

# A brother or a sister with CP

How much it makes a difference in childhood and adulthood?

Eulália Calado MD

Department of Pediatric Neurology

Lisboa

Portugal



Federação das Associações Portuguesas  
de Paralisia Cerebral

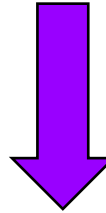
PARENTS AND PROFESSIONALS WORKING TOGETHER  
Barcelona, 18-19 Nov. 2011

# Cerebral Palsy children and siblings



**CP is the most common developmental disorder associated with lifelong motor impairment and disability**  
(prevalence 2-3/1000 in developed countries)

**general agreement**



**siblings of children with CP can act as change agents to minimize disability, encouraging emotional, social and cognitive development.**

**whether or not** siblings are adversely affected by their disabled CP

**brothers or sisters**



# Sibling Relationships and Cerebral Palsy

- Sibling relationships are the most human powerful bonds
- Siblings share family, home, friends, environment, experiences, joys and sadness from infancy to adolescence
- They act as parents substitutes, informal teachers and best reliably friends

**A FRIENDSHIP AND A CUMPLICITY FOR LIFE...**

**It will be the same with these siblings?**

**As professionals how should we target the family towards  
an “healthy” childhood and adolescence of these kids that  
have a brother or sister with CP**

**?**



# A brother or a sister with CP

Looking at the other side of the story...

What does the literature tell us? Very few...

**Relationships Between Adolescent Children and Their Siblings with Cerebral Palsy: A Pilot Study** . Mophosho M et al. J Dev Disabil 2010: **positive and negative feelings**

In many families, **the amount of time devoted by parents to the one child with cerebral palsy** may lead to problems with siblings

Literature has shown that **having a sibling with disability can be both rewarding and stressful** and that it may have positive and negative affects for the child without disability

**Family size, socioeconomic status and parental attitudes and expectations** affect how the sibling reacts to their sibling with cerebral palsy

Gallagher & Powell, 1989

Schleichkorn, 1993

# A brother or a sister with CP

## Bibliographic search in Pubmed

Key-words	Nº papers	Selected→ 5
<b>Cerebral palsy, siblings</b>  (cited in title and/or abstract)	<b>92</b>	<ol style="list-style-type: none"><li>1. Dallas E, et al. Cerebral-palsied children's interactions with siblings--II. Interactional structure. J Child Psychol Psychiatry. 1993;34(5):649-71.</li><li>2. Dallas E, et al. Cerebral-palsied children's interactions with siblings--I. Influence of severity of disability, age and birth order. J Child Psychol Psychiatry. 1993;34(5):621-47.</li><li>3. Rehn E, von Eye A. Siblings of children with cerebral palsy: a parallel sample-configuration frequency analysis and their adjustment. Z Klin Psychol Psychopathol Psychother. 1990;38(3):245-52.</li><li>4. Breslau N. Siblings of disabled children: birth order and age-spacing effects. J Abnorm Child Psychol. 1982;10(1):85-96.</li><li>5. Flatman B. Impact of mental retardation associated with cerebral palsy on parents and siblings. Can J Psychiatr Nurs. 1970;11(2):8-11.</li></ol>

# A brother or a sister with CP

Bibliographic search in Pubmed

Key-words	Nº papers	Selected → 42
<b>Disabled children, siblings</b>  (cited in the title and/ or abstract)	142	<ol style="list-style-type: none"> <li>1. Unal N, Baran G. Behaviors and attitudes of normally developing children toward their intellectually disabled siblings. <i>Psychol Rep.</i> 2011;108(2):553-62.</li> <li>2. Puttick N. Siblings of children with disabilities: improving health well-being through creativity. <i>J Fam Health Care.</i> 2011;21(1):25-8.</li> <li>3. O' Brien I, Duffy A, Nicholl H. Impact of childhood chronic illnesses on siblings: a literature review. <i>Br J Nurs.</i> 2009;18(22):1358,1360-5.</li> <li>4. Dauz Williams P, Piamjariyakul U, Graff JC, Stanton A, Guthrie AC, Hafeman C, Williams AR. Developmental disabilities: effects on well siblings. <i>Issues Compr Pediatr Nurs.</i> 2010;33(1):39-55.</li> <li>5. Denis Y. A self help group for brothers and sisters of handicapped or sick children. <i>Soins Pediatr Pueric.</i> 2009;(247):33-5.</li> <li>6. Floyd FJ, et al. Sibling relationship quality and social functioning of children and adolescents with intellectual disability. <i>Am J Intellect Dev Disabil.</i> 2009;114(2):110-27.</li> <li>7. Dyke P, Mulroy S, Leonard H. Siblings of children with disabilities: challenges and opportunities. <i>Acta Paediatr.</i> 2009;98(1):23-4.</li> <li>8. Reichman NE, Corman H, Noonan K. Impact of child disability on the family. <i>Matern Child Health J.</i> 2008;12(6):679-83</li> </ol>

# A brother or a sister with CP

## Bibliographic search in Pubmed

Key-words	Nº papers	Selected → 12
<b>Chronic ill children, siblings</b>  (cited in title and/ or abstract)	26	<ol style="list-style-type: none"><li>1. O' Brien I, Duffy A, Nicholl H. Impact of childhood chronic illnesses on siblings: a literature review. Br J Nurs. 2009;18(22):1358,1360-5.</li><li>2. Batte S, Watson AR, Amess K. The effects of chronic renal failure on siblings. Pediatr Nephrol. 2006;21(2):246-50.</li><li>3. Williams PD. Siblings and pediatric chronic illness: a review of the literature. Int J Nurs Stud. 1997;34(4):312-23.</li><li>4. Stawski M, Auerbach JG, Barasch M, Lerner Y, Zimin R. Behavioural problems of children with chronic physical illness and their siblings. Eur Child Adolesc Psychiatry. 1997;6(1):20-5.</li><li>5. Boeger A, Seiffge-Krenke I. Siblings of chronically ill adolescents: does chronic illness have effects on their development potentials?. Prax Kinderpsychol Kinderpsychiatr. 1996;45(10):356-62.</li><li>6. Quittner AL, Opipari LC. Differential treatment of siblings: interview and diary analyses comparing two family contexts. Child Dev. 1994;65(3):800-14.</li></ol>

# The burden of CEREBRAL PALSY: impact on parents



Parents spend **6-8 hours** per 24 hours caring for children with CP

The average person spends about **13 hours** per day on essential activities:

personal hygiene .....	49 min
eating .....	1.5h
sleeping .....	8.5h
housework .....	2.25h

When demands of caring lie above the threshold **stress** and **depression** take place...

THERE IS A SIGNIFICANT POSITIVE RELATIONSHIP BETWEEN:

MATERNAL DEPRESSION AND CARE GIVING TIME REQUIRED PER **24 HOURS**

Sawyer GM et al. *Dev Med Child Neurol* 2011

King G, King S, Rosenbaum P, Goffin R. *J Ped Psychol* 1999

# A FAMILY with a child with CP at home

<http://adaptedworld.wordpress.com/>

*“Erin is a **stay-at-home Mom** to Brooke, a very sweet, determined, non-verbal, non-mobile and 100% G tube fed child. Brooke suffered severe oxygen loss and reduced blood flow around the time of her birth, which caused chronic kidney failure, severe brain injury, microcephaly, cortical visual impairment, mixed cerebral palsy, sleep apnea, epilepsy, neurogenic bladder, and reflux.”*

*Erin documents **how Brooke interacts with her siblings** on Adapted World[<http://adaptedworld.wordpress.com/>].*

*Erin has a PhD in Clinical Child Psychology*

## Caregiving as an “imposed” career...

**Providing a Primary Care Medical Home for Children and Youth With Cerebral Palsy**

Liptak, Murphy. *Pediatrics* 2011;128:e1321 (family-centered care provided in the medical home)

**Medical Home and Out-of-Pocket Medical Costs for Children With Special Health Care Needs**

Porterfield, DeRigne. *Pediatrics* 2011;128:892–900

# A brother or a sister with CP

## How social class, culture and religion make it different?

- In poorer families the responsibilities of the “healthy” siblings are much bigger
- African, Muslim and Gypsies have more frequently extended families, that share the care, decreasing the burden of siblings

### The FAMILY UNIT functioning

The problem of immigrants coming from Africa with handicapped children

**Family breakdown**



# A brother or a sister with CP

Older or younger, does it matters?

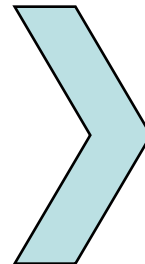
- **Older siblings are usually more well adjusted**  
(the wish to help and compensate the parents for their sorry)

but...

- **Older females may be at risk**  
(over involvement assuming mother's role)

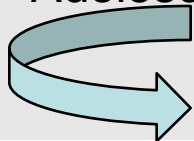


- **Younger males**
- **Close in age to the disabled child**



more vulnerable

Adolescents and the feeling they don't matter to their parents



**deviant behavior / delinquency**

# A brother or a sister with CP

How much it makes a difference in childhood and adulthood?

## The positive feelings / effects

- Friendship
- Defense
- Wishing
- Helpfulness
- Responsibility
- Maturity
- Acceptance
- Pride
- Resilience

## The sad feelings

- Anger
- Guilt
- Fear
- Shame
- Jealousy
- Embarrassment
- Loneliness
- Resentment



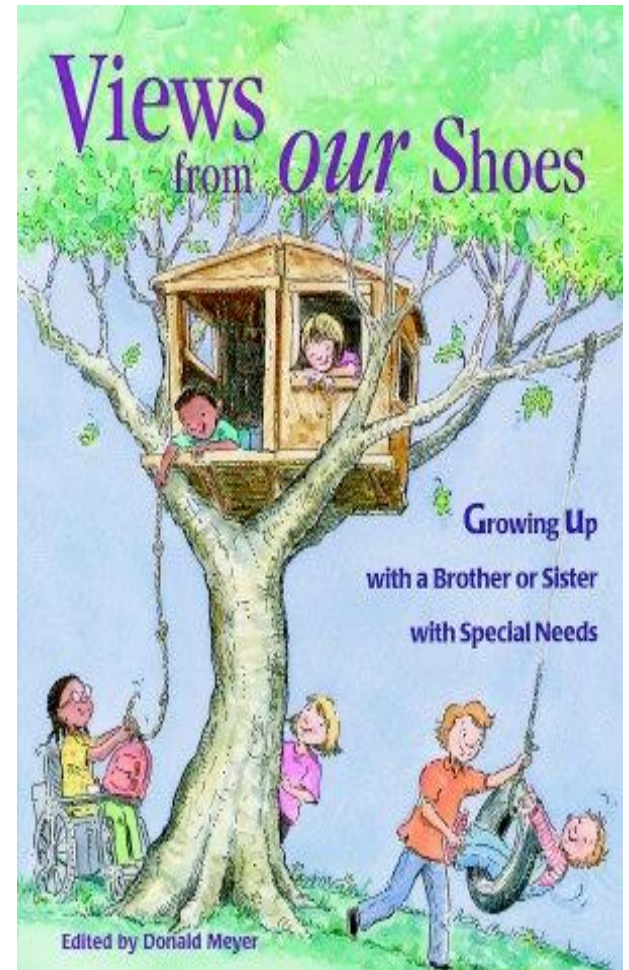
*I'm the Big Sister Now* by Michelle Emmert. Niles, Illinois: Albert Whitman & Company, 1989.

# A sibling with CP: acceptance, awareness and growing up with a brother or sister with special needs

“Life is sometimes frustrating for the whole family. Sometimes I wonder what my brother is thinking. When he yells, is it a cry of pain or anger or even joy? I get jealous sometimes---I think everybody with a disabled sibling does. So much money is spent on his equipment but when I want something, I have to use my own baby-sitting money. I understand why he can't buy his own things but it still makes me mad.”

## IT MATTERS IN EVOLUTION OF SIBLING RELATIONSHIPS

- Degree of physical disability
- Difficulties in communication
- Mental retardation
- Behavior problems



*Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs*  
edited by Donald J. Meyer. Bethesda, MD:  
Woodbine House, 1997

# A brother or a sister with CP

## How much it makes a difference in childhood and adulthood?

**Guilt** is a very common feeling referred by adolescents and adults siblings.

They feel guilty about:

- Not having the disability or illness when their brother or sister has (survivor's guilt)
- They can do things in life that their brother or sister will never be able to do
- They have had uncaring thoughts about their brother or sister
- They haven't visited, or spent time with their brother or sister as much as they feel they should
- They wish they didn't have a disabled brother or sister
- They have felt jealous of the amount of time a parent has spent with the brother or sister
- They have resented the impact of their brother or sister disability on their lives
- They have not supported their parents with care as much as they think they should

# A brother or a sister with CP evolution with age...

...as the child with cerebral palsy grows older, their siblings are likely to experience more difficulties (Gallagher & Powell, 1989)

- Adolescence (the stigma of deficiency)
- Peers, social group
- Boyfriends/ Girlfriends
- Living away ...

The transition to adulthood...

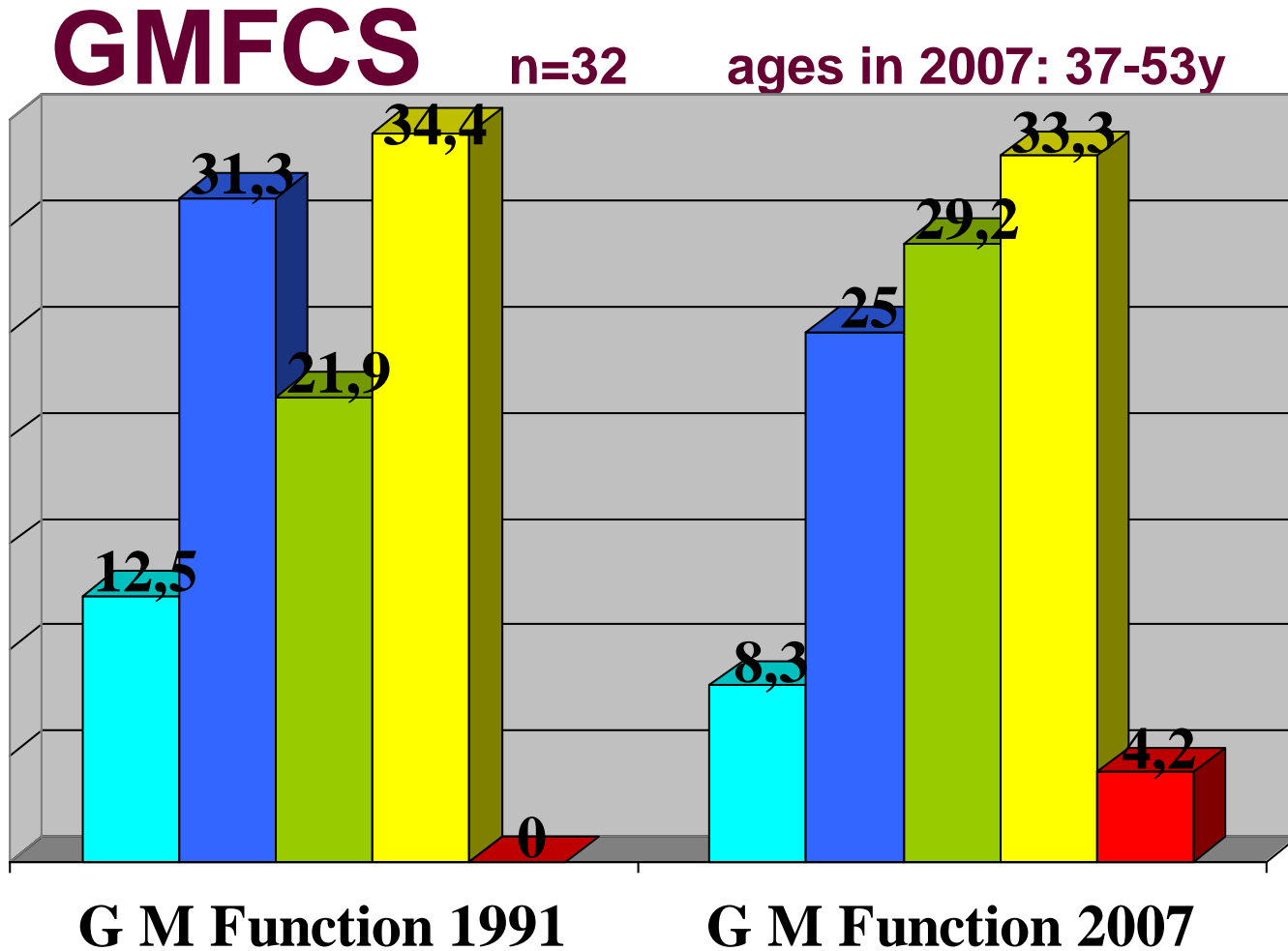
The changing of responsibility  
of care from parents to siblings!?



Survival at 19 years of age in a total population of children and young people with cerebral palsy. Westbom et al. Dev. Med. Child Neurol. 2011

# Cerebral palsy in adult life: the discontinuity of caring

Calado, Folha, Andrada ,2007

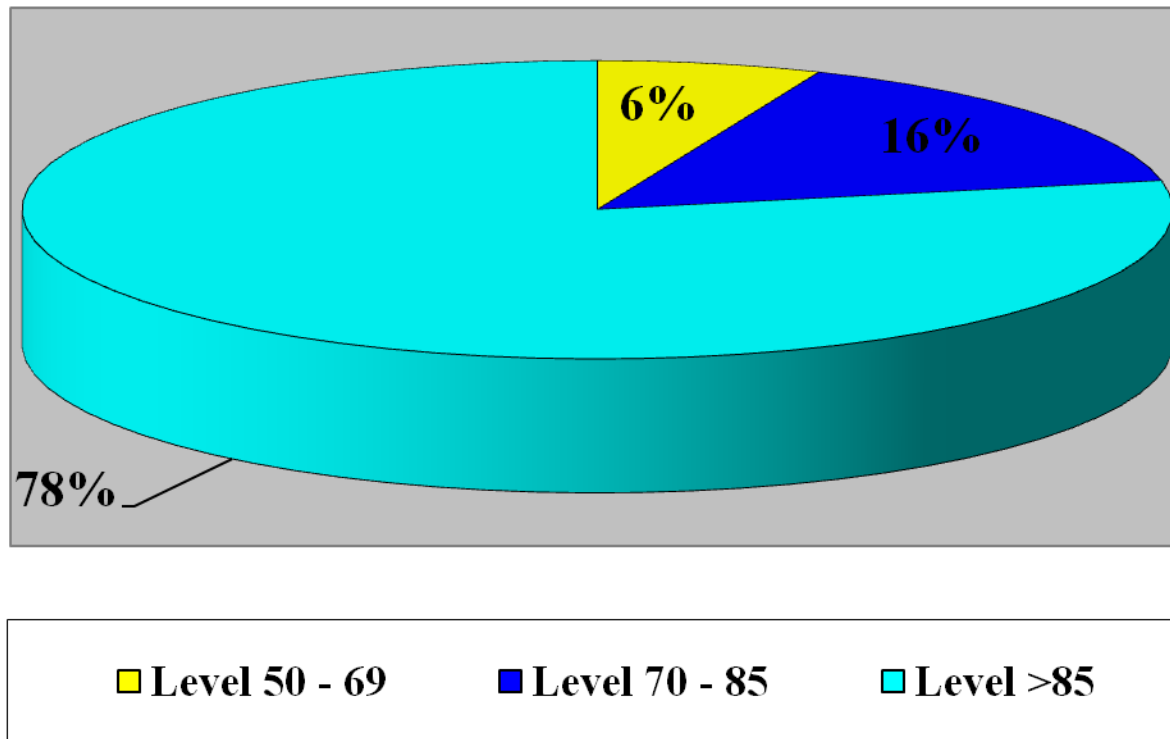


Level I Level II Level III Level IV Level V

# Cerebral palsy in adult life: the descontinuity of caring

Calado, Folha, Andrada ,2007

## Cognition



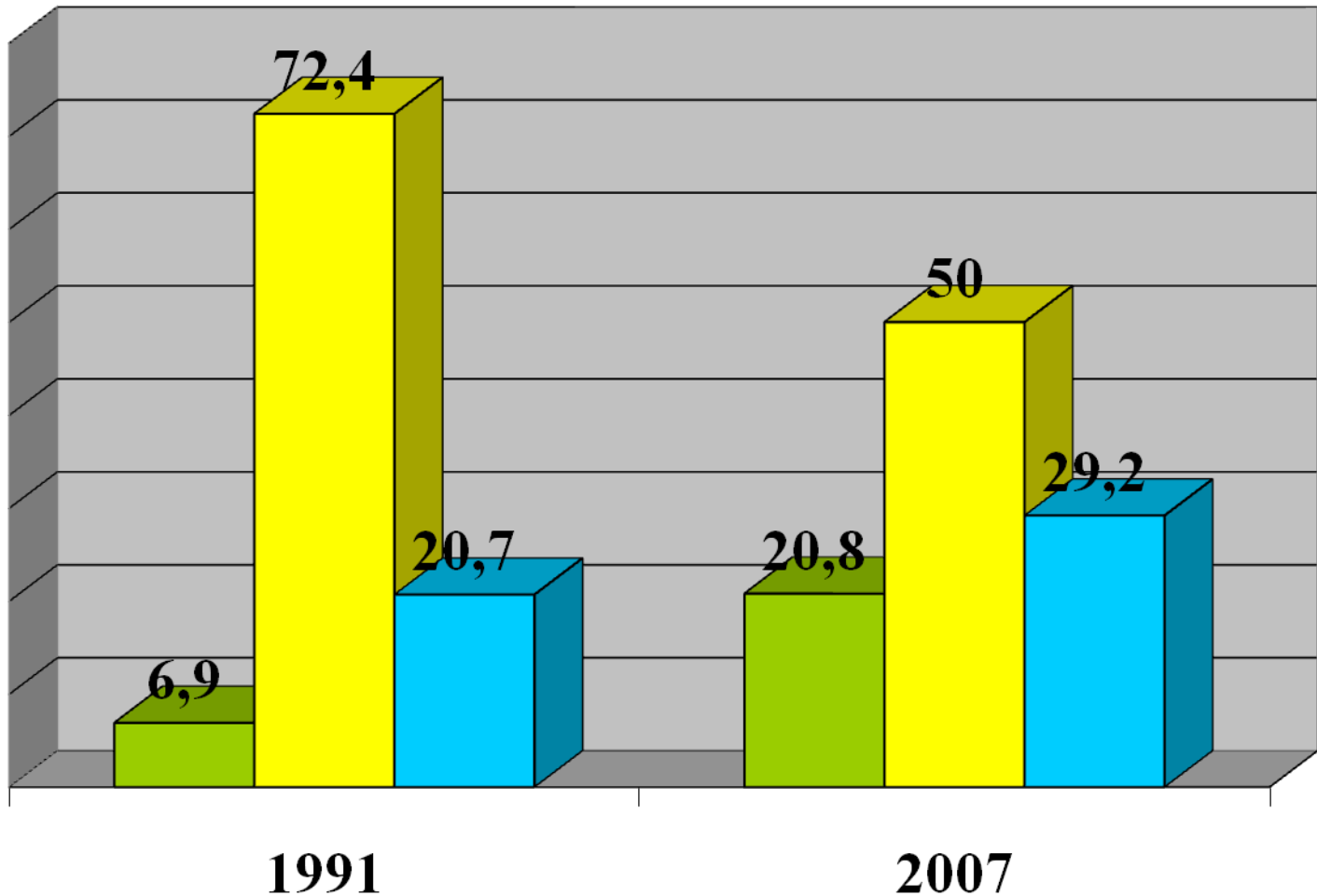
N=32, only 14 with siblings and 9 only 1 sibling.

CP child was the younger in 64%

# Cerebral palsy in adult life: the descontinuity of caring

Calado, Folha, Andrada ,2007

## Housing (n=32)



■ Self home

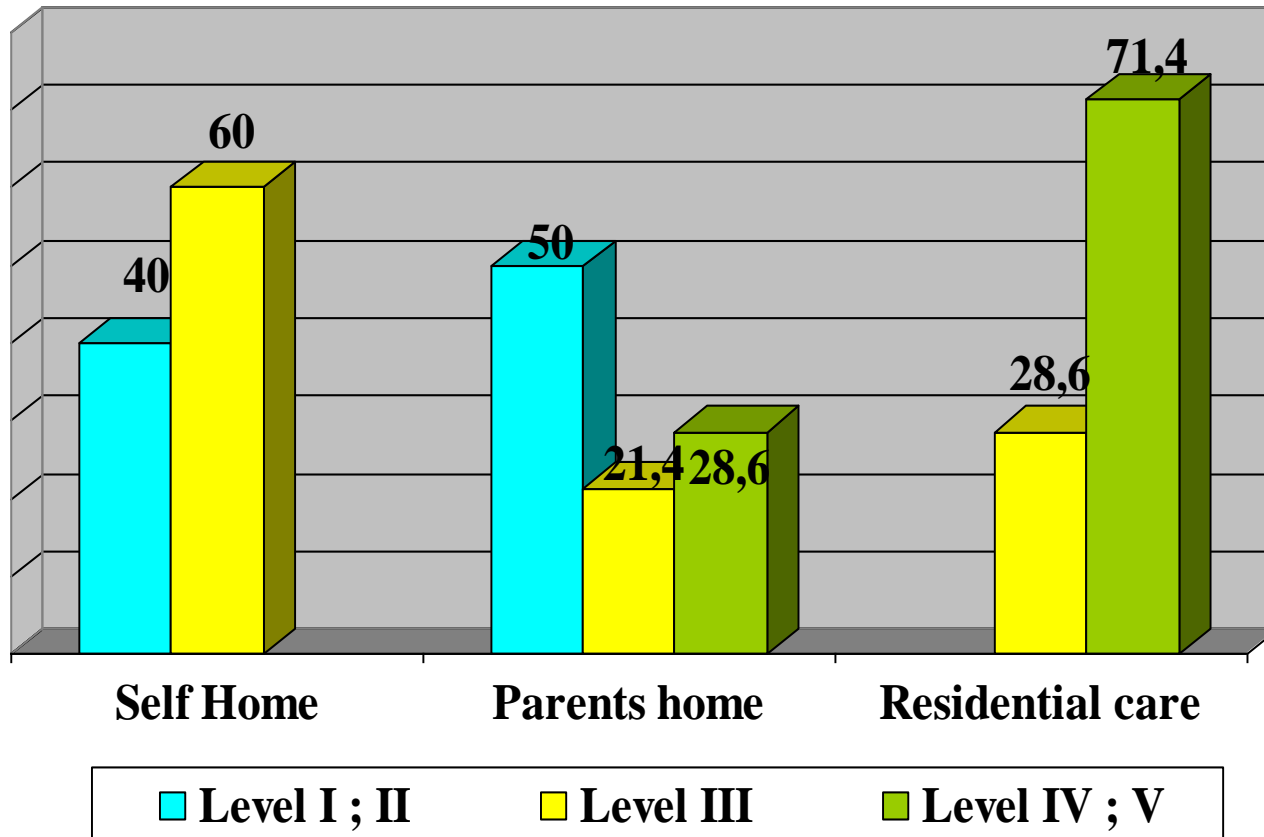
■ Parents home

■ Residencial Care

# Cerebral palsy in adult life: the descontinuity of caring

Calado, Folha, Andrada ,2007

## Housing/ GMFS n=32



**Residential care:** 4 with siblings (28,5%) and 8 without (44%)

# A brother or a sister with CP

## How professionals can help siblings?

To be aware of the problem...

### **Family centered care**

involving not only the child with CP but the whole family

**It addresses parent- identified issues such as family functioning and psycho-social support of family members**

- **Preventive strategies to avoid overburden of parents**
- **Support groups of siblings with common problems**

# A brother or a sister with CP

How much it makes a difference in childhood and adulthood ?



...each one lives with his own  
childhood experience

....each one keeps a secret...

THE MAN'S SECRET IS CHILDHOOD  
ITSELF

(João dos Santos)