

# Difficulties that siblings of children with special needs experience

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## Having a person with SEN in the family

- A child's disability may have a significant impact on the functioning of the family and on the home environment (McAndrew, 1976; Murphy, 1982) and, as a result, may affect the nondisabled siblings' psychosocial development over the long term (McKeever, 1983).
- The effect of a child's disability may be particularly significant from childhood to adolescence, when children experience major physical and psychological changes (Santrock, 1993).

- Children with special needs receive a disproportionate share of parents' attention (Dillon, 1995) and time that otherwise might have been devoted to other children in the family (Grossman, 1972).
- Alterations in family roles may give rise to feelings of anger and resentment toward increased parental demands for assistance and/or achievement (Dellve et al., 2000) and guilt for their feelings (Crocker, 1981).
- Children with disabled siblings, particularly older sisters, are extensively involved in sibling care giving and in household tasks (Cleveland & Miller, 1977; Stoneman & Brody, 1984).
- Siblings often need to "fight" for their independence, to find a balance between their own needs and the needs of their brother or sister (Burton & Parks, 1994).

- The extra time demands for family responsibilities may deprive siblings of disabled people of experiences outside the home, for instance, those with peers, that normally facilitate the development of cognitive, social and affective competencies (McHale & Gamble, 1989).
- Siblings feel lonelier, have fewer friends and experience more peer problems comparing to other children of their age without disabled siblings (Benderix & Sivberg, 2007).

- Siblings may also be the target of negative behaviours from the part of their brother or sister, ranging from indifference to physical violence and may also witness self-abuse, such as head banging, hair pulling and severe biting (Konidaris, 1997).
- Siblings need more information about their brother's or sister's condition, for their own understanding and to explain to others (Gillberg, 1999).
- Siblings of disabled children are more concerned about the future of their brother or sister (Bagenholm & Gillberg, 1991).

Some studies confirm that, in comparison with children who have nondisabled siblings, children who have siblings with disabilities show:

- **Lower self-concept** (Ferrari, 1987; Harvey & Greenway, 1984; Kaplan, 1969).
- **More behaviour problems** (Breslau, Weitzman, & Messenger, 1981; Lavigne & Ryan, 1979) mainly as a result of the **pressure** to make up for the deficiency of the siblings with disabilities (Cleveland & Miller, 1977), **reduced parental attention** and **family resources** (Siemon, 1984) and **high parental expectations** (Gath & Gumley, 1987).
- **Greater social withdrawal** (Lavigne & Ryan, 1979; Lobato et al., 1987) and **less social competence** (Dyson, 1989).
- Negative effects may also include **anxiety, withdrawal, depression, somatization, acting-out behaviours** and **school problems** (del Rosario & Keefe, 2003; Hannah & Midlarsky, 1999).

The assumed negative psychosocial development of children who have a sibling with developmental disabilities has not been consistently supported by cross-sectional research.

- Other studies report no significant differences between the two groups of siblings in **self-concept** (Dyson, 1989, 1996; Dyson & Fewell, 1989; Ferrari, 1984; Gayton, Friedman, Tavormina, & Tucker, 1977), **behaviour problems** (Dyson, 1989; Ferrari, 1984; Gath, 1972), and **social competence** (Ferrari, 1984)
- In addition, having a brother or sister with disability has been found to be related to positive characteristics, that include the **sense of responsibility, greater tolerance and understanding of people, compassion, maturity, patience, dedication, loyalty, love and social justice** (Dykens, 2005; McMillan, 2005; Swenson, 2005)

## Factors affecting siblings' psychosocial functioning

- the gender and age of the typically developing sibling,
- the birth order,
- the type and severity of the disability,
- the socioeconomic status and family size,
- the parental adjustment and coping strategies and
- the family climate and the ethnicity.

(Hannah & Midlarsky, 1999; Hodapp et al., 2005)

## Aims

- to identify the main difficulties siblings of children with special needs experience in their everyday lives in Greece
- to evaluate the self-esteem of siblings of children with special needs

## Participants

Five families with one child with SEN and non-disabled siblings participated in the study. All participants were girls attending primary mainstream schools in the broader area of Athens in Greece.

## Research instruments

1. **Self perception profile for children or adolescents** (Harter, 1985), a 30-item self-report rating scale, standardised in greek, designed to assess domains of self-perception, such as
  - ✓ **scholastic competence** (i.e. perceptions regarding academic and intellectual ability),
  - ✓ **athletic competence** (i.e. perceptions regarding athletic performance),
  - ✓ **social acceptance** (i.e. perceptions regarding friendships and social status),
  - ✓ **physical appearance** (i.e. perceptions regarding appearance and physical characteristics),
  - ✓ **behavioural conduct** (i.e. perceptions regarding behaviour at home and at school) and
  - ✓ **self-worth**.

*Subscale scores range from 1 to 4 with higher scores indicating higher self-esteem*

2. **Sibling problems questionnaire** (McHale et al., 1986), a 36-item self-report questionnaire designed to assess children's perceptions with regard to their sibling's disability. It consists of 9 subscales:

- ✓ Future concerns
- ✓ Feelings of rejection towards sibling
- ✓ Perceived favouritism toward the child with the disability
- ✓ Positive reactions by peers
- ✓ Positive reactions by parents
- ✓ Ability to cope with sibling's disability
- ✓ Feelings of being burdened
- ✓ Feelings of self-doubt
- ✓ Extra responsibilities

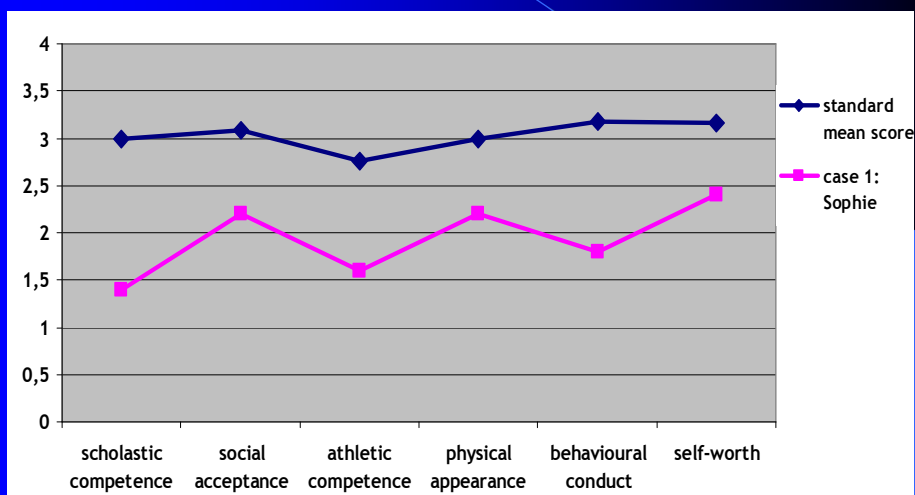
## Procedure

- Contact was made with parents of children with disabilities attending special needs units in Athens, who had nondisabled siblings, explaining the purpose of the study and requesting participation.
- Parents were asked to sign consent forms and to complete a demographic information form.
- Questionnaires were administered to siblings of children with disabilities.

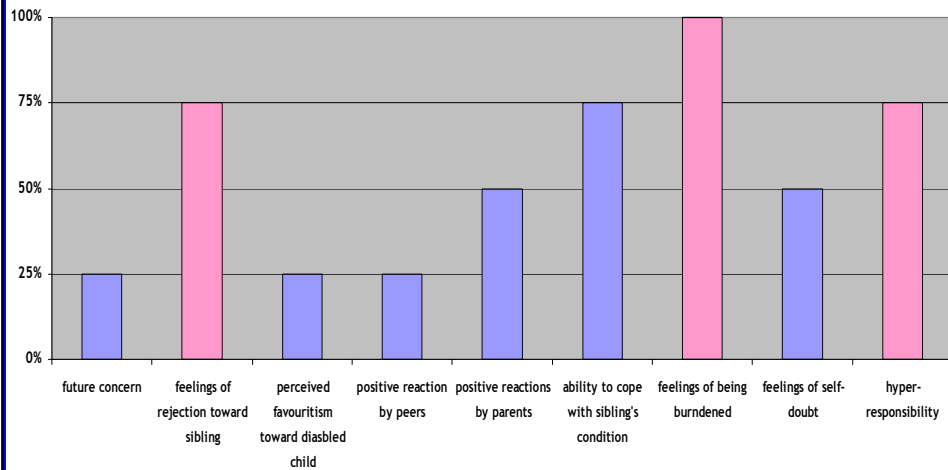
## Case 1

- Sophie
- Age: 12 years old
- Older sibling of a boy with moderate learning difficulties+hyperactivity.
- Children from the second marriage of the mother.
- Family size: three children, two parents.
- Low to medium socio-economic status

## Case 1: Self perception profile for children or adolescents (Harter, 1985)



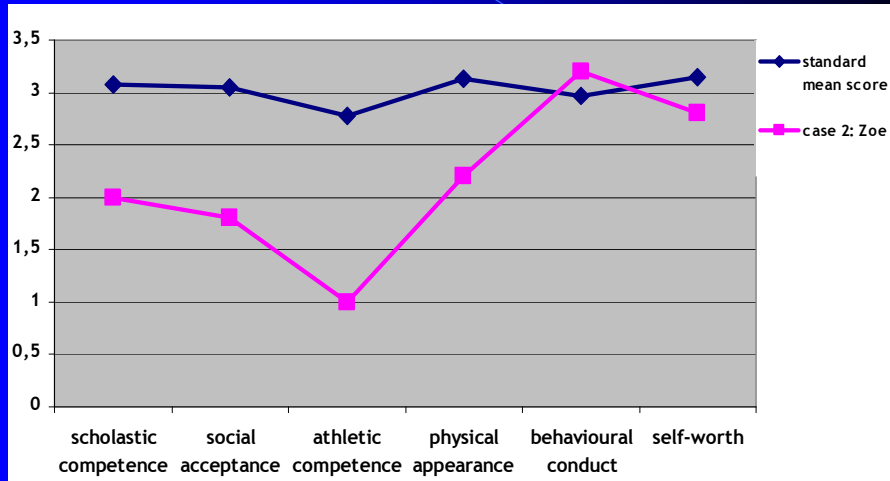
## Case 1: sibling problems questionnaire (McHale et al., 1986)



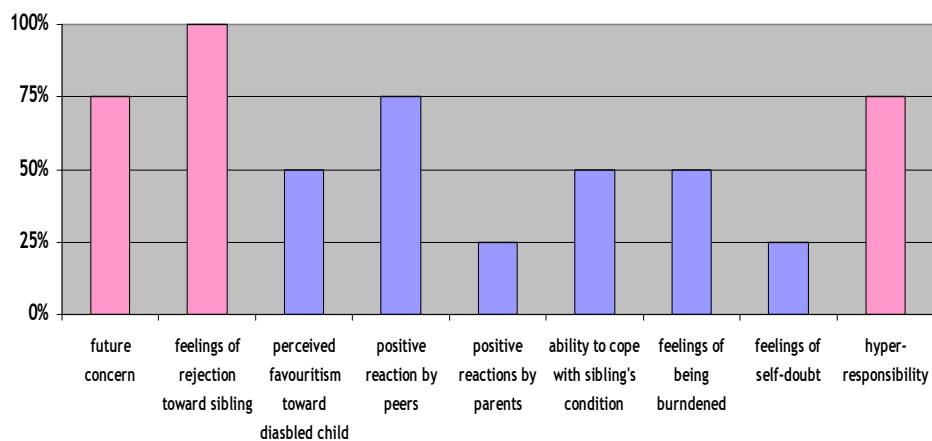
## Case 2

- Zoe
- Age: 10 years old.
- Twin of a boy with learning difficulties+hyperactivity.
- Family size: Two children, two parents.
- Medium socio-economic status.

## Case 2: Self perception profile for children or adolescents (Harter, 1985)



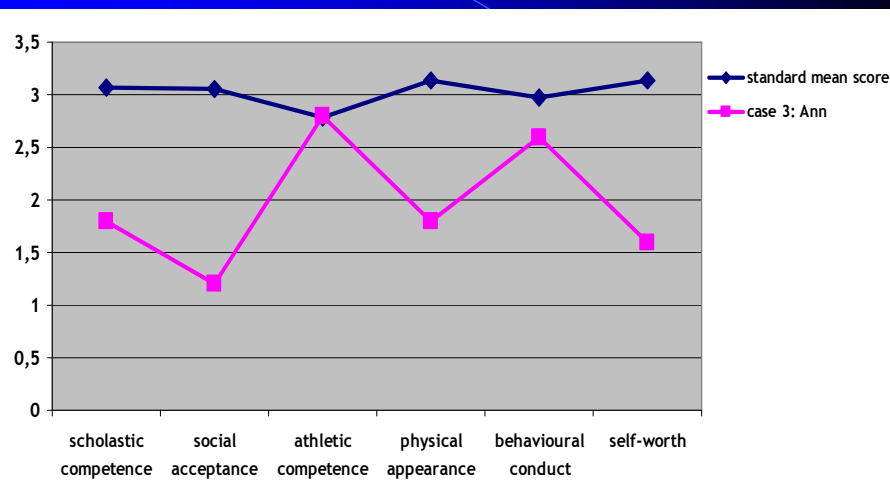
## Case 2: Sibling problems questionnaire (McHale et al., 1986)



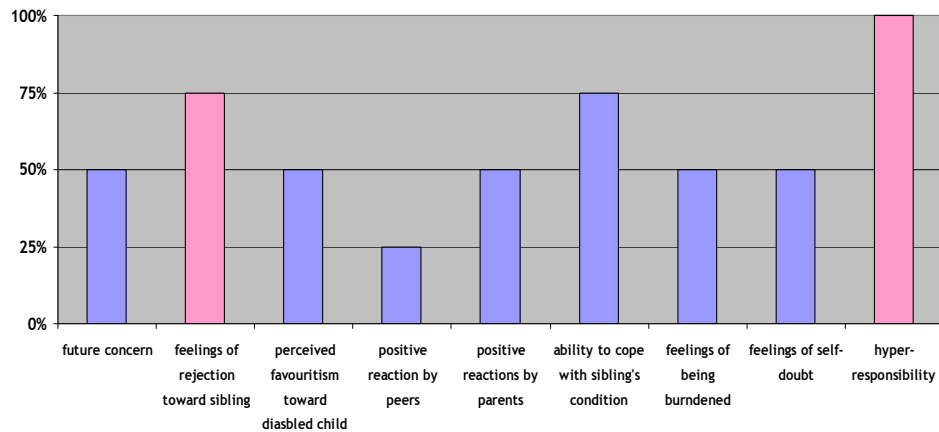
## Case 3

- Ann
- Age: 10 years old
- Younger sibling of a boy with epilepsy and learning difficulties.
- Family size: two children, one parent (mother). Father killed in an accident.
- Low to medium socio-economic status.

## Case 3: self perception profile for children or adolescents (Harter, 1985)



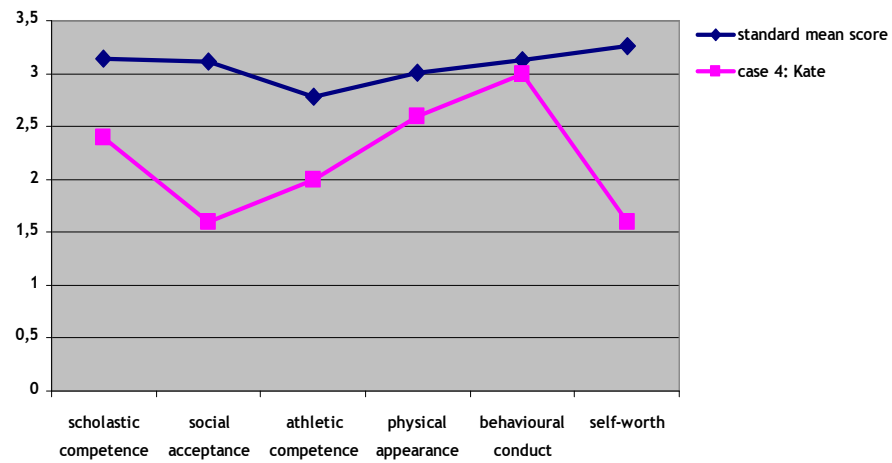
### Case 3: sibling problems questionnaire (McHale et al., 1986)



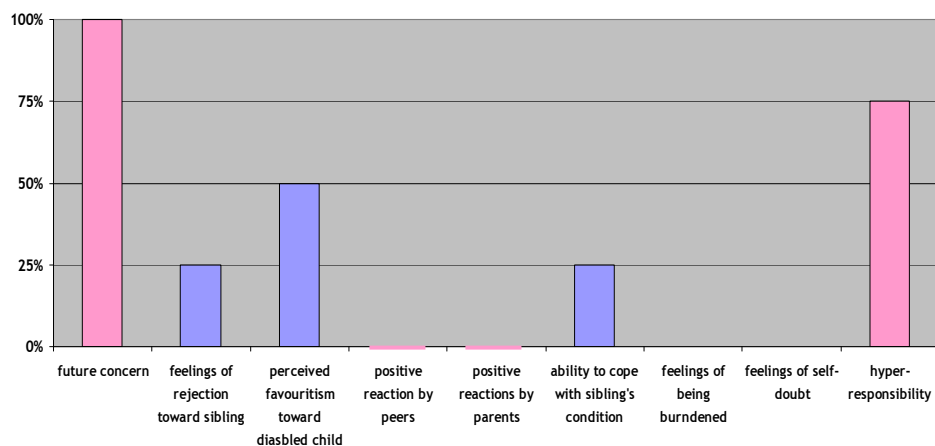
### Case 4

- Kate
- Age: 11 years old
- Older sibling of a girl with Williams syndrome.
- Family size: two children, two parents.
- Low to medium socio-economic status

## Case 4: Self perception profile for children or adolescents (Harter, 1985)



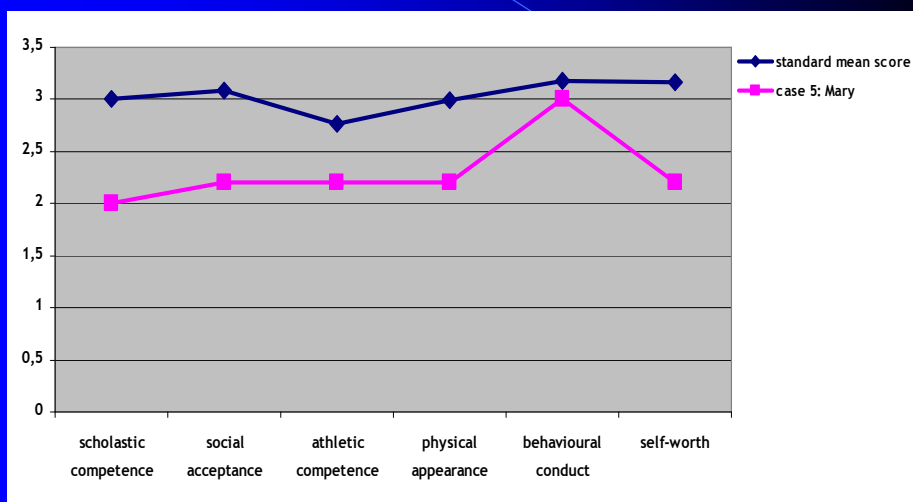
## Case 4: sibling problems questionnaire (McHale et al., 1986)



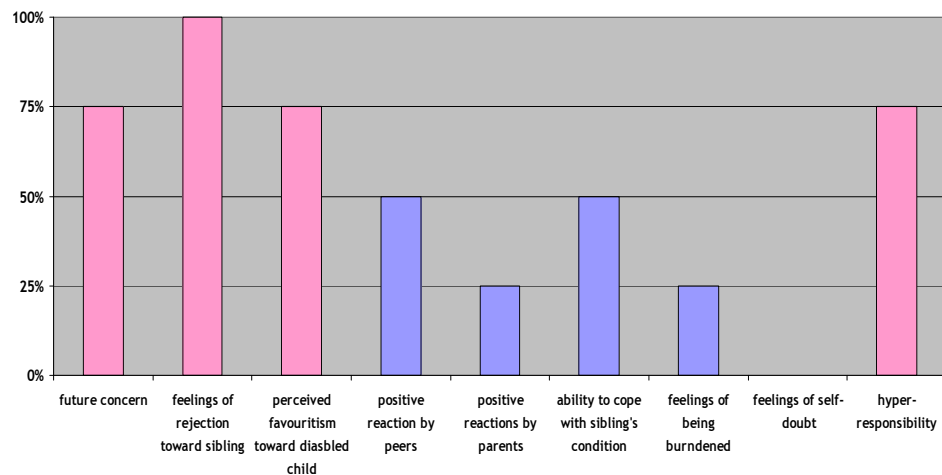
## Case 5

- Mary
- Age: 12 years old
- Older sibling of a boy with autistic spectrum disorder.
- Family size: three children, divorced family.
- Low to medium socio-economic status.

## Case 5: Self perception profile for children or adolescents (Harter, 1985)



## Case 5: sibling problems questionnaire (McHale et al., 1986)



## Conclusions

- ✓ The sample is small and therefore the findings are indicative.
- ✓ All siblings of children with SEN have low self-worth.
- ✓ All siblings of children with SEN feel less socially accepted.
- ✓ 2 out of 5 siblings report behavioural problems at school and at home.

## Conclusions

- ✓ All siblings feel that they have extra responsibilities because of their brother or sister with SEN.
- ✓ Most frequently reported problems by the siblings are concerns about the future of their disabled brother or sister (3/5) and feelings of rejection towards him or her (4/5).

