

Children's Participation: Recent results from the CFFS & FUNDES-Child

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My Experience

- Occupational Therapy
- Children/youth with disabilities & chronic illness (*Traumatic Brain Injury*)
- Interdisciplinary teams
- Measurement & Intervention Development
- Rehabilitation Outcomes Research
- Qualitative Research
- Consultation / Teaching

Presentation Objectives

1. To provide background to the concept of participation and its importance for children & youth
2. To provide an overview of the Child & Family Follow up Survey (CFFS) & recent research
3. To provide an overview of the Functioning Scale of The Disability Evaluation System – Child version (FUNDES-Child) & recent research

Participation:

What it is & why important

- Involvement in life situations
International Classification of Functioning, Disability & Health (ICF; ICF-CY) (WHO, 2001, 2007)
- Multi-dimensional & universal
 - (Coster & Khetani, 2008; Law, 2002)
- Children & youth with disabilities often restricted in participation
 - Affected by child & environmental factors
 - (Bedell, 2009; Law, 2002; King, et al., 2003; Simeonsson, et al., 2001)
- Key aim of rehabilitation, education & community programs (Bedell & Dumas, 2004; Law, 2002)

Participation:

- Enables children to interact, work and live with others and function in society
 - (Law, 2002; Larson, 2000; Mahoney, et al., 2003).
- Associated with enhanced quality of life, social competence and educational success
 - (Bedell & Dumas, 2004; Eccles, et al., 2003; King, et al., 2003; Larson, 2000; Law, 2002; Mahoney, et al., 2003; Simeonsson, et al., 2001).
- *Especially activities that promote **skill development**, and provide a **sense of accomplishment and enjoyment***
 - (Eccles, et al., 2003; Fletcher, et al., 2003; Mahoney, et al., 2003; Rutter, 1987).

ICF DOMAINS	ACTIVITY & PARTICIPATION (SUB-DOMAINS)
1. Learning & Applying knowledge	Purposeful sensory experiences; Basic learning; Applying knowledge
2. General Tasks & Demands	Undertaking a single task; Undertaking multiple tasks; Carrying out daily routines; Handling stress & other psychological demands
3. Communication	Communicating-receiving; Communicating-producing (spoken & nonverbal); Conversation & use of communication devices & techniques
4. Mobility	Changing and maintaining body position; Maintaining a body position; Transferring oneself; Carrying, moving & handling objects; Walking & moving; Moving around using transportation
5. Self-care	Washing oneself; Caring for body parts (grooming); Toileting; Dressing; Eating; Drinking; Looking after one's health
6. Domestic Life	Acquisition of necessities; Household tasks; Caring for household objects and assisting others
7. Interpersonal Interactions & Relationships	General (basic & complex) interpersonal interactions; Particular interpersonal interactions (Relating with strangers, Informal & formal social relationships, Family relationships, Intimate relationships)
8. Major Life Areas	Education; Work & employment, Economic life
9. Community, Social & Civic Life	Community life, Recreation & leisure, Religion & spirituality, Human rights, Political life & citizenship (WHO, 2001)

Social Participation & Participation

- Often used interchangeably
- *Social participation*: “taking part, involvement, engagement, doing or being **with others**” (Bedell, 2012)
- *Participation* is involvement in activities that can, should or might prefer to be done without others.

What is important to measure?

- **Key themes important to children's well-being:** 1) essential for survival, 2) supportive of child development, 3) discretionary, & 4) educational (McConachie, et al., 2006)
- **Meaningful & setting-specific goals:** 1) sustenance & physical health, 2) development of skills & capacities, & 3) enjoyment & well-being (Coster & Khetani, 2008)
- **Performance or fulfillment of social or societal roles** (Whiteneck & Dijkers, 2009).
- **Stakeholder needs & goals:** *children, families, service providers, program directors, policy makers* (Bedell & Coster, 2008; Bedell, Khetani, et al., 2012)

National Survey of Children's Participation in Taiwan

- Based on United Nations Convention on Human Rights of Persons with Disability (UNCRPD) and the Rights of the Child (UNCRC), participation has been described as the individual's right to be respected.
- The research of children's participation in Taiwan began before the new Disability Evaluation System (DES; which was launched in July 2012).
- The DES includes children's functioning in determining eligibility for social welfare based on the People with Disabilities Rights Protection Act in Taiwan.

Child & Family Follow-up Survey (CFFS)

- Originally developed as parent report measure to monitor needs & outcomes of children & youth with acquired brain injury & their families (Bedell, 2004)
- Informed by the International Classification of Functioning, Disability & Health (ICF, WHO, 2001)
- Now used in multiple settings worldwide with children & youth with other conditions, & for varied purposes and levels of focus (*population, program, child/family*)
- Evidence of reliability & validity (Bedell, 2004; 2009, Bedell & McDougall, 2013, McDougall, Bedell & Wright, 2013)
- Translations & cultural modifications:
 - Traditional Chinese (part of the **Functioning Scale of the Disability Evaluation System (FUNDES) - Child version** (Hwang, et al., 2013)
 - Spanish, Dutch, French, Hebrew, Arabic, German, Swedish, others

Overview of the CFFS (*continued*)

- **Child & Adolescent Scale of Participation (CASP)**
 - Parent report & youth report versions
 - Extent of participation compared to same age in home, school & community
- **Child & Adolescent Scale of Environment (CASE)**
 - Extent of environmental problems
- **Child & Adolescent Factors Inventory (CAFI):**
 - Extent of impairment
- **Other questions:** Child's physical & emotional health, ways of communicating & moving around, current services, family needs & quality of life

CASP: Four subsections (*20 items*)

HOME PARTICIPATION:

1. Social/ leisure (family)
2. Social/ leisure (friends)
3. Chores / Responsibilities
4. Self-care
5. Mobility
6. Communication

COMMUNITY PARTICIPATION:

7. Social/ leisure (friends)
8. Structured activities
9. Mobility
10. Communication

***Plus open-ended questions
(e.g., strategies, equipment)**

SCHOOL PARTICIPATION

11. Educational activities
12. Social / Leisure (students)
13. Mobility
14. Using educational materials
15. Communication

HOME & COMMUNITY LIVING

16. Household Activities
17. Shopping/ Managing Money
18. Managing Daily Schedule
19. Using Transportation
20. Work Activities

Compared to other children your child's age, what is your child's current level of participation in the following activities?

- **CASP 4-point rating scale is as follows:**
 - 1=無法參與活動 (unable)
 - 2=參與程度非常侷限 (very limited)
 - 3=參與程度部分侷限 (somewhat limited)
 - 4=參與程度與其年齡相符 (age-expected)
- **Not applicable**, other children your child's age **would NOT be expected** to participate in the activities

**Higher scores indicate a greater extent of participation*

The Child and Adolescent Factors Inventory (CAFI) *15 Items*

1. Paying attention or concentrating
2. Remembering people, places or directions
3. Problem solving or judgment
4. Understanding or learning new things
5. Controlling behaviors, moods or activity level
6. Motivation (lacks interest or initiative)
7. Psychological (e.g., depression or anxiety)
8. Speech
9. Vision
10. Hearing
11. Movement (balance, coordination, muscle tone)
12. Strength or energy level (e.g., weakness or fatigue)
13. Reacting to sensation or stimulation (e.g., over- or under-reaching to sound, light, touch, movement)
14. Physical symptoms (e.g., headaches, dizziness, pain): _____
15. Other health and medical conditions: _____

The Child and Adolescent Factors Inventory (CAFI)

- Assesses level of impairment and other child personal factors
- Each item or problem is rated on a 3-point scale:
 - 1= 沒有問題 (no problem)
 - 2= 有些問題 (little problem)
 - 3= 嚴重問題 (big problem)

**Higher scores indicate a greater extent of problem.*

Child and Adolescent Scale of Environment (CASE)

- Assesses physical, social and attitudinal environmental barriers
 - Adaptation of the CHIEF (initially designed for adults; Whiteneck, et al., 2004)
 - Same response options as CAFI (3-points):
 - 1= 沒問題 (no problem)
 - 2= 些許問題 (little problem)
 - 3= 嚴重問題 (big problem)
 - There is a “non applicable” response as well
- *Higher scores indicate a greater extent of problem.*

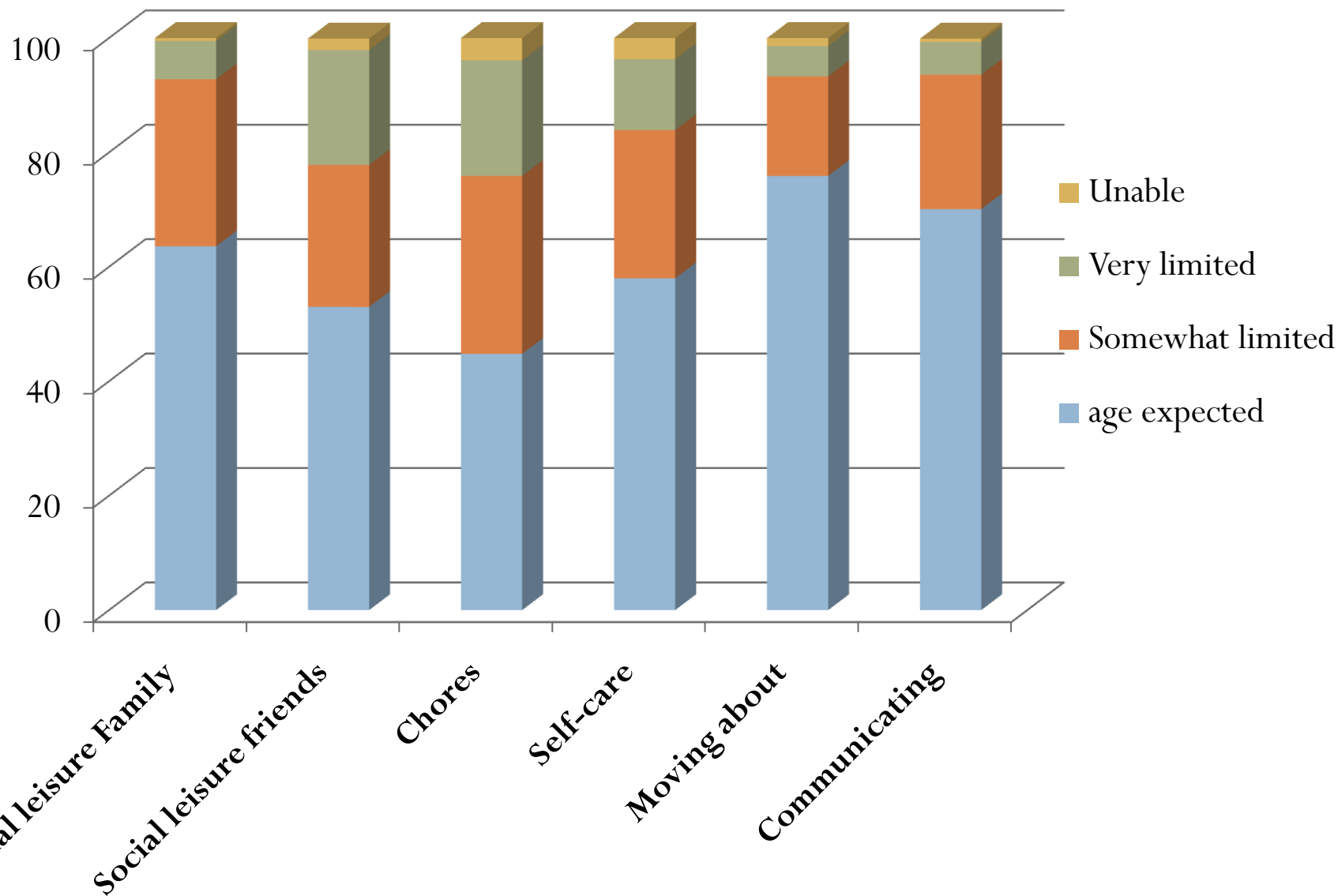
Child and Adolescent Scale of Environment (CASE) 18 Items

- (1) Problem with design and layout of home (Hard to get to places and things, or hard to see or hear important information)
- (2) Problem with design and layout of buildings and places your child uses in the *community or neighbourhood*
- (3) Problem with design and layout of school or work setting (Circle *school* or *work*)
- (4) Lack of support and encouragement for your child in the *community or neighbourhood*
- (5) Lack of support and encouragement for your child at *school or work* (Circle *school* or *work*)
- (6) Problems with people's attitudes toward your child at *school or work* (Circle *school* or *work*)
- (7) Problems with people's attitudes toward your child in the *community or neighbourhood*
- (8) Inadequate or lack of assistive devices or equipment
- (9) Inadequate or lack of assistance from people at *home* or in the *community or neighbourhood*
- (10) Inadequate or lack of assistance from people at *school or work* (Circle *school* or *work*)
- (11) Inadequate or lack of transportation
- (12) Inadequate or lack of programmes and services at *school*
- (13) Inadequate or lack of programmes and services in the *community or neighbourhood*
- (14) Inadequate or lack of family finances
- (15) Family stress
- (16) Crime or violence in the community or neighbourhood
- (17) Problems with government agencies and policies
- (18) Inadequate or lack of information about your child's diagnosis or condition or intervention approaches (e.g. educational, rehabilitation or medical)

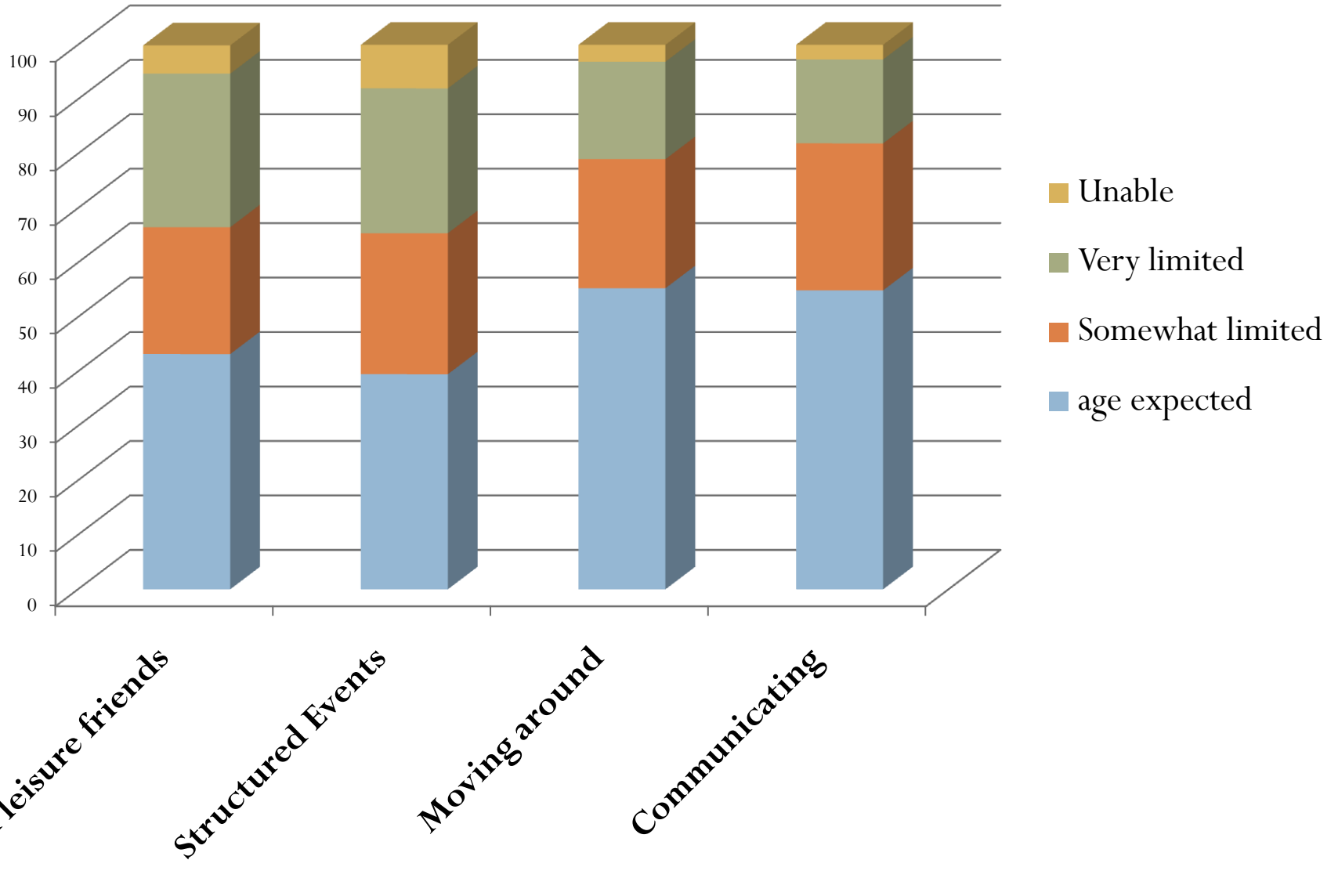
Recent findings from the CFFS ($n=793$)

- Age range: 2.5 to 27 years; Mean = 13.5 (SD=3.6); 96% ages 5 to 17.99
- Canada (60%), USA (35.4%), Australia (2.5%), Israel (2.1%)
- Male (55.3%); Female (44.7%)
- Acquired Brain Injury (35.9 %); Cerebral Palsy (18.8%); Developmental / Intellectual Disability (11.9%); No disability (6.7%)
 - Autism Spectrum (4.7%); Learning, attention, communication (4.3%); Spina Bifida (4.4%); Cleft lip/palate (4.2%); Amputee (2.1%); Other (7.1 %)

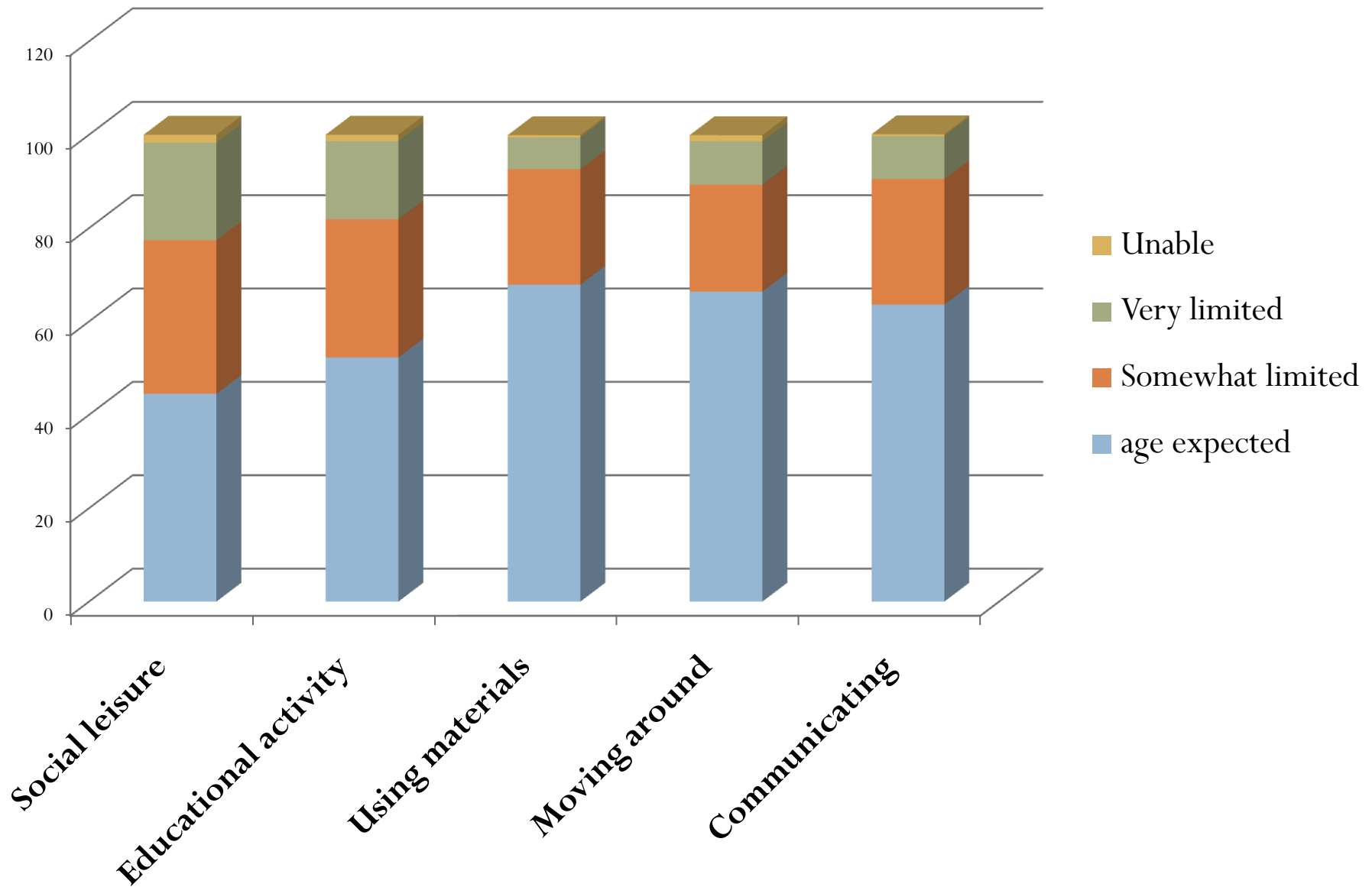
Home Participation (CASP)



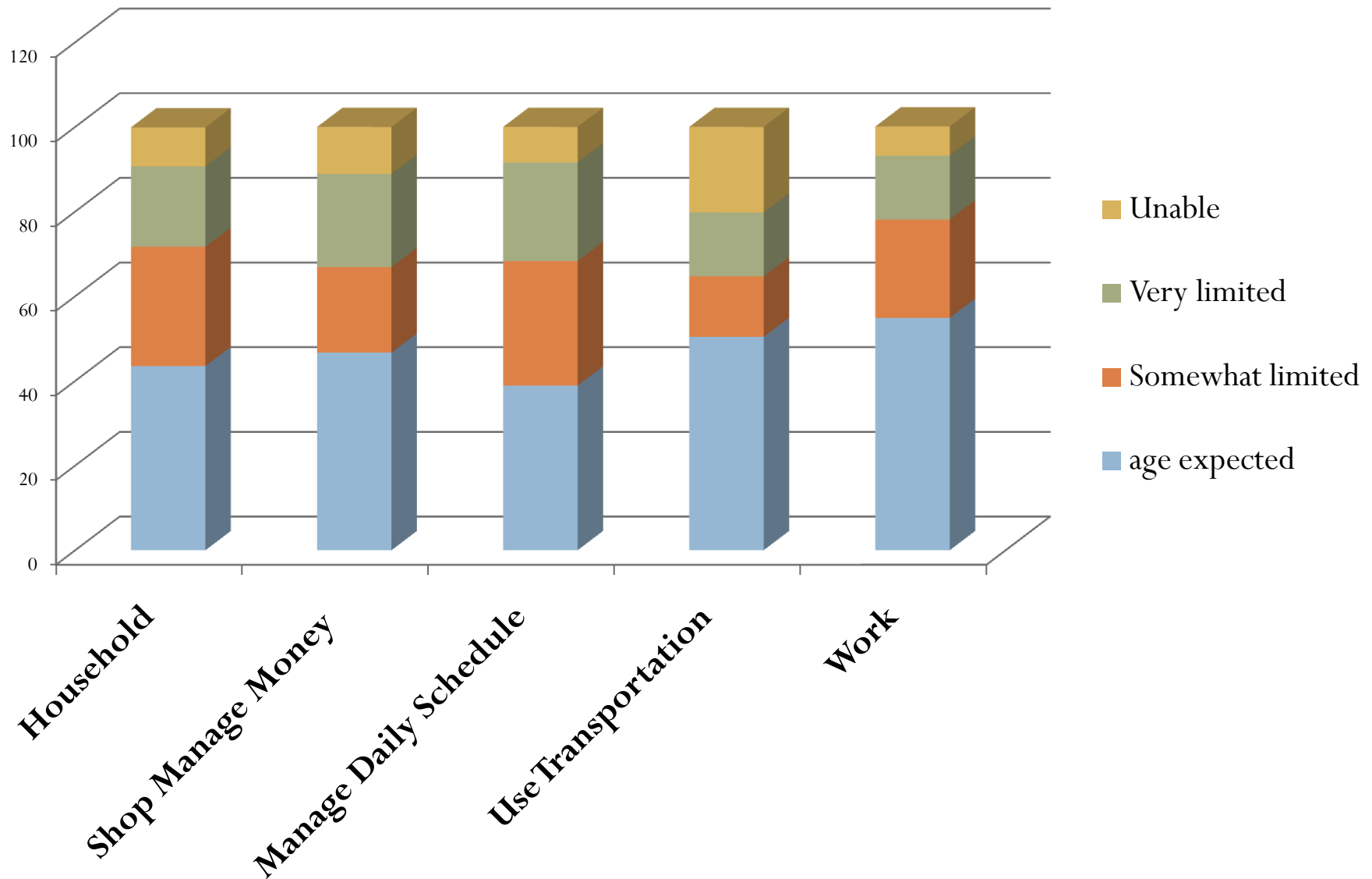
Community Participation (CASP)



School Participation (CASP)



Home & Community Living Activities(CASP)



Factors Associated with Participation (CFFS)

	CAFI	CASE	Age
CASP	-.66**	-.57**	.011
CAFI		.54**	.06*
CASE			.06

•Child & Adolescent Scale of Participation (*CASP*); Child & Adolescent Factors Inventory(*CAFI*); Child & Adolescent Scale of Environment (*CASE*)

•Pearson Correlation Coefficients (r)

**** p <.001; *p < .05**

Differences in Participation (Mean CASP Scores)

CAFI items	<i>No Problem</i> Mean (SD)	<i>Little Problem</i> Mean (SD)	<i>Big Problem</i> Mean (SD)
Cognitive (e.g., problem solving)*	<u>n=247</u> 91 (13)	<u>n=263</u> 82 (14)	<u>n=191</u> 71 (14)
Movement (e.g., balance, coordination)*	<u>n=261</u> 91 (12)	<u>n=259</u> 82 (14)	<u>n=180</u> 70 (15)
Psychological (e.g., anxiety, depression)*	<u>n=375</u> 86 (15)	<u>n=229</u> 80 (15)	<u>n=95</u> 73 (15)

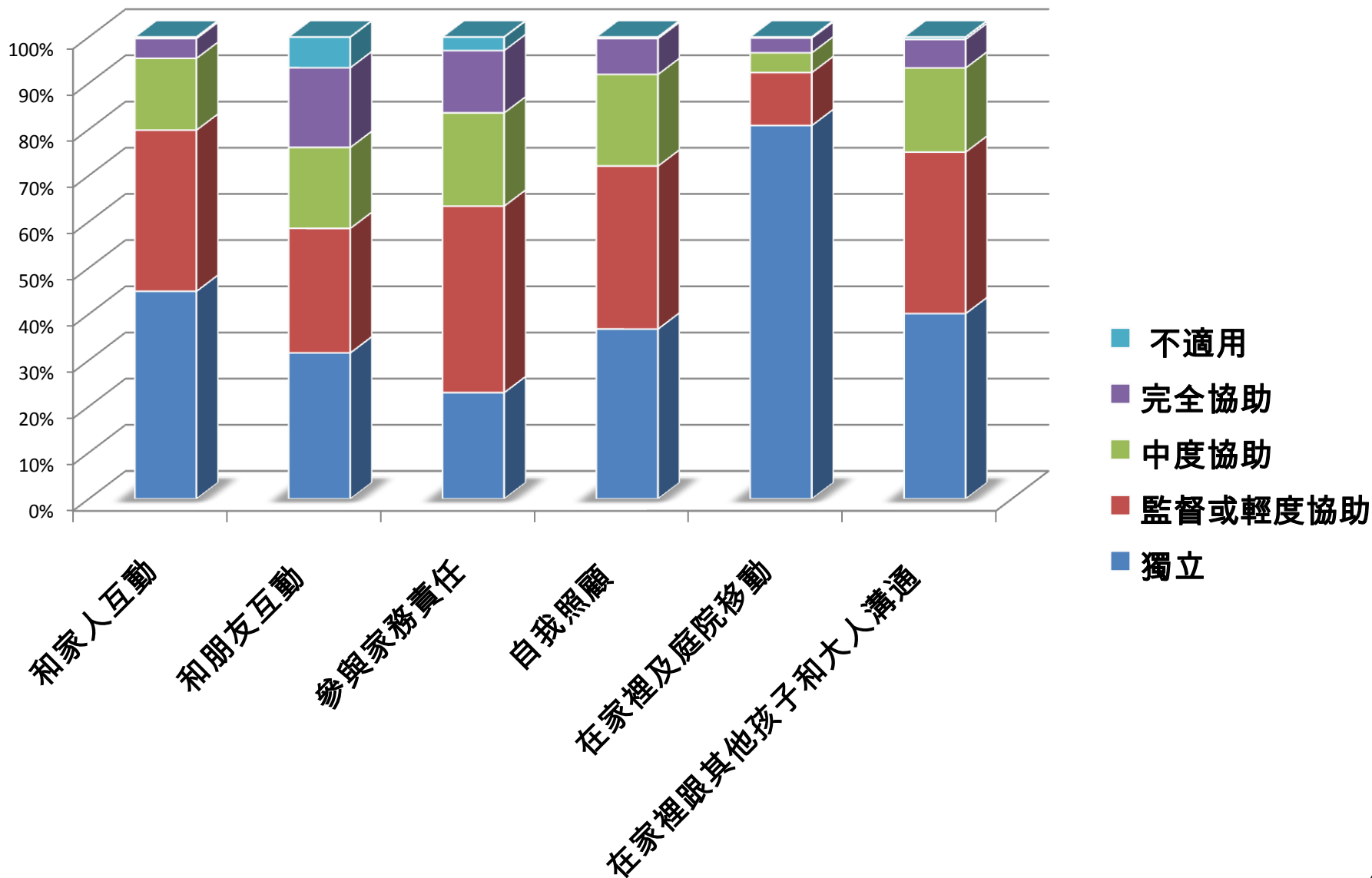
***(p < .001)**

Recent findings: FUNDES-Child ($n = 18,119$)

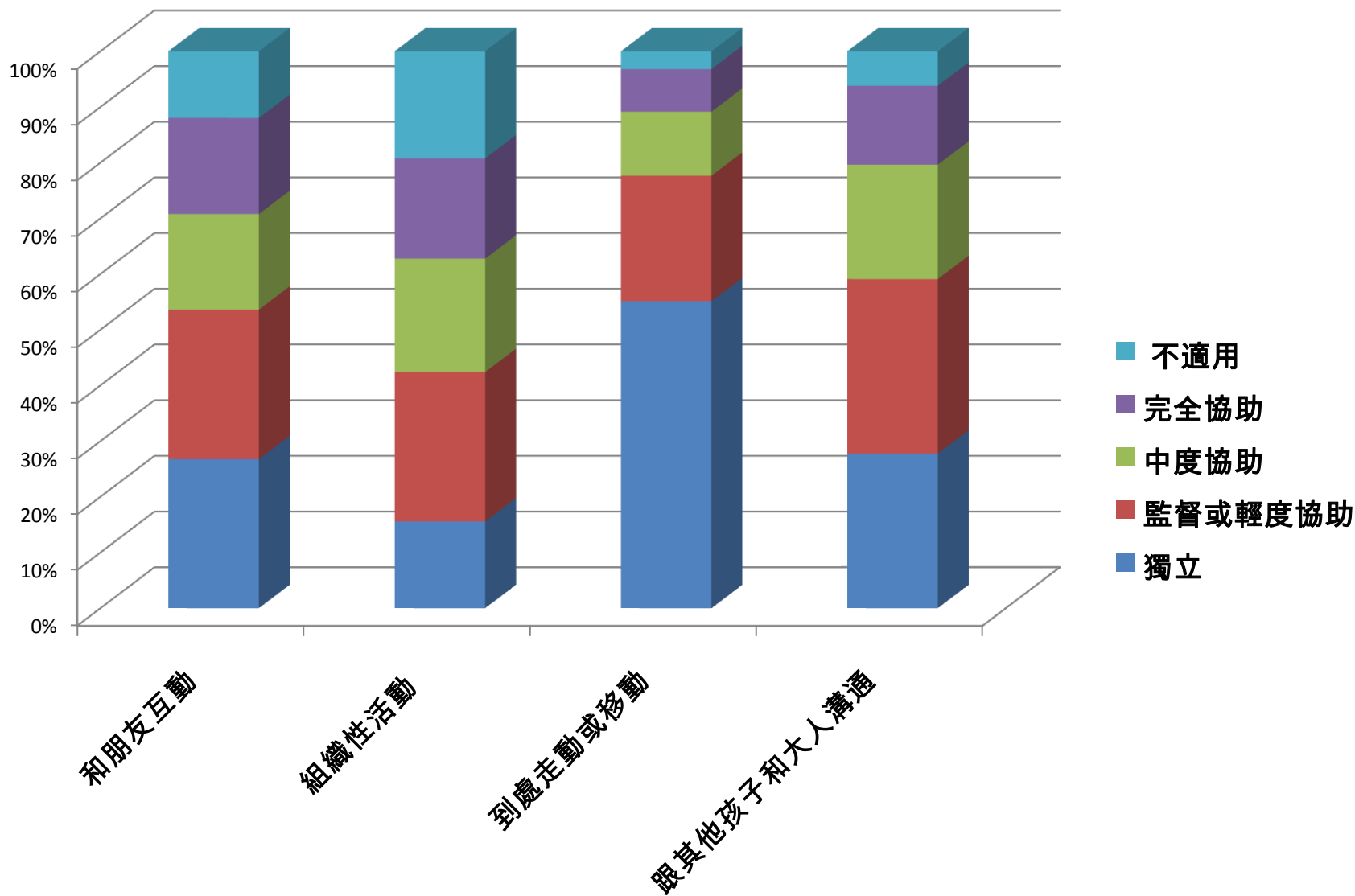
- **Age range:** 6- 17.99; **Mean** = 12.1 (SD=3.5);
- **Male** (64.6 %); **Female** (35.4%)

Diagnoses/ICD-9 codes	Frequency (%)
Intellectual disability/317-319	10310 (56.9 %)
Autism/299.01-299.90	4013 (22.1 %)
Language delay/315.31-315.39, 318.1	801 (4.4 %)
Cerebral palsy/343.9,	602 (3.3 %)
Hearing impairment/389	448 (2.5 %)
Schizophrenia/295.10-295.90	191 (1.1 %)
Visual impairment	89 (0.5 %)
CVA	58 (0.3 %)
Depression/296	31 (0.2 %)
SCI	20 (0.1 %)

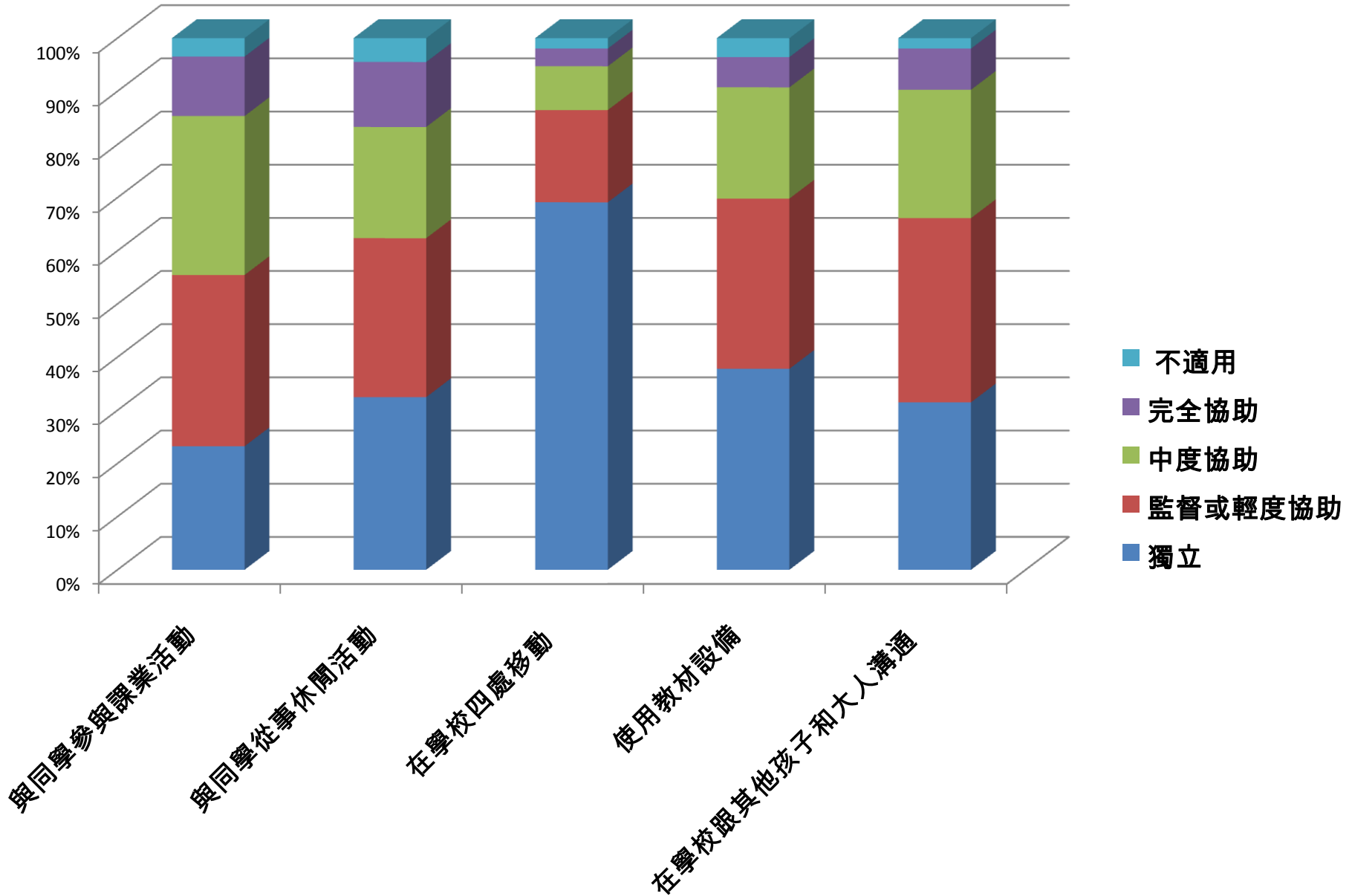
Home Participation (FUNDES-Child)



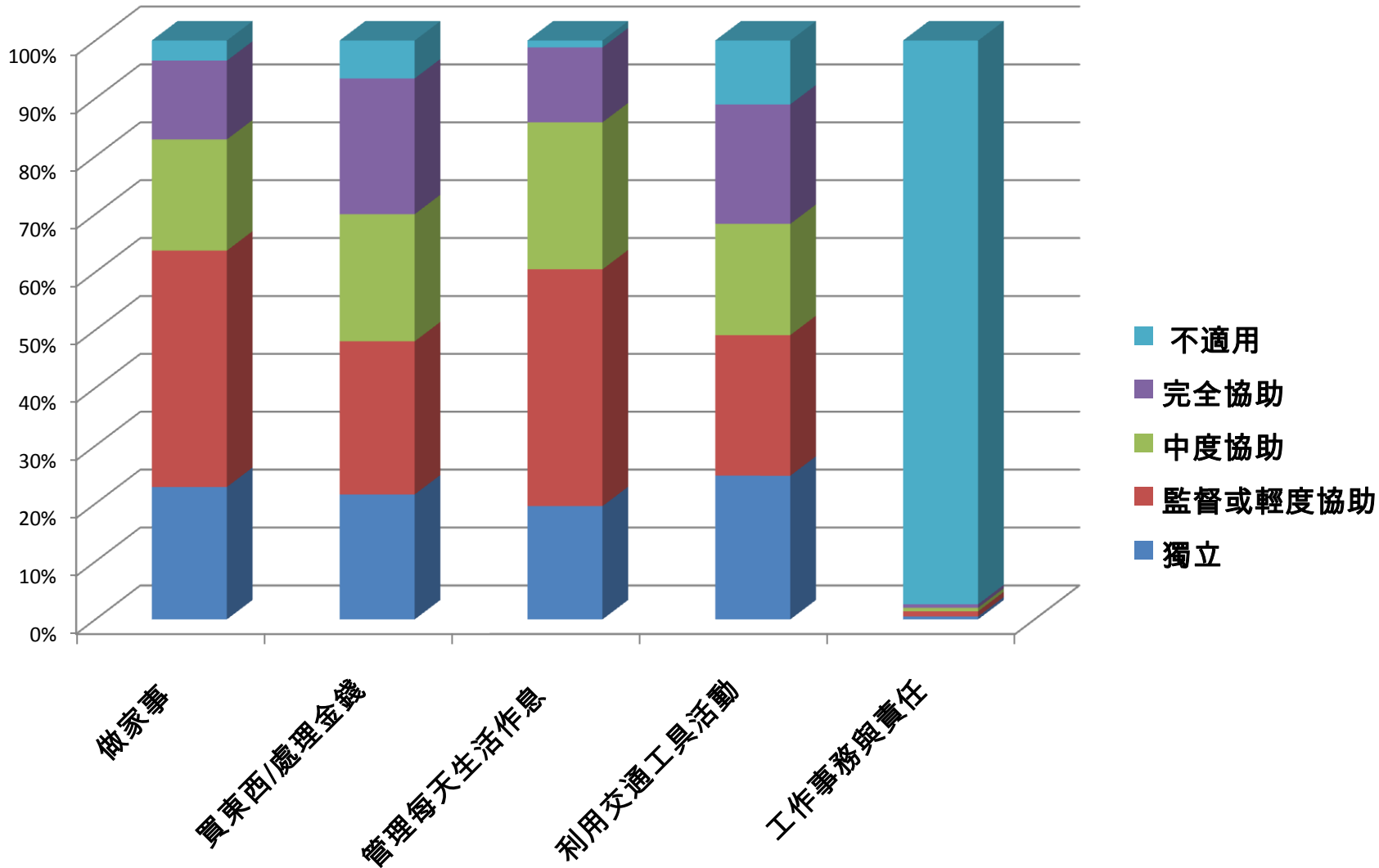
Community Participation (FUNDES-Child)



School Participation (FUNDES-Child)



Home & Community Living Activities (FUNDES-Child)



Factors Associated with Participation (FUNDES-Child)

	Body function impairments	Environmental barriers	Age
Participation-Capability restriction	.73***	.37***	-.17***
Body function impairments		.45***	.08***
Environmental barriers			.00

Pearson Correlation Coefficients (r)

***** p <.001**

Differences in Participation (Mean FUNDES-Child Scores)

CAFI items	<i>No Problem</i> Mean (SD)	<i>Little Problem</i> Mean (SD)	<i>Big Problem</i> Mean (SD)
Cognitive (e.g., problem solving)*	<u>n=2416</u> 4.2 (4.2)	<u>n=7569</u> 7.1 (4.3)	<u>n=8132</u> 12.7 (5.9)
Movement (e.g., balance, coordination)*	<u>n=10530</u> 7.3 (5.0)	<u>n=5558</u> 10.4 (5.4)	<u>n=2029</u> 16.0 (6.7)
Psychological (e.g., anxiety, depression)*	<u>n=6978</u> 6.6 (5.1)	<u>n=8019</u> 9.5 (5.2)	<u>n=3120</u> 14.3 (6.4)

***(p < .001)**

Summary

- Both the CFFS & FUNDES have evidence of reliability & validity (*responsiveness to change not yet studied*)
- Recent CFFS results are consistent with prior results:
 - children with greater impairment and environmental problems have more restricted participation
 - greater participation restrictions are noted in
 - social leisure with friends (across settings)
 - Structured events in the community
 - Educational activities with others at school
 - All home and community living activities (especially managing daily activity)
 - no clear pattern for sex or age categories
- **Recent FUNDES-Child:** Results were similar to U.S. data except there was a positive association with participation capability and age in Taiwan.

Implications

- Results provide broad picture of participation patterns & factors affecting participation
 - at the population or societal level
- Results might inform policy & services:
 - Types of participation to target
 - Child & environmental factors that need to be addressed to promote participation
- Foundation for next presentation:
 - how to use the CFFS and FUNDES for goal setting, intervention planning, and program evaluation and improvement

THANK YOU!

ANY QUESTIONS?

References

- Bedell, G. (2012). Measurement of Social Participation. In V. Anderson, & M. Beauchamp (Eds.), *Developmental Social Neuroscience and Childhood Brain Insult: Implication for Theory and Practice*. New York, NY: Guilford Publications.
- Bedell, G. (2009). Further validation of the Child and Adolescent Scale of Participation (CASP). *Developmental Neurorehabilitation*, 12(5), 342-351.
- Bedell, G. M. (2004). Developing a follow-up survey focused on participation of children and youth with acquired brain injuries after discharge from inpatient rehabilitation. *NeuroRehabilitation*, 19, 191-205.
- Bedell, G. & Coster, W. (2008). Measuring participation of school-aged children with traumatic brain injuries: Considerations and approaches. *Journal of Head Trauma Rehabilitation*, 23(4), 220-229.
- Bedell, G. M. & Dumas, H.M. (2004). Social participation of children and youth with acquired brain injuries discharged from inpatient rehabilitation: A follow-up study. *Brain Injury*, 18(1), 65-82.
- Bedell, G., Khetani, M.A., Cousins, M.A., Coster, W.J., & Law, M.C. (2011). Parent perspectives to inform development of measures of children's participation and environment. *Archive of Physical Medicine & Rehabilitation*, 92, 765-773.
- Coster, W., & Khetani, M. A. (2008). Measuring participation of children with disabilities: Issues and challenges. *Disability and Rehabilitation*, 30(8), 639-648.

References

- Bedell, G., & McDougall, J. The Child and Adolescent Scale of Environment (CASE): Further validation with youth who have chronic health conditions. (2013). *Developmental Neurorehabilitation*, Early online, 1- 7.
- Eccles, J. S., Barber, B.L., Stone, M., & Hunt, J. (2003). Extracurricular activities and adolescent development. *Journal of Social Issues*, 59(4), 865-889.
- Fletcher, A. C., Nickerson, P., & Wright, K. L. (2003). Structured leisure activities in middle childhood: Links to well-being. *Journal of Community Psychology*, 31(6), 641-659.
- Hwang, A.W., Liou, T.H., Bedell, G., Kang, L.J., Chen, W.C., Yen, C.F., & Chang, K.H., Liao, H.F., and Component Task Force of Disability Evaluation System (2013). Psychometric Properties of the Child and Adolescent Scale of Participation – Traditional Chinese version. *International Journal of Rehabilitation Research*, 36, 211-220.
- King, G., Law, M., King, S., Rosenbaum, P., Kertoy, M. K., & Young, N. (2003). Conceptual model of the factors affecting recreation and leisure participation of children with disabilities. *Physical and Occupational Therapy in Pediatrics*, 23, 63-90.
- Larson, R. W. & Verma, S. (1999). How children and adolescents spend time across the world: Work, play, and developmental opportunities *Psychological Bulletin*, 125(6), 701-736.
- Law, M. (2002). Participation in the occupations of everyday life. *American Journal of Occupational Therapy*, 56(6), 640-649.

References

- Mahoney, J. L., Cairns, B.D., & Farmer, T.W. (2003). Promoting interpersonal competence and educational success through extracurricular activity participation. *Journal of Educational Psychology, 95*(2), 409-418.
- McConachie, H., Colver, A.F., Forsyth, R.J., Jarvis, S.N., & Parkinson, K.N. (2006). Participation of disabled children: How should it be characterised and measured? *Disability and Rehabilitation, 28*, 1157-1164.
- McDougall, J, Bedell G, Wright V. (2013). The youth report version of the Child and Adolescent Scale of Participation (CASP): Assessment of psychometric properties and comparison with parent report. *Child: Care, Health and Development, 39*, 512-522.
- Rutter, M. (1987). Psychosocial resilience and protective mechanisms. *American Journal of Orthopsychiatry, 57*, 316-331.
- Simeonsson, R. J., Carlson, D., Huntington, G.S., McMillen, J., & Brent, L. (2001). Students with disabilities: A national survey of participation in school activities. *Disability and Rehabilitation, 23*, 49-63.
- Whiteneck, G. & Dijkers, MP. (2009). Difficult to measure constructs: Conceptual and methodological issues concerning participation and environmental factors. *Archives of Physical Medicine and Rehabilitation, 90*(11 Supplement 1), S22-35.
- World Health Organization [WHO]. (2001). *International Classification of Functioning, Disability and Health*. Geneva: WHO.
- World Health Organization [WHO]. (2007). *International Classification of Functioning, Disability and Health. Version for Children and Youth*. Geneva: WHO.

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