\_/\_\_\_/\_\_\_\_ \_\_\_ Unknown**

**SCHOOL SETTING (the following items may require caregiver response)**

1. **Starting with Age 6 as Year One, how many years of school have you completed?**

 **\_\_\_ *Years***

1. **What is your educational setting at this time? Check One.**
* regular education
* integrated education
* special education
* home schooling and/or hospital schooling
* other education (specify)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* not applicable/unknown

 **STOP here if *home schooling and/*or *hospital schooling* is checked.**

1. **Therapeutic services—provided in school-- you received during current school year*.***

***Check All That Apply.***

* medical care attendant (related to your SCI/D injury)
* physical therapy
* occupational therapy
* speech/language therapy
* counseling/mental health
* social work/case management
* adapted physical education

€ vocational services

€ other, if so specify\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

€ not applicable

€ unknown

**SCHOOL PARTICIPATION (this item may require caregiver response)**

**4. Thinking about your last 4 weeks of school, have you missed 5 or more days due to health related issues?**

 € Yes € No € Unknown

**The remaining items are designed for STUDENT RESPONSE**

**5. Your current academic performance as reported by the student.**

***Check One.***

* Doing at least as well as classmates ***in all*** academic or course subjects
	+ Not doing as well as classmates ***in some*** academic or course subjects
	+ Not doing as well as classmates ***in all*** academic or course subjects

**6. Activities you may do in school.[[1]](#footnote-1) Check One Response For Each Statement.**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **DO YOU DO IT?** | **I DON’T DO IT**  |  | **I DO IT** | **N/A** |
| ***Check the square that is most like you*.** |  |  | **A lot less than I want** | **A little less than I want**  | **As much as I want** |  |
| 6.1 I eat with my friends/classmates at school |  |  |  |  |  |  |
| 6.2 I go on school trips with my friends/classmates |  |  |  |  |  |  |
| 6.3 When in gym class (P.E. or formal school-arranged  sporting activities) I do the  same activity as the other kids |  |  |  |  |  |  |
| 6.4 At school I go to recess and/or play outside with my friends/classmates |  |  |  |  |  |  |

**BARRIERS AND ATTITUDES**

**7. Current physical/environmental barriers at school[[2]](#footnote-2)**

|  |  |  |
| --- | --- | --- |
| **Label** | **Question** | **Response Options:** **Mark One** |
| 7.1 School access | **Do inaccessible or inadequately accessible school places cause a problem for you?** (eg, stair lift, elevator, classroom space, classroom furniture, bathroom, use of other school spaces)  | € has no influence € makes school a little harder€ makes school a lot harder € unknown |
| 7.2 Transportation to school | **Does lack of, or inadequately adapted transportation to school cause a problem for you getting to school?** (eg, no adapted car, hard to use public transportation)  | € has no influence € makes school a little harder€ makes school a lot harder€ unknown |
| 7.3 Communication devices | **Does lack of, or insufficient, communication devices cause a problem at school?** (eg, writing devices, voice recognition software, mouse, telephone --other device such as computers with Bluetooth, modem, smart phone, Wi-Fi)  | € has no influence € makes school a little harder€ makes school a lot harder€ unknown |
| 7.4 Other education supports | **Does lack of, or insufficient, education supports cause a problem at school?** (eg, personal assistant or scribe, extended time for assignments or tests, computer access, changes in your school curriculum)  | € has no influence € makes school a little harder€ makes school a lot harder€ unknown |
| 7.5 Attitudes of school staff  | **Do negative attitudes of teachers and/or other school staff cause you a problem** (eg., prejudice, lack of support, overprotective behavior) | € has no influence € makes school a little harder€ makes school a lot harder€ unknown |

**8. How do you feel about school at present?[[3]](#footnote-3) Check One Response.**

€ I like it a lot

€ I like it a bit

€ I don’t like it very much

€ I don’t like it at a

1. Source: Mulcahey MJ, Slavin MD, Ni P, Vogel LC, Thielen CC, Coster WJ, Jette AM. The Pediatric Measure of Participation (PMoP) short forms. **Spinal Cord** 2016; 54(12):1183 - 1187. [↑](#footnote-ref-1)
2. Based on the Nottwil Environmental Factors Inventory – Short Form. NEFI

Ballert CS, Post MW, Brinkhof MW, Reinhardt JD; SwiSCI Study Group. [Psychometric Properties of the Nottwil Environmental Factors Inventory Short Form.](https://www.ncbi.nlm.nih.gov/pubmed/25264112) Arch Phys Med Rehabil. 2015 Feb;96(2):233-40. [↑](#footnote-ref-2)
3. HBSC: Health Behavior in School-Aged Children (WHO**).Questions MQ59***.* Curie C, van der Sluijs W, Whitehead R, Currie D, Rhodes G, Neville F, Inchley J. . HBSC 2014 Survey in Scotland National Report. Child and Adolescent Health. Research Unit (CAHRU), University of St Andrews. 2015 September. [↑](#footnote-ref-3)