A brother or a sister with CP
How much it makes a difference in childhood and adulthood?

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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 CUMPPLICITY 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

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A brother or a sister with CP

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# A brother or a sister with CP

Bibliographic search in Pubmed

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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
- Caregiving time required per 24 hours

Sawyer GM et al. Dev Med Child Neurol 2011
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
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

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

“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
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!?
GMFCS

n=32       ages in 2007: 37-53y


Cerebral palsy in adult life: the descontinuity of caring
Calado, Folha, Andrada, 2007
N=32, only 14 with siblings and 9 only 1 sibling.

CP child was the younger in 64%
Cerebral palsy in adult life: the discontinuity of caring
Calado, Folha, Andrada, 2007

Housing (n=32)

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<td>20.8</td>
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Cerebral palsy in adult life: the descontinuity of caring
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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)