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Siblings and disability: A study on social attitudes toward disabled brothers and sisters

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Abstract

The purpose of this study was the exploration of attitudes toward disabled brothers/sisters in 140 typically developed siblings (13-18 years) with brothers or sisters with Down syndrome (DS), autism (AUT), or intellectual disability (ID). Results showed that siblings of brothers/sisters with DS thought that they could “be entered into the world of work” and “achieve personal autonomy”; siblings of brothers/sisters with ID and AUT assumed that they could be “unfortunate persons”, “marginalized by other people”, and “putting a strain on the siblings”. Siblings of brothers/sisters with AUT considered that 1) they could be “incomprehensible individuals”, “persons with difficulty in social integration”, “a limit for their own family”, and “not leading a normal life”; 2) they felt “displeasure”, “anger”, and “personal fulfilment for the improvements achieved by disable people”; 3) inclusion at school is “a useful project but not always feasible” and “an experience feasible only in a special context”. In addition, siblings of brothers/sisters with AUT expressed more negative representation of self-concept than the others. These results suggest the necessity to realize supporting actions on the whole family for managing of disabled siblings.

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1. Introduction

Sibling relationship is one of the most important precursors of peers and adults relationships and it represents one of the most powerful bonds and human interactions because siblings act as surrogate parents, informal teachers, and friends (Lobato, 1990; Davidoff, 2006). In presence of brothers/sisters with disability, this special bond can be characterized by positive or negative aspects: in fact, researches addressed the analysis of quality of life in families with disabled children in relation to both factors that positively influence the growth of young people with disability and their siblings such as coping strategies (Yeh-Chen, 2000), social adjustment (Cuskelly & Gunn, 2006; Dew, Baladin, & Llewellyn, 2008), altruism, resilience, and acceptance of diversity (Valtolina, 2004) and factors that have a negative impact on the well-being of siblings as stress (Núñez & Rodriguez, 2005; Stoneman, 2005), social isolation by peers and loneliness (Bagenholm & Gillberg, 1991). Findings showed the complexity of the situation of siblings with disabled brothers and sisters in function of the type of disability (see Ponce, 2007). For example, Kaminsky and Dewey (2001) found that siblings reported less intimacy, nurturance, and less prosocial behaviour toward their brothers or sisters with autism than the siblings of children with Down syndrome and of typically developed children. In addition, as reported by Rodrigue, Geffken and Morgan (1993), siblings of children with

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Down syndrome showed better adjustment than siblings of children with autism even though both groups reported more psychological maladjustment than the siblings of developmentally typical children.

Another important aspect of sibling relationships regards the area of self-concept and, again, researches reported mixed findings relating to the effects of the presence of disabled brothers or sisters on their siblings' quality of life. For example, Dyson (1999) found that the psychosocial functioning of siblings remains stable over time, independently of the presence of a brother or sister with a disability: siblings who had a disabled brother or sister showed greater stability in their self-concept than siblings with a non-disabled brother or sister. Siblings who reported higher levels of satisfaction with their relationships with brothers/sisters demonstrated more positive representation of self-concept (see Gousmett, 2006). Some studies suggested that there are no differences in self-esteem and self-concept, levels of stress, and loneliness between siblings of disabled children and siblings of children without disabilities (see Argirakouli & Zafeiropoulou, 2003; Tsamparli, Tsibidaki, & Roussos, 2011), while other studies, focused on siblings of children with autism, assumed that they are at risk of negative outcomes (such as depression and internalizing psychological disorders) compared to control groups and also to siblings of children with other disabilities (Fisman, Wolf, Ellison, & Freeman, 2000; Hastings, 2003; Verte, Roeyers, & Busse, 2003). The discrepancies between these findings suggest that several factors affected on results such as the individual characteristics of the sibling and the child with a disability and the characteristics of the entire family (Hastings, 2007).

Little evidence was found in relation to the effects of positive or negative representation of self-concept and of social attitudes on sibling relationships with disabled brothers or sisters (see Moyson & Roeyers, 2012), especially in Italian social context. For this rationale, we believe that it's very important to investigate these aspects in siblings of brothers/sisters with different disabilities and, in particular, with autistic spectrum disorders (ASD), Down syndrome (DS), and intellectual disability (ID) to the extent of knowing the psychological dimensions in which it is possible to make active supporting interventions.

2. Methodology

The purpose of this study was focused on the exploration of social attitudes toward disabled brothers or sisters expressed by 140 typically developed siblings, who had a brother or a sister with Down syndrome, autistic spectrum disorders, or intellectual disability. We hypothesized that:

H1 - siblings of brothers/sisters with autistic spectrum disorders (ASD) will show more negative attitudes than siblings of brothers/sisters with Down syndrome (DS) or with intellectual disability (ID);

H2 - siblings of brothers/sisters with autistic spectrum disorders (ASD) will show more negative representation of self-concept and of disabled brothers or sisters than the others.

2.1. Participants

The sample was composed of 140 typically developed first-born siblings, balanced for sex and aged from 13 to 18 years ($M=15,7$, $sd=1,3$), who had a brother or a sister with one out of the three different types of disability: $n=44$ with Down syndrome (DS), $n=46$ with autistic spectrum disorders (ASD), and $n=50$ with intellectual disability (ID). Participants were recruited partly from three Centres of Rehabilitation in which their brothers or sisters were subjected to specific treatments and partly from several Senior High Public Schools in Catania.

2.2. Measures

Materials were constituted by a self-report questionnaire divided in three sections and administered in individual setting by an expert researcher. Siblings responded in absolute anonymous way after parental consent for research participation. The first section of questionnaire included the background information regarding the characteristics of participants (sex and age of siblings, and type of brothers/sisters disability), the second section was composed of Siblings Attitudes toward Disability Questionnaire (SADQ: see De Caroli & Sagone, 2008), and the third one by Semantic Differential Technique (De Caroli, Sagone, & Falanga, 2007).

The SADQ, originally used to analyze the attitudes of special needs teachers toward disabled students, in this version consisted of five Likert scale questions used to investigate siblings' social attitudes toward brothers or sisters with disability; the participants were asked to express their degree of agreement with proposed statements in 7-points (ranging from 1=*totally disagree* to 7=*totally agree*). The first scale included 7 statements regarding the future of brothers/sisters with disability: e.g. "to achieve personal autonomy", "to be entered into the world of work" (Cronbach's $\alpha=.65$). The second one consisted of 8 statements related to the characteristics attributed to brothers or sisters with disability: e.g. "an unfortunate person", "an individual in need of care and attention" (Cronbach's $\alpha=.61$). The third scale was formed by 8 statements referred to popular prejudices about disabled people: e.g. "they are a limit for their own family", "they are a burden for society" (Cronbach's $\alpha=.63$). The fourth scale was composed of 7 statements related to the feelings that siblings had towards their brothers/sisters with disability: e.g. "suffering", "affection and tenderness" (Cronbach's $\alpha=.70$). The fifth scale consisted of 7 statements related to ideas about the inclusion at school for brothers/sisters with disability: e.g. "an experience feasible only in a special context", "a useful project but not always feasible" (Cronbach's $\alpha=.64$).

The Semantic Differential Technique was aimed to investigate the affective or connotative meaning of the following concepts: "Me as I am" and "My brother/sister with disability". These scales were composed of a set of 36 pairs of bipolar adjectives for each concept (e.g., weak-strong, secure-insecure) assessed on a Likert 7-point scale. Cronbach's alpha for the two concepts was equal to .83 and .93, respectively.

2.3. Data analyses

The type of disability was used as independent variable, while mean scores obtained in Likert-scales of SADQ and of Semantic Differentials were computed as dependent variables. The statistical analyses were conducted applying the analysis of variance with SPSS 15th version.

3. Results

3.1. Attitudes of siblings toward disabled brothers/sisters: Analysis for type of disability

3.1.1. Future of disabled brothers/sisters.

Significant differences were found for type of brothers/sisters disability (Table 1): in fact, siblings of brothers/sisters with DS expressed higher degrees of agreement than the others (especially those of brothers/sisters with ASD with the ideas that they could "be entered into the world of work" and "achieve personal autonomy". The same trend, but with low degrees of agreement, was found in reference to "get married" and "participate in politics".

Table 1. The future of disabled brothers/sisters - Differences for type of disability

Scale	DS (n=44)		ASD (n=46)		ID (n=50)		One-way Anova	
	M	SD	M	SD	M	SD	F-value	Sig.
to be accepted as he/she is	5.84	1.6	5.91	1.8	5.80	1.6	.056	ns
to be entered into the world of work	3.86	1.4	1.07	0.3	2.76	1.9	46.39	.000
to achieve personal autonomy	5.61	1.1	4.07	1.7	4.60	1.6	12.06	.000
to overcome the disability	1.05	0.3	1.02	0.2	1.10	0.4	.935	ns
to sensitize the awareness of the others about the disability	6.32	1.2	5.91	1.6	5.86	1.3	1.49	ns
to get married	2.02	1.6	1.00	0.0	1.34	0.9	11.25	.000
to participate in politics	1.86	1.5	1.00	0.0	1.38	1.0	7.95	.001

Note: 7-point Likert scale intervals

3.1.2. Characteristics attributed to disabled brothers/sisters.

Siblings of brothers/sisters with ID and ASD expressed higher degrees of agreement with the ideas that they could be “unfortunate persons”, “marginalized by other people”, and “persons who put a strain on the siblings” than those indicated by siblings of brothers/sisters with DS. In addition, siblings of brothers/sisters with ASD expressed higher degrees of agreement than the others with the ideas that they could be “persons with difficulty in social integration” and “a problem for the classroom” (Table 2).

Table 2. Characteristics attributed to disabled brothers/sisters - Differences for type of disability

Scale	DS (n=44)		ASD (n=46)		ID (n=50)		One-way Anova	
	M	SD	M	SD	M	SD	F-value	Sig.
a problem for the classroom	1.43	1.28	3.11	1.55	1.56	1.07	23.35	.000
a resource for others	6.61	1.17	6.74	0.58	6.52	1.14	.574	ns
persons with difficulty in social integration	2.07	1.78	5.15	1.38	3.52	1.84	37.73	.000
special and sensitive persons	6.93	0.33	6.85	0.47	6.78	0.73	.895	ns
individuals in need of care and attention	6.75	0.75	6.87	0.40	6.92	0.27	1.369	ns
individuals marginalized by other people	4.45	1.63	5.17	1.83	5.76	1.70	6.722	.002
unfortunate persons	4.16	2.17	4.57	1.89	5.54	1.93	6.021	.003
persons putting a strain on the siblings	2.20	1.56	4.67	1.56	3.86	1.82	25.80	.000

Note: 7-point Likert scale intervals

3.1.3. Popular prejudices about disabled people.

Siblings of brothers/sisters with ASD expressed higher degrees of agreement than the others with the ideas that disabled persons are “a limit for their own family”, “irretrievable students”, “aggressive and incomprehensible individuals”, and “not leading a normal life because of their difficulties” (Table 3).

Table 3. Popular prejudices about disabled people - Differences for type of disability

Scale	DS (n=44)		ASD (n=46)		ID (n=50)		One-way Anova	
	M	SD	M	SD	M	SD	F-value	Sig.
a limit for their own family	2.70	1.61	4.41	1.63	3.66	1.56	12.91	.000
irretrievable students	1.20	0.79	3.13	1.90	1.14	0.70	37.94	.000
not leading a normal life because of their difficulties	2.55	2.06	4.39	1.37	4.18	1.63	15.86	.000
eliciting tenderness	6.23	1.64	6.46	1.09	6.14	1.26	.70	ns
life expectancy are short-term	1.52	1.42	1.65	1.55	1.42	1.41	.30	ns
aggressive individuals	2.52	1.15	3.59	1.51	2.68	1.46	7.83	.001
a burden for society	1.16	0.74	1.37	1.16	1.04	0.28	2.05	ns
incomprehensible people	1.36	1.33	3.13	1.61	1.12	0.85	33.68	.000

Note: 7-point Likert scale intervals

3.1.4. Feelings that siblings have toward their disabled brothers/sisters.

Siblings of brothers/sisters with ASD expressed significantly higher degrees of agreement than the others with feelings of “displeasure”, “anger”, and “personal fulfilment for the improvements achieved by disabled people”, while siblings of brothers/sisters with ID assumed higher degrees of agreement than the others with feelings of “protection by difficulties” and “inadequacy and feelings of helplessness” (Table 4).

Table 4. Feelings that siblings have towards their disabled brothers/sisters - Differences for type of disability

Scale	DS (n=44)		ASD (n=46)		ID (n=50)		One-way Anova	
	M	SD	M	SD	M	SD	F-value	Sig.
affection and tenderness	6.61	1.08	6.93	0.44	6.64	1.31	1.41	ns
displeasure	4.73	1.84	6.26	1.37	6.06	1.45	12.90	.000
inadequacy and feelings of helplessness	3.05	2.28	3.91	2.35	4.28	2.46	3.29	.04
suffering	5.11	1.69	6.09	1.56	6.08	1.76	5.06	.008
protection by difficulties	6.30	1.55	6.70	0.89	6.86	0.53	3.48	.034
Anger	5.43	1.82	6.43	1.27	6.12	1.79	4.33	.015
fulfilment for the improvements achieved by disabled people	6.34	1.58	6.91	0.41	6.76	0.98	3.32	.04

Note: 7-point Likert scale intervals

3.1.5. Inclusion at school for disabled brothers/sisters.

Siblings of brothers/sisters with ASD expressed high degrees of agreement with the ideas that inclusion at school is “a useful project but not always feasible”, “an experience feasible only in a special context”, and “difficult to realize” (Table 5).

Table 5. Inclusion at school for disabled brothers/sisters - Differences for type of disability

Scale	DS (n=44)		ASD (n=46)		ID (n=50)		One-way Anova	
	M	SD	M	SD	M	SD	F-value	Sig.
utopia	1.80	1.73	2.89	2.32	1.54	1.57	6.74	.002
experience difficult to realize	2.84	2.17	4.09	2.37	2.76	2.01	5.39	.006
an experience feasible only in a special context	2.41	1.99	5.17	1.79	2.76	1.90	28.96	.000
a useful project but not always feasible	5.36	1.78	6.74	0.90	5.90	1.40	11.04	.000
useful to promote a positive contact with other students	6.70	0.90	6.93	0.44	6.98	0.31	2.30	ns
a limit to the development of society	1.45	1.42	1.22	1.05	1.12	0.85	1.09	ns
feasible with the support of institutions	6.11	1.63	6.41	1.15	6.30	1.66	.46	ns

Note: 7-point Likert scale intervals

3.2. Representation of self-concept and of disabled brothers/sisters.

Significant differences regarding type of disability were found only in relation to self-concept ($F_{(2,137)}=43.91$, $p<.001$): in fact, siblings of brothers/sisters with ASD reported a more negative representation of self-concept ($M=3.40$, $sd=.51$) than those of brothers/sisters with DS ($M=4.68$, $sd=.48$) and with ID ($M=4.20$, $sd=.87$). The representation of self-concept profile in siblings of brothers/sisters with ASD is defined overall in terms of “apathy”, “coolness”, and “passivity” (all for $p<.001$). No significant differences for representation of disabled brothers/sisters were found.

4. Conclusion

Findings of this investigation confirmed H1 and H2. In relation to the H1, in most of the analyzed data, siblings of brothers/sisters with autistic spectrum disorders (ASD) showed more negative social attitudes than those expressed by siblings of brothers/sisters with Down syndrome (DS) or intellectual disability (ID). Compared to other siblings, they expressed a more negative representation of their autistic brothers or sisters’ life as well as their own. The representation of their autistic brothers or sisters’ future seems to be characterized by a perceived reduction of the chance to work and reach the personal autonomy and this datum could be explained in terms of a symptomatic perception of their siblings as a “burden” for both their family and social community in which they live. It is possible to imagine that the siblings of autistic young people have a holistically negative view of their brothers or sisters, perceived as responsible for their own social and scholastic segregation, as well as a burden for their typically developed siblings. As for the feelings toward their autistic brothers or sisters, siblings expressed negative emotions (that is, displeasure and anger) more than those of brothers or sisters with different types of disability. Finally, regarding inclusion at school, it is possible to highlight a pessimistic vision expressed by siblings of brothers or sisters with autistic spectrum disorders more than the others, in the sense that they believed it is a utopia and a practicable possibility only in special contexts. According to H2, results confirmed that siblings of brothers/sisters with ASD expressed a more negative representation of self-concept than the others.

The explanation of these results could be addressed to the main central impairments which characterized brothers/sisters with autistic spectrum disorders (ASD); that is, the lack of social reciprocity, reduced or totally absent skills of communication, and stereotyped behaviour. These are fundamental aspects in sibling relationships and, if absent or compromised, could be the reasons supporting the expression of negative social attitudes toward disabled brothers or sisters.

A limitation of the current study could be referred to the absence of a group of siblings with typically developed brothers or sisters to compare with other analyzed groups. In fact, by comparing siblings of children with disabilities and siblings of typically developed children, some studies demonstrated that siblings of disabled brothers or sisters are at “high risk” of maladjustment and show high levels of stress more than those with typically developed brothers or sisters (see Stoneman & Berman, 1993; Giallo & Gavidia-Payne, 2006) while other studies found out that the presence of disabled brothers or sisters has a positive effect on the psychological well-being of siblings (Eisenberg, Baker, & Blacher, 1998; Cuskelly & Gunn, 2000). This datum will represent further purpose of future research in Italian context to explore the similarities and the differences among groups of siblings with and without disabled brothers/sisters.

The results of this investigation suggest the necessity to realize supporting actions for managing of disabled individuals not only on parents but also on the whole family context (especially on siblings), as reported by some of studies focused on the effectiveness of the “sibling support group” (see Evans, Jones, & Mansell, 2001; Smith & Perry, 2004).

References

- Argirakouli, E., & Zafeiropoulou, M. (2003). The influence of disabled children in their siblings’ self-esteem [in Greek]. *Pedagogical Review*, 36, 135-153.
- Bagenholm, A., & Gillberg, C. (1991). Psychosocial effects on children with autism and mental retardation: A population based study. *Journal of Mental Deficiency Research*, 35, 291-307.

- Cuskelly, M., & Gunn, P. (2000). *Sibling relationships in families with a child with Down syndrome*. Seattle, WA: International Association for the Study of Intellectual Disability.
- Cuskelly, M., & Gunn, P. (2006). Adjustment of siblings of a child with Down syndrome. *Journal of Intellectual Disability Research*, 50, 917-925.
- Davidoff, L. (2006). The sibling relationship and sibling incest in historical context. In P. Coles (Ed.), *Sibling relationships*. London: Karnac Books, Ltd.
- De Caroli, M.E., & Sagone, E. (2008). Direction of biases, burnout levels, interpersonal adaptation, and professional self-representation: a survey about special education support teachers. *Life Span and Disability*, 11, 41-59.
- De Caroli, M.E., Sagone, E., & Falanga, R. (2007). Professional Self and direction of social attitudes towards disability in special needs teachers in kindergarten, primary, and secondary school. *The Italian Journal of Disabilities*, 3, 15-26.
- Dew, A., Baladin, S., & Llewellyn, G. (2008). The psychosocial impact in siblings of people with lifelong physical disability: a review of the literature. *Journal of Developmental and Physical Disabilities*, 20, 485-507.
- Dyson, L. (1999). The psychosocial functioning of school-age children who have siblings with developmental disabilities. *Journal of Applied Developmental Psychology*, 20, 253-271.
- Eisenberg, L., Baker, B., & Blacher, J. (1998). Siblings of children with mental retardation living at home or in residential placement. *Journal of Child Psychology and Psychiatry*, 39, 355-363.
- Evans, J., Jones, J., & Mansell, I. (2001). Supporting siblings: Evaluation of support groups for brothers and sisters of children with learning disabilities and challenging behaviour. *Journal of Learning Disabilities*, 5, 69-78.
- Fisman, S., Wolf, L., Ellison, D., Gillis, B., Freeman, T., & Szatmari, P. (1996). Risk and protective factors affecting the adjustment of siblings of children with chronic disabilities. *Journal of the American Academy of Child and Adolescent Psychiatry*, 35, 1532–1541.
- Giallo, R., & Gavidia-Payne, S. (2006). Child, parent and family factors as predictors of adjustment for siblings of children with a disability. *Journal of Intellectual Disability Research*, 50, 937-948.
- Gousmett, S. L. (2006). *Families of children with developmental disabilities: family environment, social support, and sibling well-being* (Master Thesis of Arts in Psychology). Canterbury: University of Canterbury.
- Hastings, R. (2003). Brief report: Behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, 33, 99-104.
- Kaminsky, L., & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 43, 225-232.
- Lobato, D. (1990). *Brothers, sisters and special needs*. Baltimore, MD: Paul H. Brookes.
- Moyson, T., & Roeyers, H. (2012). 'The overall quality of my life as a sibling is all right, but of course, it could always be better'. Quality of life of siblings of children with intellectual disability: the siblings' perspectives. *Journal of Intellectual Disability Research*, 56, 87-101.
- Núñez, B., & Rodríguez, L. (2005). *Los hermanos de personas con discapacidad: una asignatura pendiente*. Buenos Aires: Asociación AMAR.
- Ponce, A. (2007). *Apoyando a los hermanos. Tres propuestas de intervención con hermanos de personas con discapacidad intelectual*. Madrid: FEAPS.
- Rodrigue, J. R., Geffken, G. R., & Morgan, S. B. (1993). Perceived competence and behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, 23, 665-674.
- Smith, T., & Perry, A. (2004). A sibling support group for brothers and sisters of children with autism. *Journal on Developmental Disabilities*, 11, 77-88.
- Stoneman, Z. (2005). Siblings of children with disabilities: research themes. *Mental Retardation*, 43, 339-350.
- Stoneman, Z., & Berman, P. W. (1993). *The effects of mental retardation, disability, and illness on sibling relationships: Research issues and challenges*. Baltimore: Brookes.
- Tsampanli, A., Tsidaki, A., & Roussos, R. (2011). Siblings in Greek families: raising a child with disabilities. *Scandinavian Journal of Disability Research*, 13, 1-19.
- Valtolina, G. G. (2004). *L'altro fratello. Relazione fraterna e disabilità*. Milano: FrancoAngeli.
- Verte, S., Roeyers, H., & Busse, A. (2003). Behavioral problems, social competence and self-concept in siblings of children with autism. *Child: Care, Health and Development*, 29, 193-205.
- Yeh-Chen K. (2000). *Siblings of a child with an intellectual disability: identifying those at risk*. Canada: National Library of Canada.