

Functioning and Disability in Children with Brain Tumour: a Pilot Study with ICF-CY



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Project RF ex art. 56 funded by Italian Health Ministry
“Cure and Care of a Child with neuro-
oncological pathology”:

A pilot study to define multidisciplinary and integrated pathways for care of children and adolescents with brain tumours using ICF-CY and related instruments



Project Coordinator
INNCB
Dr. Matilde Leonardi

Data collection:

Foundation INT-Milan



Foundation Besta- Milan



**Hospital Bambino Gesù-
Rome**



**Validation of an Observational
Grid for recreational and
playing activities:**



**Associazione
Bambino in
Ospedale**

Coordination of the project:



**Struttura Semplice Dipartimentale
Neurologia, Salute Pubblica,
Disabilità (HEADNET)**

“Cura and Care” in short...

- The project started in June, 2006
- It will end in December, 2008
- Duration 24 months + 6 months extension
- Funded by Italian Ministry of Health

Observational qualitative pilot study on 30 children and adolescents affected with cerebral tumours in three National Research Institutes involved in the study

Objectives of “Cura and Care”

- **Application of ICF-CY** in neuro-oncological pediatrics field
- Creation of **common language** (through the training on ICF, ICF-CY, ICF checklists and questionnaires)
- **Analysis of needs** centered on child
- Valorization of work inside a **multidisciplinary team**
- Creation of a **database based on ICF-CY**
- Validation of an **ICF based Play Grid** for Lay NGOs working in hospitals

Instruments used for data collection

- **ICF-CY Questionnaires** (versions specific to age range: 0-3; 4-6; 7-12; 13-17)
- **WHO-DAS II e WHO-DAS proxy**
- **KIDSCREEN** (Quality of Life Health related questionnaire)
- **VINELAND** (Adaptive Behavior Scales)
- **Observational Play GRID** “Osserva e Racconta”

Epidemiology of tumours of the CNS in children

Tumours of the CNS represent $\frac{1}{4}$ of all tumours in children

Incidence **2.4/100.000** → In Italy **250** new cases per year

Between age of **4-8 years** higher frequency of primary brain tumours

Slight prevalence of medulloblastoma and pituitary gland tumours in boys

Source: Bonadonna, Robustelli e Valagussa (2007), Neoplasie solide dell'infanzia in Medicina oncologica. Elsevier Masson, pp. 1272-1294

Inclusion criteria

Primary or secondary brain tumour

Children and adolescents from 0 to 18 years

Enrolment no more than 40 days after surgical intervention

Children who need follow-up

Children coming from neurosurgery departments of other institutes, not directly involved in a project

Time points of data collection

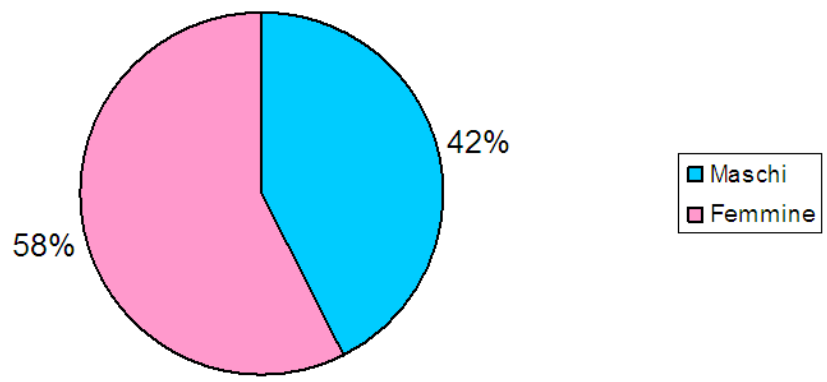
- T0: after surgery, during 40 days after intervention
- T1: follow-up after 3 months
- T2: follow-up after 6 months from T0

Number of interviews in database

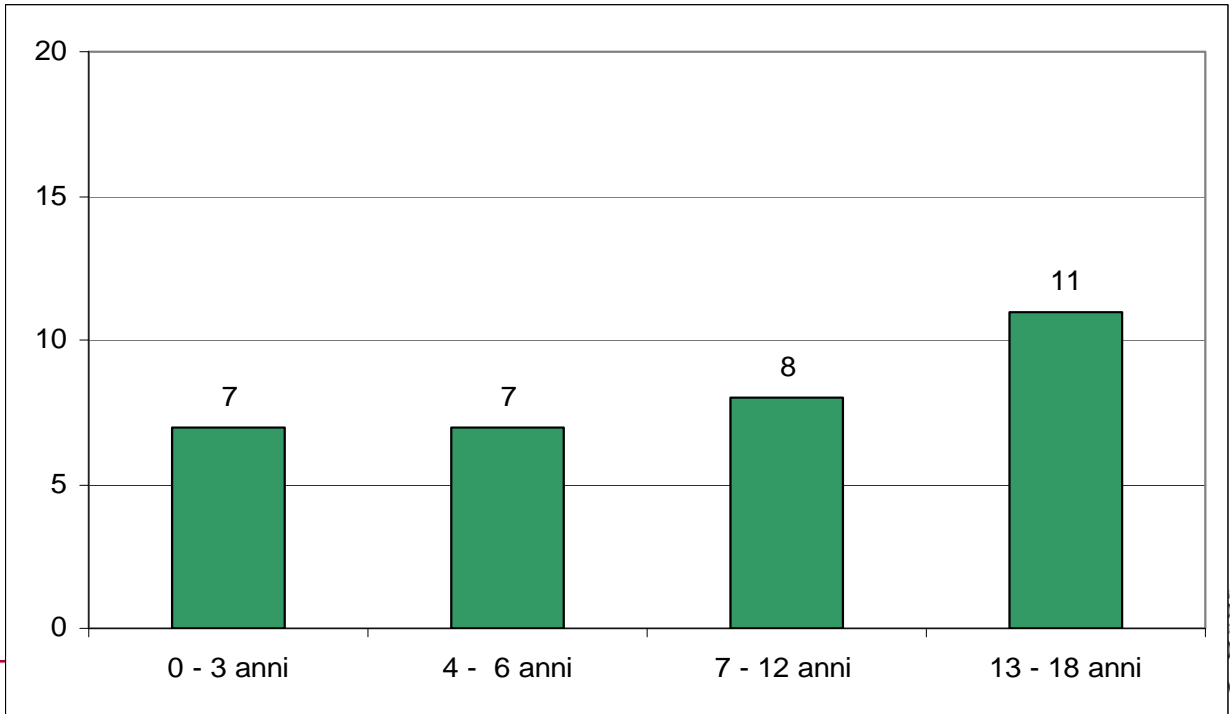
	T0	T1	T2	Tot
Istit. Naz. Tumori INT	12	10	8	30
Besta INNCB	12	7	4	23
Bambino Gesù OPBG	9	3	2	15
Total	33	20	14	68

TOTAL n. Children enrolled in June 2008: 33

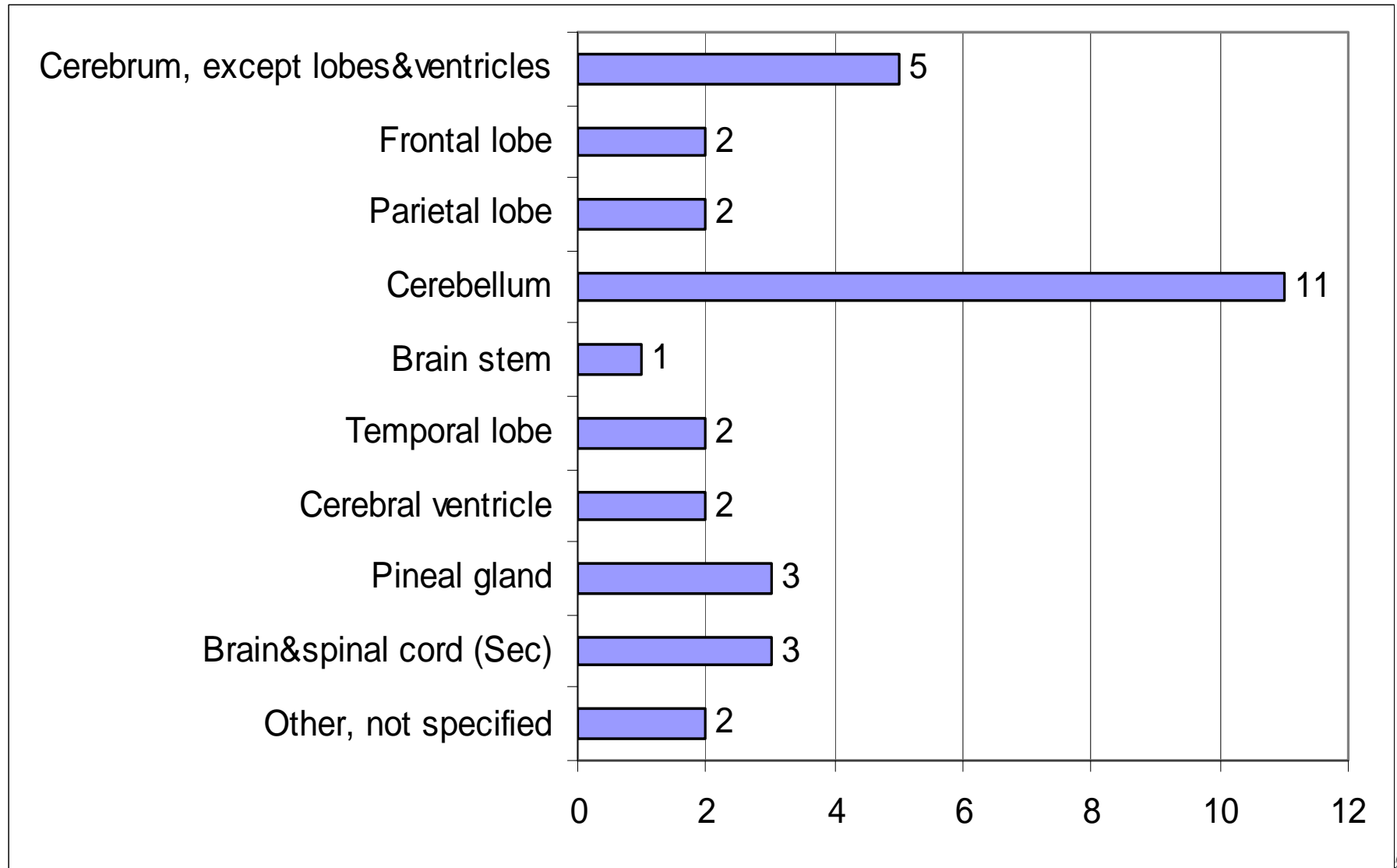
Gender



Age range



Diagnosis according to ICD-10: localization in brain



Body Functions

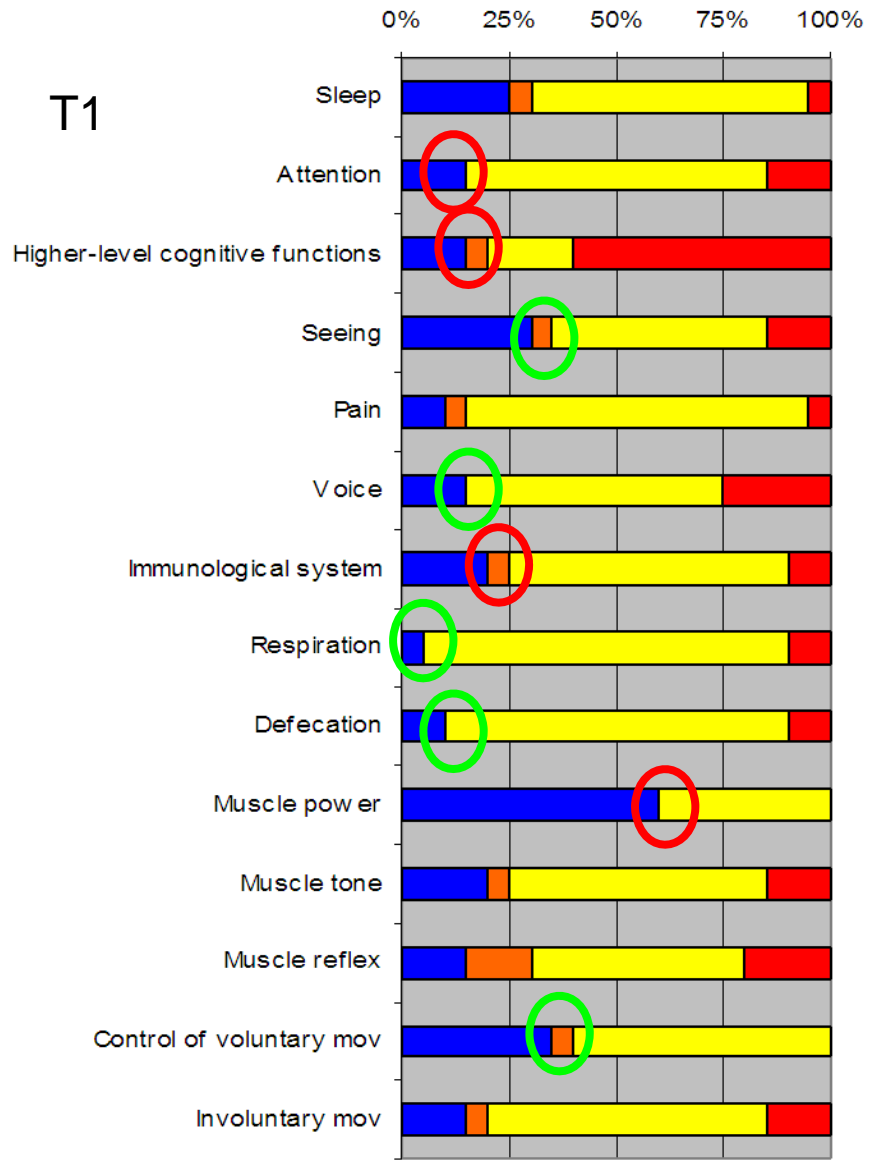
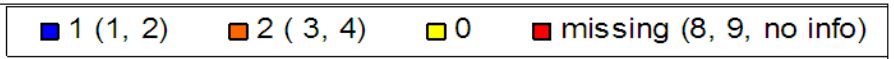
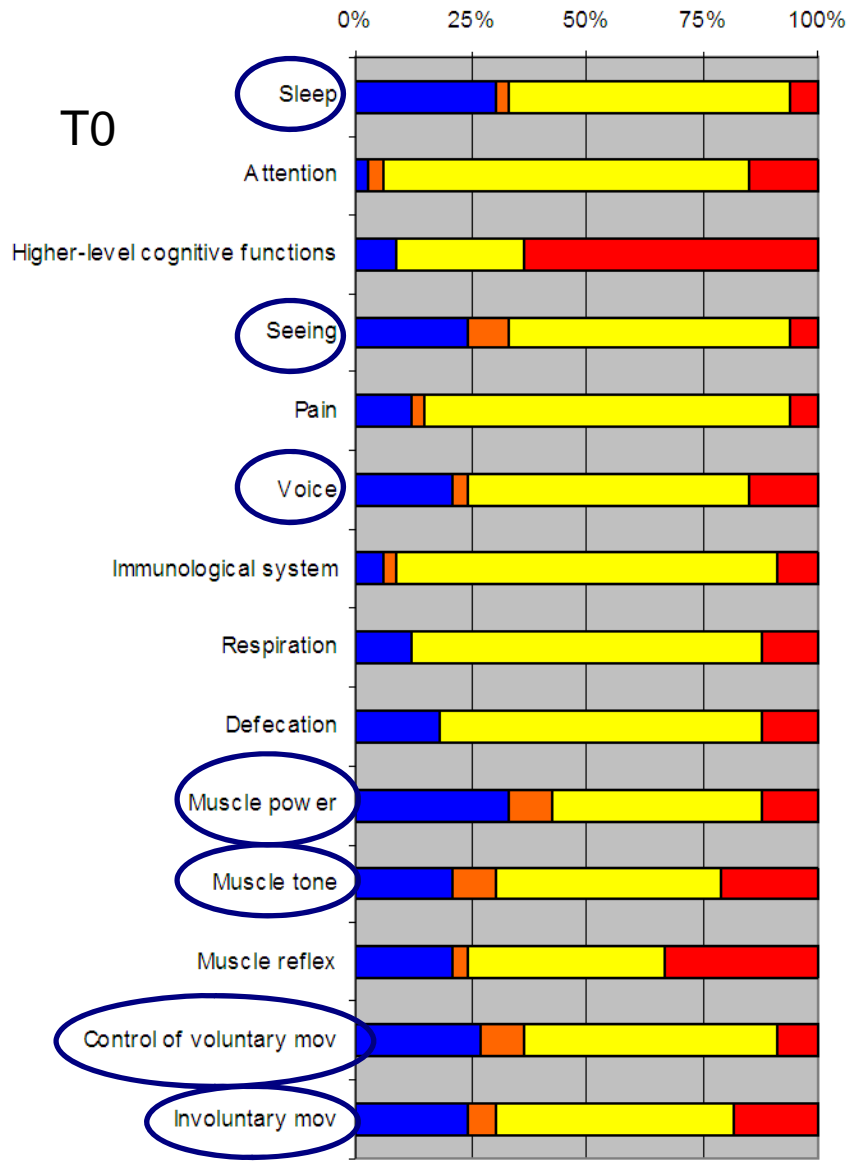
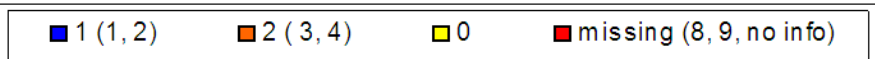
“Physiological functions of body systems (including psychological functions)”

1 → mild, moderate problem - it groups qualifiers 1 and 2

2 → severe, complete problem- it groups qualifiers 3 and 4

0 → no problem

Missing → not applicable, data not collected, not sufficient to give a qualifier



Main problems in Body Functions in T0&T1

- Sleep (b134)
- Seeing (b210)
- Voice (b310)
- Muscle Power (b730)
- Muscle Tone (b735)
- Control of voluntary movement (b760)
- Involuntary movement (b765)

Body Structures

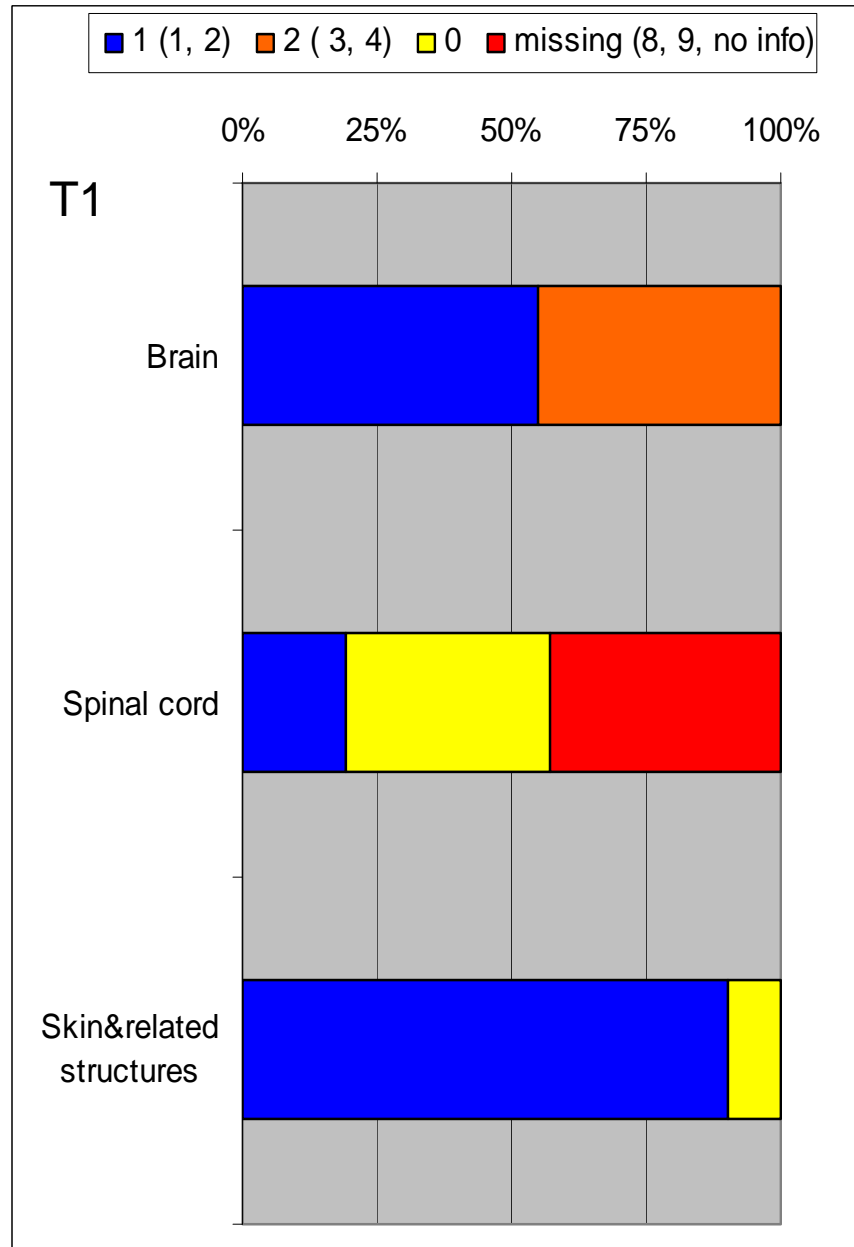
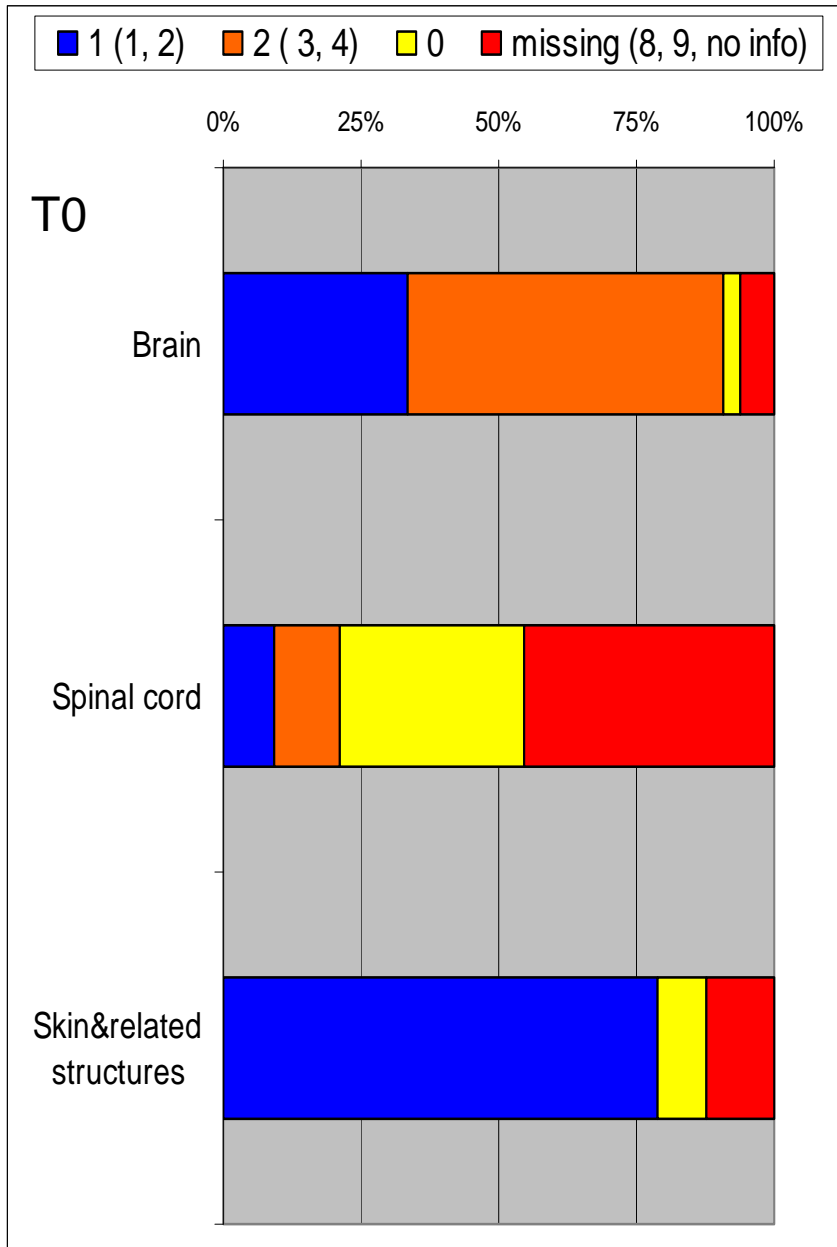
“Anatomical parts of the body such as organs, limbs, and their components”

1 → mild, moderate problem - it groups qualifiers 1 and 2

2 → severe, complete problem - it groups qualifiers 3 and 4

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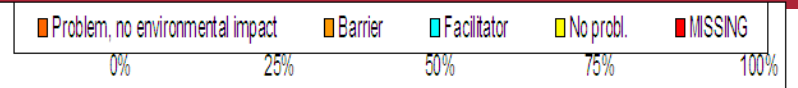
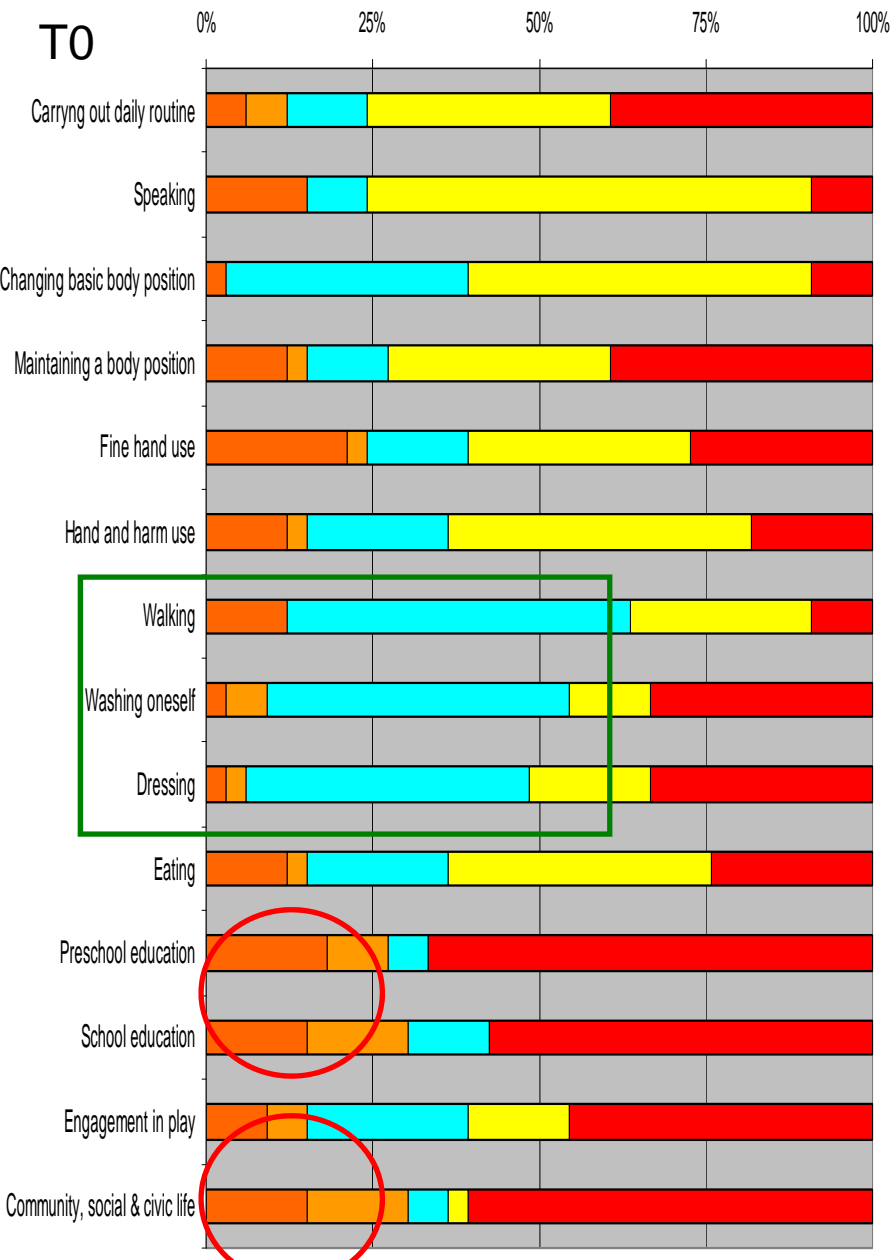
Activities and Participation

“Activity is the execution of a task or action by an individual.

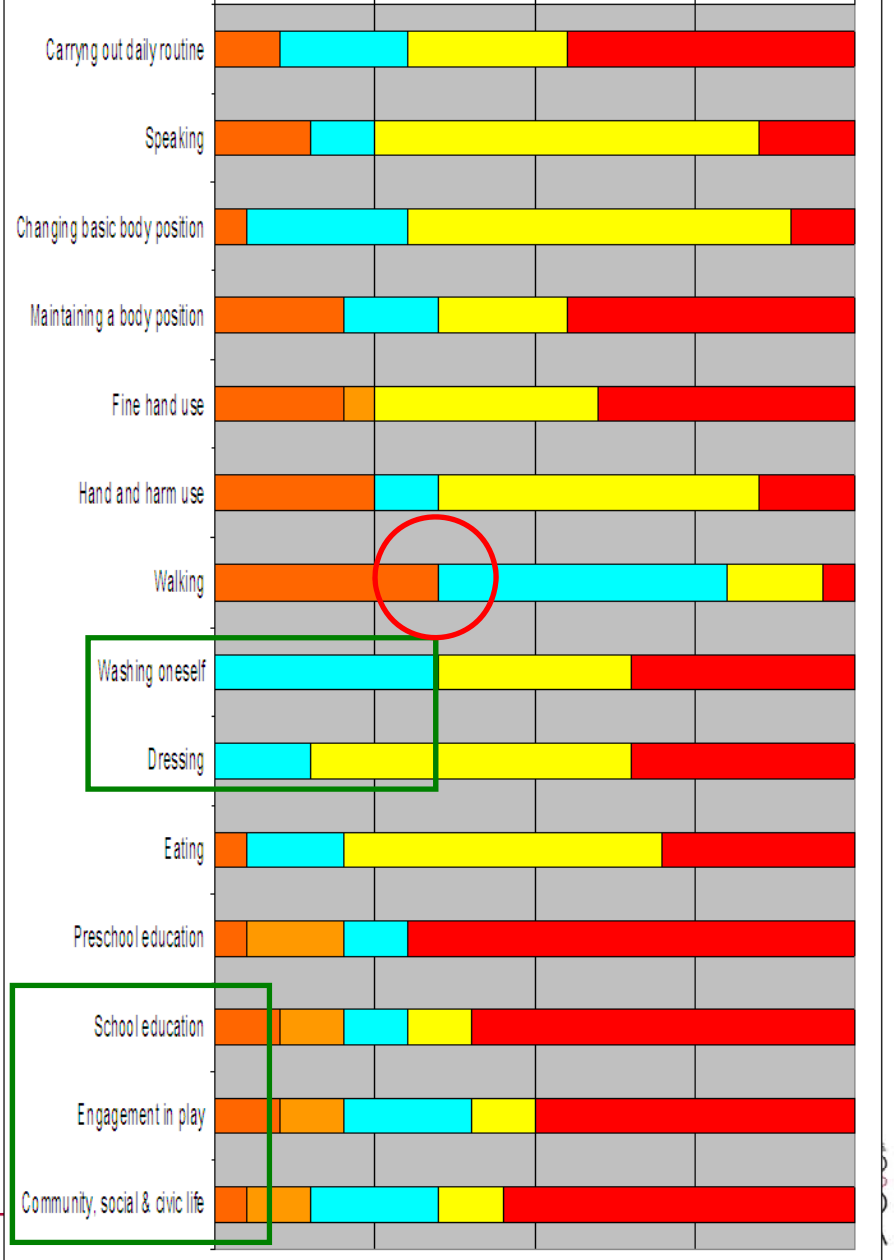
Participation is involvement in a life situation”



TO



T1



Main Problems in Activities&Participation

- D4 Mobility (walking)
- D5 Self-care (washing oneself; dressing)
- D7 Interpersonal interactions and relationships
- D8 Major life areas (preschool and school education; play)
- D9 Social life (leisure)

Environmental factors

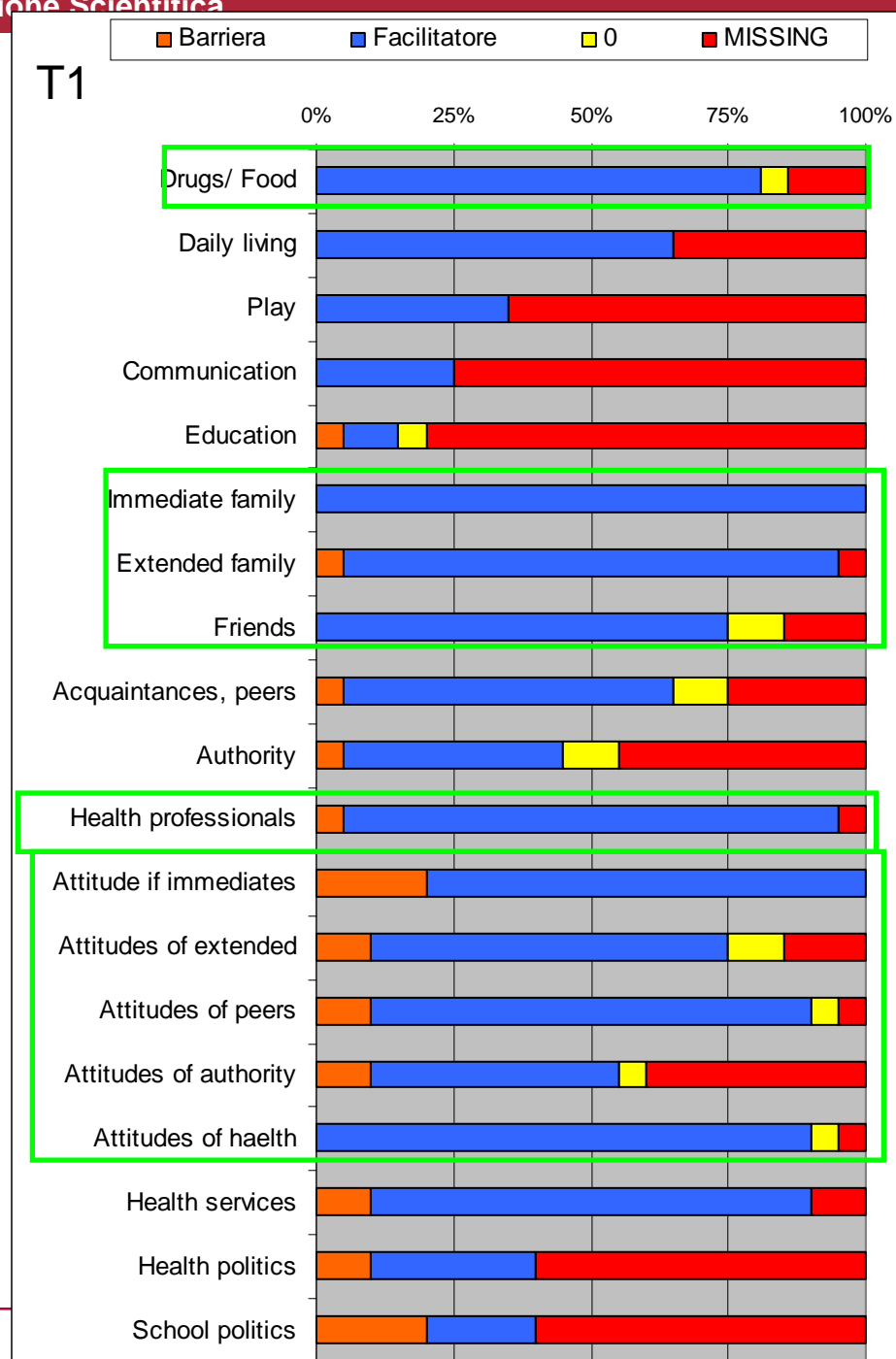
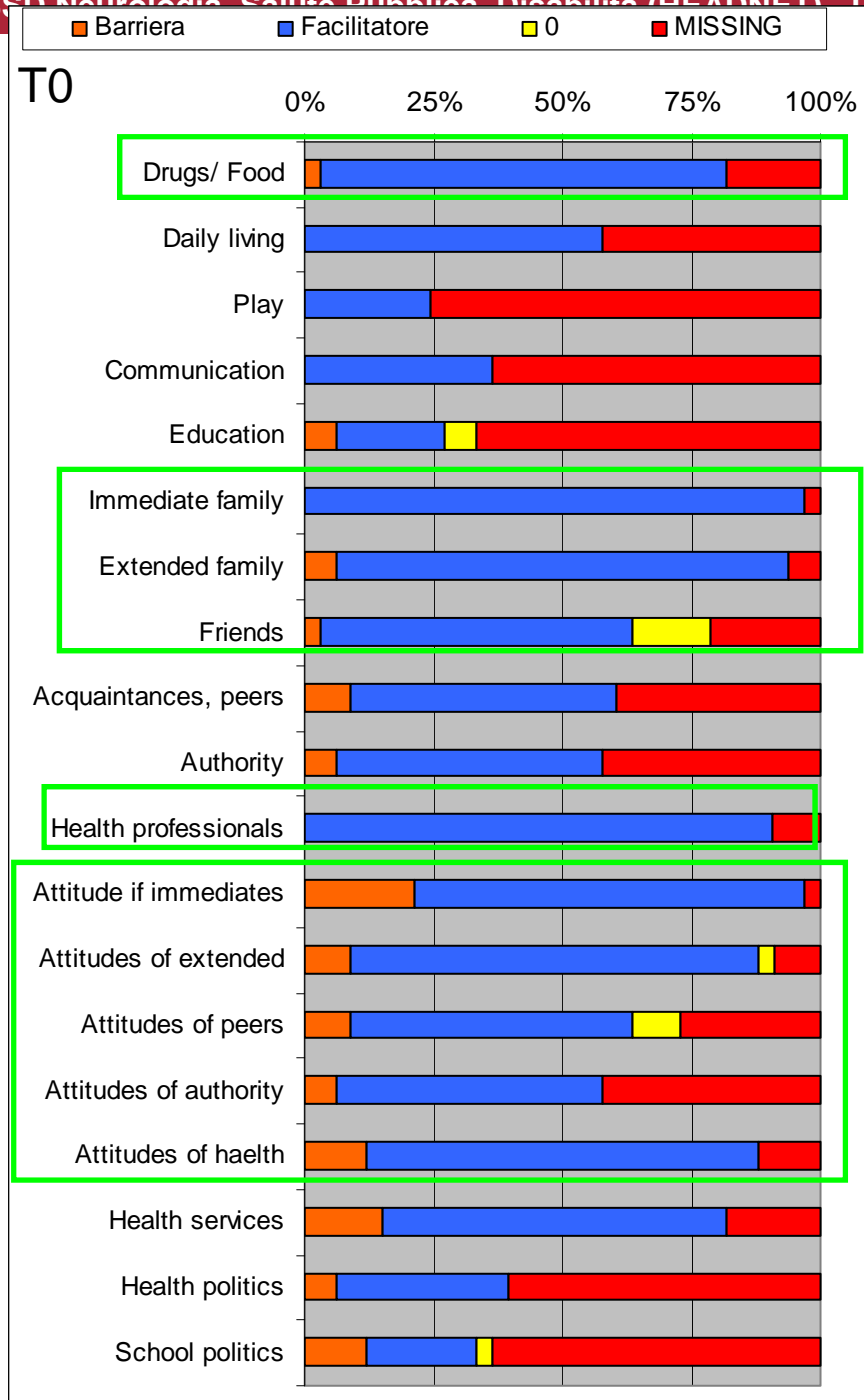
“..make up the physical, social and attitudinal environment in which people live and conduct their lives”

Barrier 1,2 → mild or moderate barrier

Barrier 3,4 → severe or complete barrier

Facilitator 1, 2 → mild or moderate facilitator

Facilitator 3, 4 → substantial or complete facilitator



Main facilitators

- Medicine
- Immediate family
- Extended family
- Friends
- Health professionals
- Attitudes of immediate and extended family members
- Attitudes of acquaintances; persons in authority; health professionals

Conclusions (1)

- Different professionals (doctors, psychologists, nurses, volunteers) already working in network with children or adolescents with brain tumour now share the ICF common language
- Focus not only on the medical aspects of a child's functioning but also functioning at school, in relations with peers, in family

Conclusions (2)

- Better collection and rational analysis of all relevant information with ICF-CY: personalized therapeutic plans involve all areas of life of children
- Highlights the role of “new” communication technologies as a facilitator (e.g. cell-phone, computer, forum, chat)