



Foundations for Emotional Intervention with Siblings of the Mentally Disabled

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Abstract

Introduction. It is very important to attend to the emotional experience of disabled persons' siblings. Instead of ignoring, minimizing or exaggerating their psychosocial needs, this article promotes thoughtful consideration of the wide range of emotional aspects -both positive and negative- that arise from having a disabled brother or sister. This consideration will become quite helpful when later addressing these issues with brothers and sisters. With this in mind, the present article delves further into what this emotional experience is like.

Method. We have selected and reviewed a broad range of literature from the last 9 years that deals with the issue of siblings and disability. In order to adopt a global perspective and set things in order, we take a deeper look at each type of emotion found, whether positive or negative. All of the emotions addressed in this research are used as categories for analyzing data from interviews (AQUAD six, 2008) with 22 sisters and 11 brothers of people with disabilities between the ages of 8 and 35 years ($\bar{x} = 18.7$ years and $s = 7.7$).

Results. The emotions most often mentioned by brothers and sisters were worry and unease. The causes of these emotions are: the disabled sibling's future, differential treatment in the home in favor of the disabled sibling, and conflicts due to discrimination and insults toward the sibling at school and in social contexts.

Discussion and Conclusions. It is necessary to deal with the negative emotions that arise in these types of sibling relationships. Support groups and workshops with siblings have proven to be useful for this purpose. Toward this end, we review various inputs on how to intervene and address these issues with brothers and sisters.

Keywords: Siblings, Emotional impact, Intellectual disability, Interviews

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Resumen

Introducción. El presente trabajo pone de relieve la necesidad de prestar atención a la vivencia emocional de la discapacidad intelectual por parte de los hermanos. Lejos de ignorar, minimizar o sobredimensionar sus necesidades psicosociales se apuesta por tener en cuenta el amplio abanico de aspectos emocionales tanto positivos como negativos que puede conllevar el hecho de tener un hermano con discapacidad intelectual. Ello resultará tremendamente útil a la hora intervenir y abordar estos temas con los hermanos. En este sentido el artículo ahonda en el conocimiento de cómo es dicha vivencia emocional.

Método. Para ello se ha realizado una amplia selección y revisión bibliográfica de trabajos de los últimos 9 años que tratan el tema de la fratría y la discapacidad. En un intento de adoptar una perspectiva global y dar orden se profundiza en cada una de las emociones tanto de carácter positivo como negativo. Además, todas estas emociones recogidas en la investigación se utilizan a modo de categoría para analizar los datos de las entrevistas (AQUAD seis, 2008) realizadas a 22 hermanas y 11 hermanos de personas con discapacidad ($n=33$) con edades comprendidas entre los 8 y los 35 años ($\bar{x} = 18.7$ años y $s = 7.7$).

Resultados. Las emociones más señaladas por los hermanos son la preocupación y el malestar y los motivos que las generan son: el futuro del hermano, el trato diferenciado a favor del hermano con discapacidad en casa y los conflictos por discriminación e insultos al hermano en el contexto escolar y social.

Discusión y Conclusiones. Es necesario abordar las emociones negativas que surgen en este tipo de fratrías. Los grupos de apoyo o talleres con hermanos demuestran su utilidad para este fin. Para ello, se revisan diversas aportaciones acerca de cómo intervenir y abordar estos temas con los hermanos.

Palabras Clave: Hermanos, Impacto emocional, Discapacidad intelectual, Entrevistas

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Introduction

It is unclear, at least from the literature, whether having a disabled brother or sister causes difficulty in the psychological adjustment of the non-disabled sibling. It is not clear because authors have found significant data for and against a relationship between the disabled person and a general effect on the psychological adjustment of brothers and sisters. A representative, and moreover significant, sample of this situation can be found in an article by Dew, Baladin and Llewellyn (2008), analyzing results from 21 empirical studies published between 1972 and 2005 with regard to the psychosocial impact and adjustment of siblings of children with a variety of different disabilities.

Although we speak of support programs and specific care, this article does not seek to perpetuate or insulate a psychopathological model that assumes that siblings of disabled children have psychological maladjustments due to living with a sibling who has some kind of disability; neither do we take the opposite theoretical model, inspired on positive psychology (Conners & Stalker, 2003; Dykens, 2006; Knox, Parmenter, Atkinson & Yazbeck, 2000; McMillan, 2005; Scorgie & Sobsey, 2000; Swenson, 2005), whereby disability is not seen as a family stressor and that living with a disabled child brings basically benefits. The current trend follows the stress/coping model, but the literature and the experiences of families present topics, concerns and specific needs that must be allowed to emerge, to be addressed and processed with brothers and sisters who so require. In our understanding, it is possible to undergo very positive feelings, emotions and experiences with regard to disability and at the same time be undergoing negative, stressful experiences and emotions. As Dykens (2006) points out, “siblings can simultaneously have positive and negative responses” (p.49), or as Voizot (2003) puts it: “the birth of a sibling with a disability can have a revitalizing effect or an immobilizing effect (fixation of behavior)” (p.359).

It is precisely this diverse emotional response, in conjunction with a personal experience that requires adaptation, which tells us siblings may have specific needs in the adaptation process. This is precisely what we wish to analyze in this article: to locate positive and negative aspects and provide pertinent communication channels, so that the ambivalencies, questions, and guilt that may arise in this type of sibling relationship can be talked out and worked through. On most occasions these communication channels are not available, according to Basquin (2003). In the opinion of Scelles (2003) and Scelles, Bouteyre, Dayan and Pi-

con (2007), these channels can be very beneficial, converting special emotions into common, manageable ones that can be dealt with (Núñez & Rodríguez, 2005, p.57-58), providing personal, specific recognition to siblings (Germain, 2008), and also the possibility for siblings to express themselves, allowing them to authentically work through the affects and representations that they make concerning their reality (Lefebvre & Sarfaty, 2008).

Next, we will analyze resilient aspects and strengths that have been detected in research that explores the experience of a child with a disabled sibling. In the literature, most research addresses the case of siblings with mental retardation; fewer studies include siblings diagnosed with mental illness, cerebral palsy and autism. Except for certain cases where we wish to present more detailed information (and despite knowing that each pathology has its own specificity), we have opted to collect information and speak in general terms; when we think of support interventions or protocols for measures taken with siblings, the set of siblings is often varied and there is a diversity of disabilities represented, so that we are looking for common factors.

Positive experience of the disability on the part of siblings: positive emotions, strengths, adjustment-adaptation and resilience

Let us begin with the positive aspects that we have drawn from the literature. In the case of persons who give support to siblings that are not adapting well, the latter can make use of this person as a benchmark for meaning, and as an option or possibility toward change. Resilient siblings can serve as models to the extent that they have been able to turn the situation around and convert seemingly unfavorable circumstances into strong points or strengths of character (Scelles, 2003). In this author's view, siblings who sublimate suffering or who are resentful do not fall into this category, nor do those whose positive point of view is the result of an adaptive, adjustment process more than authentic elaboration and integration.

In research by Knox et al. (2000) and Scorgie and Sobsey (2000), siblings indicate that living with a disabled sibling: has made them better people, has meant a positive transformation for themselves or their family environment, has made them find within themselves new abilities for adapting to a changing world. They describe a full, rich life experience even though not an easy one. Siblings in research by McMillan (2005) and Swenson (2005) indicate that having a sibling with a disability has given them greater empathy, love, and a sense of social justice. They also developed a sense of protection and support toward others, the

ability to defend those who need it, and increased loyalty, understanding and acceptance of differences. Cuskelly and Gunn (2003, 2006) discuss the development of empathy to the extent that one participates in caring for the sibling. In the words of Stoneman (2005), there is improved perspective, increasing these siblings' ability to understand the feelings of others.

Yeh-Chen Kuo (2000) indicates the following positive aspects that can produce maturity and competence in siblings of children with disabilities, as compared to siblings of the non-disabled: (1) sharing with parents the experience of a sense of loss when the disabled sibling is born (in the case of older siblings); (2) increased responsibilities in caring for the sibling, bringing a sense of greater competency and consequently higher self-esteem; (3) more developed prosocial behavior and greater sensitivity; and finally, (4) the opportunity to learn and to try out coping strategies, reducing problems with adjusting to stress in adult life. The experience of living in a sibling relationship with a disabled brother or sister reinforces such siblings against stress in the future.

More recently along these lines, Dyke, Mulroy and Leonard (2009) indicate that living with disabled siblings raises tolerance and consciousness of differences and diversity, as well as increasing compassion and a caring nature. In comparison to siblings of undiagnosed children, the siblings of disabled children show greater maturity.

For Cox et al. (2003) [cited in Dew et al.(2008)], having a sibling with a disability causes non-disabled siblings to act proactively, as if each day they were moving in a paradigm, a training arena for problem-solving, making them experts in the use of cognitive, behavioral and interpersonal coping strategies of an active and proactive nature. Núñez and Rodríguez (2005) indicate the following strengths in siblings: they are fighters, self-driven, persevering, resourceful, caring, always willing to take on the problems of others. As for Orjales and Polaino-Lorente, in 1993 they had already identified the following strengths in these siblings: greater tolerance of differences, altruism and compassion, a higher degree of collaboration between siblings, strengthened family ties because of this special bond, the chance to have enriching experiences in life, developing greater personal strength, happiness at the disabled sibling's smallest achievement, greater sensitivity and a more affectionate attitude towards persons with disabilities.

From the point of view of resilience, another important topic is the positive emotional connection between siblings. It is evident that strengthening a positive atmosphere for living together, where the siblings feel harmony and an emotional connection, is also very desirable for the development of the disabled sibling. The brother or sister bond offers a huge sphere for emotionally significant experiences, be they affective, cognitive or social, and which moreover are specific and differentiated from experiences with parents. For Bert (2008), life as a brother or sister helps one regulate relationships. Listening, caring, and keeping secrets stimulate thought and learning, facilitate adaptation to the environment and help one know how to behave toward adults. It takes on the problem of coexistence and how it is worked out mentally (hierarchies, age, status, power, privileges). Bonding with another human being is a dense, complex task that facilitates the mental work of differentiating oneself from others, encouraging a person's individuation. Consequently, sibling relationships open one to a state of stimulation and receptivity between psyches. As Lobato et al. (1989) [in Cagigal & Prieto-Ursúa, 2006] point out, sibling relationships are one of the most important precursors of peer relationships and of adult relationships. Siblings act as socializers and educators of each other, intervene in parental care and control, and provide a similar context to that of peers for coping with intense emotional experiences and negotiating for power. For Scelles (2003, p.393, in Stern, 1989) emotional harmonization [between siblings] and affective agreement is what makes possible the experience of inter-subjective communication. Repetition over time of these manifestations of agreement or understanding allows the child to feel recognized as someone with mental states and to acquire the certainty that the other child, like himself/herself, is also the possessor of subjective mental states. This kind of attachment is therefore stimulating for the child with the disability.

In order to examine how this positive connection between siblings unfolds in practice, we extracted some variables used in research by Orsmond and Seltzer (2000), and adapted them for our purposes (see Table 1). In this investigation, 87% of participating siblings indicated that their relationship with their brother/sister (an adult with Down Syndrome) had influenced important aspects of their life such as their choice of career and their couple relationships, and they considered this positive. Curiously, 53% of siblings of adults with mental illness considered these same influences to be something negative. In addition, we point to the second column, "affection toward the sibling" where this quality of the relationship is emphasized at the same level. In fact, in order for things to go well, the non-disabled sibling needs also needs, to some extent, to feel sought after, recognized, loved, and respected in the sibling

relationship. Mother-father figures are decisive in modulating this process, since they are the ones that must be the facilitators. As Scelles (2003) says, children look to the eyes of their parents in order to know how they can and ought to live out the brother-sister bond. For some authors, the emotional quality of the relationship between siblings is a predictor of instrumental and affective involvement with the disabled sibling both at the present time and in the future (Seltzer, Greenberg, Orsmond & Lound, 2006). In this respect, Stoneman (2005) points out the need to question the socialization of siblings for the purpose of their adopting parental functions in the future, making clear that this is a topic of value and of conflict that must be taken into account in the research and in intervention with siblings. Stoneman advocates freeing siblings from this responsibility and for promoting self-determination, since there are also disabled persons who do not want to be dependent either on parents or on their siblings in the future.

Table 1. Adaptation of affective and instrumental involvement variables, used in research by Orsmond and Saltzer (2000)

Care	Affection toward the sibling	Emotions
<ul style="list-style-type: none"> - Knowledge of the sibling's skills and needs - Support for the sibling - Feelings related to this support - Anticipation of future support - Arguments with parents because of the sibling - Shared activities - Contact with the sibling (in person, by telephone) 	<ul style="list-style-type: none"> - To what extent do you feel like doing activities with your sibling (and your sibling with you?) - Do you understand your sibling (does your sibling understand you?) - Are you trustworthy (is he/she worthy of <i>your</i> trust?) - Are you reasonable with your sibling (is your sibling reasonable with you?) - Are you fair with your sibling (is your sibling fair with you?) - Are you respectful with your sibling (is your sibling respectful with you?) 	<ul style="list-style-type: none"> - I feel good - I feel burdened - I feel appreciated - I feel tense - I feel nervous and restless - I feel resentful - I feel isolated - I feel sad - I feel powerless - I feel guilty

In any case, regardless of future needs, creating an emotionally healthy, positive environment between siblings can help the brother-sister relationship take on a restructuring role

and become a resource for building the future of all members of the sibling relationship (Scelles, 2003). Along these lines, Stoneman's objective (Stoneman, 2005) would be to provide strong support for the non-disabled siblings, with intent to create—and recreate, we might add—healthy relationships between the siblings.

Having looked briefly at some of the tangible benefits of living in a brother-sister relationship with these characteristics, we will now analyze some of the emotions found in the literature that are linked to psychological adjustment problems.

Negative emotions and the psychological adjustment of children with disabled siblings

The study of the most common negative emotions in living with a disabled sibling will give us some direction about the topics to be engaged directly or indirectly in interventions with siblings. In our introduction we defended the need to address these topics in support groups, in families or at school without falling into a pathologizing use of the non-diagnosed sibling. But it is true that at some time in his/her life, this sibling must work through feelings of loss or sorrow with respect to the disability (Seltzer, Graus, Hong & Orsmond, 2001) and being able to talk about these emotions can be highly useful in this process. As Dykens (2006, p.49) points out, examining the benefits that this type of sibling relationship brings about does not exclude analyzing stressful and negative responses as well. Tiredness, embarrassment, resentment, jealousy, anxiety, and overload all make their appearance in the lives of parents and siblings, and the two perspectives—strengths and difficulties—allow us to get a complete picture of this phenomenon.

Let us clarify that having a sibling with a disability (isolated variable) is not a sufficient factor for determining psychological adjustment or maladjustment. Even knowing that parental characteristics, family resilience and cohesion, parental stress, family time and routines, communication and problem-solving abilities (Giallo & Gavidia-Payne, 2006; Van Riper, 2000) are probably the most predictive of difficulties in sibling adjustment (Williams, Williams, Hanson, Graff, Ridder, Curry, Liebergen & Karlin-Setter, 1999), there are many other mediating variables: sex, birth order, age, difference in age, personality of both siblings, type and severity of the disability, community support, and so on (Ponce, 2007). According to Giallo and Gavidia-Payne (2006), there is a need for more research on the variables that might

serve as support, and that are important for interventions, such as perception of stress, social skills and the siblings' social support.

For Stoneman (2005), in fact, the sibling's disability is not the construct which can explain why some brothers and sisters of children with disabilities are optimistic about life, adapting admirably at school and in the social environment, while others develop behavioral problems; why some siblings show constant rivalry, jealousy and anger, while other siblings play together cooperatively for hours; or why some siblings are delighted to fill their house with friends, while others seem embarrassed about the disability and remain socially isolated.

With this reality in mind, our objective is not to demonstrate that negative emotions necessarily form part of this sibling relationship, but to take them into account in order to act advantageously. Toward this end we have selected several studies from the last 9 years about sibling relationships and disability, where some aspect of the emotional experience is being studied. Focusing on negative emotions that become evident, we have prepared a table where we compare author(s), research year and negative emotions highlighted in these articles, whether by their own research (empirical study), or otherwise collected (Table 2).

We are aware of the methodological limitations involved in doing this, and that it is precisely the opposite of what some researchers like Stoneman (2005) have called for, recommending that "samples be well dissected" so as not to draw conclusions from siblings with diverse ages, sex, or sociocultural circumstance, with variability in the disability diagnosed, and so on. Nonetheless, we have already justified that this is not our purpose, but instead to open ourselves to possible emotional needs that may need to be explored and treated.

Next, we will comment briefly on each of the emotions identified in the context of research shown in Table 2, and also others that are drawn from the bibliography. As one can see with a quick glance, the emotions most often indicated are first, the feeling of loneliness and social isolation, followed by stress, a feeling of diminished parental attention, feelings of guilt and of embarrassment. Let us look at each one in greater detail.

Table 2. Negative emotions in siblings of the disabled, as found in the literature

	Yehchen kuo 2000	Voizot 2003	Scelles 2003	Korff- Sausse 2003	Dew et al. 2008	Stone- man 2005	Núñez & Rodriguez 2005	Cagijal et al. 2006	APPS 2005	Orjales & Polaino 1993
Getting mad/inhibition, concealment	•	•					•			
Irritability	•									
Loneliness/social isolation	•				•	•	•	•	•	•
Aggressiveness	•							•		
Deprivation of parental care	•			•	•		•			
Stress	•				•	•	•			•
Tiredness from increased responsibilities / overprotection	•						•		•	
Unease	•								•	
Frustration over reduced social or after-school activities	•						•			
Resentment	•									
Guilt	•						•		•	•
Indifference			•							
Depression						•		•		
Fear/Angst									•	•
Jealousy/Envy							•		•	•
Confusion/perplexity							•		•	•
Worry							•		•	•
Anger/Rage									•	•
Embarrassment			•				•		•	•
Insecurity (lack of self-esteem)			•		•					
Anxiety					•	•				
Hate/hostility			•				•			
Rivalry			•				•			
Pressure to compensate for the sibling's limitation	•						•			

Getting mad and inhibition, concealed angry feelings / Irritability

Angry feelings (irritability, for Yeh-chen Kuo, 2000) result from the experience of unfairness, when the disabled child is not subjected to the same rules or demands, and is seen as privileged (Núñez & Rodríguez, 2005). For Voizot (2003), inhibition or concealment of these feelings is justified: aggressiveness triggered by the disabled sibling cannot be released, since “he is not well”. This same author warns against the danger of idealizing the disabled child, turning him or her into the child who is “ill”, where siblings may not get mad at him or her. Not being able to talk back can create *aggressiveness* in the sibling.

Loneliness/ Social isolation

Children with disabled siblings feel lonely inside and outside the family, according to data collected by Dew et al. (2008), due to the special care that must be given to the disabled sibling, and also because the latter does not have friends and needs the company and support of siblings (Stoneman, 2005). For Núñez and Rodríguez (2005), parents have more support channels than do siblings, and the latter often feel more isolation and neglect. For Orjales and Polaino-Lorente (1993), this feeling of isolation and/or rejection can come from school mates as well as from family members or from other families, since the sibling views his/her own family as different. For APSS (2005), this emotion is typical of the group of adolescent siblings, and results from awareness of differentness.

Giallo and Gavidia (2006, p.942) compared two samples by applying the SDQ [Strengths and Difficulties Questionnaire by Goodman and colls. (1998)] to 49 children divided between a sample who had disabled siblings, and a normative sample with undiagnosed siblings. They observed significant differences precisely in these two variables (among others): *problems with peers* and *prosocial behavior*, with higher values for the former and lower values for the latter in the case of children with disabled siblings.

Deprivation of parental care

This aspect is often pointed out in the research. For Núñez and Rodríguez (2005, p.13) “from the moment that the disability is confronted, siblings become the least cared-for members of the family, they may even be passed over as a consequence of the care required by the child who has the limitation”. So much so that according to Yeh-chen Kuo (2000), it is not the birth of the disabled child that may affect the sibling, but rather the parental treatment that he or she receives from that point forward. Korff-Sausse (2003) even speaks of children who are

psychically forgotten by the mother. This stems from the idea that, despite appearances (attentive father), siblings of disabled children at an unconscious level are not present or have been erased from the mother's psyche. For Dew et al. (2008), the overload experienced by the mother in caring for the disabled child is what hinders proper care toward the siblings.

Stress

Siblings of disabled children are more susceptible to suffering daily stress, according to Dew et al. (2008). For Orjales and Polaino-Lorente (1993), this stress may originate from the healthy child undergoing excessive pressure to compensate, the responsibility of being a good example, of being a good child, and excessive responsibility in caring for the brother or sister. For Lefebvre and Sarfaty (2008), this constant effort would explain the "hypermatur-ing" that is shown by siblings.

Tiredness from increased responsibilities

Aside from the key roles that a sibling can have over a lifetime, he or she will play a role of caring for the disabled brother or sister, at least peripherally, and typically will anticipate future care responsibilities. It seems that this occurs to a greater extent in women (sisters) who anticipate this role as part of their future family responsibility. Regardless of gender, it appears that contact, care, and emotional closeness to the disabled sibling increase and become stable at around 30-40 years of age (Orsmond & Seltzer, 2000). This research confirms that women are more apt than men to maintain contact with the diagnosed brother or sister, to do more things together, to empathize with the skills and needs of the disabled sibling, to discuss the disabled sibling's future with parents, to show intimacy (feel closer) in the brother-sister relationship. In short, they assume the responsibility of providing continuity to the parental care role; it is also true that sisters more than brothers show poorer adjustment, more neurological symptoms and more family problems (Yen-Chen Kuo, 2000). In other words, they have a worse time of it, but they connect, empathize and provide care, generally speaking, more than brothers do. Hannah and Midlarsky (2005), without distinguishing between genders, speak of overload and altruism. In their research, siblings of the mentally retarded were mostly motivated to help in caring for the brother or sister, or to relieve the mother of the care burden.

Unease

According to reports from siblings in support groups (APPS, 2005), this emotion is typically linked to the experience that the birth of the brother or sister has altered the family. At certain moments one might have notions of ending this situation, even drastic ones like “*I wish he would fall down the stairs*”. Similarly, detecting the difference between the disabled sibling and everyone else can also cause unease, and/or it may be provoked by the fact that activities cannot be shared with the disabled sibling.

Frustration over reduced social or after-school activities

Closely connected to tiredness from increased responsibilities, Yeh-chen Kuo (2000) considers that intensive involvement in caring for the sibling is part of the negative impact, since it requires a large proportion of time, emotional energy and resources. This entails increased household tasks and reduced social and after-school activities. Activities with peers seem to be most affected. This can create resentment, guilt and their associated psychological problems. Adolescent siblings report along these lines in APSS (2005).

Resentment

According to Marina (2007): *hate, which we will speak of later, rancor and resentment involve an aversion toward someone (or something). In the case of resentment, this is directed exclusively toward persons, includes the memory of the offense or insult and entails the powerlessness of not being able to avenge the wrong, to forgive it or to forget it. Rancor and resentment are feelings of remembering and reiterating. In short, resentment is a sad kind of hate that invades a person's affective organism and persists longer than its cause* (p.1). Some authors who have researched sibling relationships have mentioned it. According to Scelles (2003), it is the motive for some siblings to build their social identity around an associative or professional activity in the sector of disability or assistance. This social identity can sublimate the suffering caused by guilt from feeling this resentful hate toward the sibling. The lack of self-esteem in siblings of disabled children, linked to feelings of guilt, can manifest itself in altruism that functions as a self-inflicted punishment or as a way of finding pardon.

Guilt

Since siblings, overall, find little tolerance for the open expression of their feelings, especially if these are negative (hostility, shame or jealousy), they keep up the appearance of only having positive feelings toward their brother or sister, and are left alone to deny what

they are feeling (I am a bad child, I am a bad brother or sister) (Núñez & Rodríguez, 2005). Similarly, siblings may sabotage their own achievements in order to lessen their guilt or because they feel sorry for their sibling who cannot achieve – guilt specifically for being able to do more, for meeting objectives that the disabled child cannot, for thinking that he or she personally is not receiving much care, for not being a good enough child and doing more to offload his or her parents, for moving away or making an independent life (APPS, 2005).

Orjales and Polaino-Lorente (1993) and Meynckens-Fourez (2007) indicate that guilt often originates from the mere fact that they feel healthy, or from the awareness of feelings like anger, jealousy and aggressiveness towards the sibling. In the same sense as Scelles (2003), they point out that these guilt feelings can manifest in a reactive or compensatory fashion as in an exaggerated desire to help out.

Indifference

As in any sibling relationship, hate, anger, rivalry and indifference can appear (Scelles, 2003). For example, Orsmond and Seltzer (2000) indicate that the more siblings distance themselves from the disabled brother or sister, the greater is their emotional well-being. The opposite occurs in the sample of siblings with mental retardation, where greater involvement means greater well-being, although tiredness increases as well. In addition, it seems that brothers act more indifferently toward their sisters with disability, but are more involved with disabled brothers. Therefore, a greater emotional connection is produced, and less indifference between siblings (with and without disability) when they belong to the same gender.

Depression-sadness

These emotions are less often mentioned in the literature on siblings and disability. Stoneman (2005) finds this linked to dissatisfaction that is caused in the non-disabled sibling due to differentiated parenting and a lack of care. Cagijal and Prieto-Ursúa (2006) find a higher level of behavioral and emotional problems in minor children with diagnosed siblings (n=153 children from 4 to 18), including depression (assessed with the CBCL, Child Behavior Checklist).

In Lefebvre and Sarfaty (2008), siblings also show depression, intellectual inhibition, school failure or feelings of neglect. They attribute to these siblings a specific kind of suffering, which they consider worthy of treatment. They also believe, along with Fernández-

Castillo and Gutiérrez (2009), that this suffering is hard for parents to detect, and it is necessary for other professionals such as the pediatrician, the educator or the school psychologist to intervene for screening and treatment.

Fear/angst

Orjales and Polaino-Lorente (1993) list the following fears as typical in the sibling population: fear of the limitation being contagious, fear about the disabled child's future, fear of abuses that the sibling might experience, fear of how friends or future spouses will react when they find out, fear of having children with the same disability.

Unlike fear that is experienced with respect to a real danger or threat that can be defined, angst has no concrete object; the threat is a vague one. It can be transmitted (unconsciously) by anxious parents as well as by the situation or the uncertainty of the future. Similarly, confusion and lack of information can provoke angst in siblings (APPS, 2005). In this document, siblings report that angst is an aspect that is commonly linked to disability and stems from feeling that everything is different. Muñoz and Lucero (2007) feel likewise.

For Nixon and Cummings (1999), having a brother or sister with a disability is a predictor of emotional angst in siblings.

Jealousy/ envy

A common feeling in any group of siblings, in this case it is linked to feeling clearly discriminated against by differential parenting in favor of the disabled sibling. APPS (2005) stresses that siblings do not always remember jealousy as a feeling, and this may be related to not being "allowed" to feel jealousy toward their disabled sibling. The jealousy is then concealed by feelings of guilt.

Confusion/perplexity

For Orjales and Polaino-Lorente (1993), siblings may feel confused regarding their own role in the family, regarding their role as siblings or as a parental substitute, and may have doubts in terms of prioritizing their own needs compared to their sibling's. According to APPS (2005), perplexity is an emotion typical of a sibling's childhood, linked to "not understanding what is happening" in different circumstances such as: 1) more time devoted to the

disabled sibling, 2) the appearance of other family members who are offering support, or 3) what the sibling's disability means.

Worry

Worry revolves around the following themes: 1) the disabled person's future (care, available services) and how it may clash with one's own life plans; 2) possible effects of the disability in one's genetic inheritance, acceptance of the disability by emotionally significant others (friends, girlfriends/boyfriends, spouses).

Anger/Rage

Anger occurs over being unable to share daily activities with the sibling and over the differentness involved in having a sibling with a disability (APPS, 2005). For Orjales and Polaino-Lorente (1993), feelings of rage are directed toward the sibling, parents, society or even God, and also as a response to jealousy or against school mates who treat the disabled sibling with cruelty.

Embarrassment

Embarrassment emerges over having a sibling with a disability, over the sibling's inappropriate behaviors in public, or when being introduced to emotionally significant persons (APPS, 2005; Orjales & Polaino-Lorente, 1993).

Insecurity (lack of self-esteem)

Some studies analyzed by Dew et al. (2008) find that siblings of children with disabilities show low self-esteem, more anxiety and less integration in groups.

Anxiety

For Stoneman (2005), siblings of children with disabilities have more behavior problems, including internalization of behaviors such as anxiety. This stems from dissatisfaction with differential parenting. In a sample of 153 minor children between 4 and 18 (control group 95 minors without disabled siblings) who were screened using the CBCL (*Child Behavior Checklist*, Achenbach & colls. 1983), Cagigal and Prieto-Ursúa (2006) find problems of internalizing and externalizing, isolation, somatic complaints, anxiety, depression, social problems and aggressive behavior.

Hate/hostility

For Scelles (2003), hate, angry feelings, rivalry and indifference appear in these types of families as they may in any sibling relationship. Núñez and Rodríguez (2005) and Meynckens-Fourez (2007) draw attention to the difficulty of siblings expressing such negative emotions toward the brother or sister. This difficulty requires individualized treatment, even outside the support groups that the sibling may be involved in (Germain, 2008).

Rivalry

Núñez and Rodríguez (2005, p.28) express it this way: “Parental postures of unequal treatment among their offspring can drive siblings to competition and be a source of feelings of jealousy, rivalry and injustice. If the sibling has the chance to express and share these negative feelings which are present in the sibling relationship – feelings which are common to sibling relationships in general – it will help him or her to not feel like a bad child”.

Pressure to compensate for the sibling's limitation

For Núñez and Rodríguez (2005), siblings from the time they are quite small can tune into a family climate of worry, angst or sadness. They feel that their parents are vulnerable and unhappy, and adopt behaviors for the purpose of cheering them up [model behavior, being a good pupil, being a good child, not giving parents more work, being autonomous (getting by on their own, not worrying parents with their concerns), responsible, intelligent and emotionally balanced and positive].

A study of siblings' emotions as pertains to living with the disability

In undertaking a research and collaboration project (financed by the Government of Navarra) between the University of Navarra Education Department and the Family Guidance Center of the Ciganda Ferrer Foundation (El Molino School), we established as our principal objective the analysis of the needs of siblings of persons with a mental disability and the exploration of their experiences and feelings, in order to design a well-suited intervention (Lizasoáin, 2007).

Method

Participants

A convenience sample was drawn from the population of siblings of pupils in El Molino School, Pamplona, $n=33$ (22 sisters and 11 brothers), age distribution as follows: six were between the ages of 8 and 12; eight were between 13 and 16, and nineteen siblings were over 18 years of age ($\bar{x} = 18.7$ years and $s = 7.7$).

Instrument

33 semi-structured interviews were carried out. The key points forming the basis of the interview were as follows:

- 1) Siblings' type of disability, characteristics, severity and time it appeared.
- 2) Information and knowledge about the disability. Satisfaction with information received.
- 3) Person who has offered them the most information about the disability, and who they think ought to be informing them.
- 4) The moment at which they became aware that they have a sibling with a disability.
- 5) Changes in the family since the disability was diagnosed. Initial reactions.
- 6) Concrete memories of the most concern and anxiety over the sibling's disability.
- 7) Different treatment (if they feel that the treatment from parents, grandparents or other relatives is much different with respect to the disabled sibling).
- 8) Social support (siblings are asked if there has been anything or anyone special who has really helped them cope with the situation at difficult times).
- 9) Social relationships, professional and leisure activities.
- 10) What they think they have lost due to having a disabled sibling, and whether this loss might have been minimized.
- 11) Benefits (gains experienced as a result of having a sibling with a disability).

12) Principal concerns at this time (in relation to the brother or sister, and with respect to themselves).

13) Principal concerns for the future.

Interviews lasted approximately 45 minutes and were carried out by Carmen Esther Onieva, family guidance counselor for El Molino School and the Ciganda Ferrer Foundation, and member of this project team. Members of the research team performed transcription of the recorded interviews.

Procedure

For the analysis of emotions, we used the 24 emotions collected from the theoretical review (explained in detail in Table 1 and Section 2) as categories of analysis in the AQUAD Six program (Huber & Gürtler, 2008), to see which of them would be reflected in our sample. In the following pages we extract the data from the interviews that corroborates the presence of these emotions. The information is expressed more synthetically in Table 4 (see Appendix 1), with a double-entry matrix showing the 24 emotions that serve as search categories in our research on both axes, in order to present which of them appear in our sample and also how the emotions are associated with each other.

Indicated in the boxes marked with an asterisk is the number of the interview(s) where the sibling manifests this emotion, without it being associated with other emotions. When the information given by siblings reveals a relationship between one emotion and another, for example, cause-effect relationships, one emotion becomes secondary or instrumental to another. In this case, it will appear in the boxes where the two emotions connect, where the primary emotion is found in the left-hand column of the table in all instances.

Results

Out of the 24 search categories programmed in AQUAD Six, 13 were found in our sample: getting mad, loneliness/social isolation, aggressiveness, stress, tiredness from increased responsibilities/overprotection, unease, frustration, fear/angst, jealousy, worry, rage, embarrassment and anxiety. Results from the interviews are shown below in the following

fashion: the name of the emotion, followed by the numbers of the interviews (the same numbering as seen in the Appendix 1 table), the motive that prompted the emotion (in italics) and the literal comments from the interview (between quotation marks) or as interpreted from the information contained in the interview.¹

Getting mad/angry feelings

Interview 2, feels bothered *because of lesser requirements*, “it bothers me a little, when she gets home it’s just music and TV” [age 26].

Interview 10, *because of lesser requirements*, “it makes me a little mad that I have to do homework and he doesn’t” [age 9].

Interview 29, *because of discrimination and insults*, “they tease him because he is disabled and they keep teasing him (...) it gets to me (...) I remember them hitting him and insulting him in grade school (...) I would defend him but it pissed me off (...) some of them wind him up” [age 16].

Loneliness/ social isolation

Interview 4, *cannot share what she is living*, in the sense that her girlfriends do not understand what disability is like (“they can support you, but it’s hard for them to understand”). She cannot share this topic or her concerns, despite the fact that her friends accept her brother [age 21].

Interview 24, *lack of care*, “well, I used to live well, I was treated very well until my brother was born and they had to devote all their time to him, of course. Then somehow I remember, as a young girl, that my parents, eh, I was a bit, yeah, godforsaken (...) I recall how I didn’t have the mother that I should have had or ... especially a mother (...) was what I was missing” [the sister puts these words in her mother’s mouth: “X has made her own way, she has raised herself”] (the lack of maternal care recurs over the course of the interview) [age 26].

Interview 25, *because of caring for his brother*, “well, to tell the truth when my parents worked in the summer the one who stayed with my brother was me, ever since I was small, till mid-afternoon. Maybe that, that might have screwed up some vacations for me when I was small, yeah, but not really” [age 24].

¹ *Translator’s note:* the following references to interviews do not explicitly indicate whether the interviewee is male or female. In some cases the speaker’s gender is revealed through the Spanish words used in speaking, otherwise the English will reflect the ambiguity of the original.

Interview 29, *because of caring for his brother*, “I have lost friends because of going with my brother, but I don’t care” [age 16].

Interview 32, *because of caring for her brother*, “well in the summer my mother goes to work, I have to stay to take care of him and I can’t go out with my friends and all that” [age 14].

Aggressiveness

Interview 13, *because of insults toward the disabled brother*, when they insult or tease the brother (“it’s my weak point”) [age 19].

Stress

Interview 30, *problems with teachers*, “when I saw that the teacher would strike him (...) I got supernervous, she hit him!” (now she is more calm, improvement after a change of school) [age 11].

Tiredness because of increased responsibilities/ overprotection

Interview 4, *because of overprotection*, does not refer to overload, since she considers it her duty, she manifests a hyperactivity toward helping, supporting her parents, keeping things running smoothly, and protecting her brother. She feels more mature, playing a mother role [age 21].

Interview 13, *because of overprotection*, does not speak of overload, but rather of excessive protection toward his brother to the point of being like his father [age 19].

Interview 20, *because of overprotection*, “I feel that I have become a more mature person (...) I’ve always tried to be a kind of strong, you know, to be strong. You know, my mother is more sensitive than I am, and when something happens to my brother she has a hard time of it (...) and I try to be a little stronger so she can see that everything isn’t so awful (...) the three of us stick together, if there is a problem we three stick together, since I am a daughter I don’t distance myself (...) I get very involved” [overall she has a positive experience from all this] [age 23].

Interview 22, *because of caring for her, bad memories*, “well xxx would poop her pants, would pee her pants, and they would have me leave class, go to xxx because she’s pooped her pants, change her (...) in the middle of class, you would miss out on things, but you did it willingly, but (emotionally moved)” (...) “you’re a little more attentive (yes I was quite attentive) to what she was eating, where she was, keeping track of her, you know? (...)

but well these are responsibilities, I don't know how to say it, you take them on because you want to" [age 28].

Interview 25, *doubts and burden with respect to taking charge of the brother*, "I should move out on my own ... sometimes I feel that way, like, he's my brother, and then I always turn back, I dunno. I can't just leave him there (...) I can't just dump him. So, about this, maybe it's a burden? Yeah maybe it's a burden, I dunno, but" [age 24].

Interview 27, *because of protecting the brother* (responsibility x rage), "more than once I have had to defend him, even physically I have had to defend him (...) and besides the responsibility, much responsibility, I have also lived (...) a lot of anger" [age 14].

Unease

Interview 6, *because of the differentness involved in having a disabled sister, because of insults, annoyance* at not being able to understand one's sister, at being different, would like her to not have this syndrome. Also *unease* and *rage* when they laugh at the sister. *Feeling bad* that she is like that [age 7].

Interview 7, *because of discrimination, pain*, says, "*it hurts me*, when they insult my brother and call him mongoloid" [age 12].

Interview 11, *because of discrimination*, is bothered when they tease the disabled brother [age 6].

Interview 16, *because of discrimination, annoyance* when they insult him and laugh at the brother, "well a lot of times I have to defend him, he bugs people and then they pay him back" [age 12].

Interview 18, *because of concern*, her sister has problems during recess, as soon as they go out to the school yard she tries to accompany her [age 25].

Interview 21, *because of discrimination, pain*, "and a lot of people would make remarks and then everyone would laugh and that hurt me, because she is my sister and if they don't know her, they shouldn't judge her (...) I dunno, you know the typical remark, oh I'm a mongoloid, I look like a mongoloid (...) yes sometimes I had to defend her, they made a remark, it bothered me, and I lashed out" [age 17].

Interview 24, *because of discrimination, suffering*, "it hurts me very much when they tease him or anyone (...) you can't do anything (...) I remember suffering so much, so very much" [age 26].

Interview 26, *because of discrimination and insults*, “I feel bad when they say things to him, when I was little they used to shout at him, telling him not to get in the swimming pool, dummy” [age 11].

Interview 30, *because of discrimination and insults*, “when he would come out of his class the little kids would be there and would look at him, watch out here comes the monster (...) I felt bad” [age 11].

Interview 33, *because of having a sister who was different*, asked about the impact of having a disabled sister, she answers: “not having a sister with whom I could share things” and she goes on to tell about the affinity of sharing secrets, comparing experiences [age 35].

Frustration

Interview 7, *because of the differentness involved in having a disabled brother*, gets bored playing with the brother, would like to have a brother but not with Down syndrome [age 12].

Interview 18, *because of the differentness involved in having a disabled sister*, of not having a sister without a disability: “well, bad, a little negative, not having a sister around your age to share with, to talk, to discuss things” [age 25].

Fear/Angst

Interview 13, *because of the disabled sibling's future and about the disabled brother taking more initiative*, “as I've gotten older I have tormented myself over this” (...) “what will happen to my brother tomorrow, what if one day this or that happens to him, typical worries that you usually take to the extreme”. With respect to his taking more initiative and having more autonomy (his brother is 15): “I'm afraid, very much afraid that something might happen to him” [age 19].

Jealousy

Interview 2, *for lack of care*, more care is given to the sister (her birth “didn't do much for me because everyone paid attention to her and me they ignored”). Now as a young adult, claims not to be aware of this feeling, but “surely it comes some time, I don't have anything in my conscious mind, but surely it comes up” [age 26].

Interview 3, *for different treatment*, is bothered because they are more lax with the sister, and she doesn't have to do homework when she gets home [age 14].

Interview 7, *for lesser schoolwork demands*, is envious because his brother has no homework, does interesting activities at school like riding horses, and he doesn't. Envy of the father's different treatment toward the brother with Down syndrome, more affinity, attention and positive affect (even though he is asked directly whether he is jealous, and he says no) [age 12].

Interview 13, *for lack of care*, jealous when he was small because the brother received more attention due to his illnesses [19].

Interview 16, *for lesser schoolwork demands*, "once in a while" (admits to feeling envy for this reason) [age 12].

Worry

Interview 1: *because of the differentness involved in having a disabled sister, and about the future*, wonders why she/he has a sister like this and is worried about the sister's future employment [age 16].

Interview 4, *because of lack of autonomy and dependency*, "you can't leave him alone", he is not autonomous, could not communicate with the neighbors [age 21].

Interview 5, *because of the differentness involved in having a disabled brother*, "I'm worried that my brother is like that", "I wish he were normal" [age 6].

Interview 8, *because of conflicts at school*, (worry x anxiety), "when he went to the normal school, people are very bad and they would tease him, and he being strong would give it back to them" [age 25].

Interview 10, *because of conflicts at school*, is worried that they insult and hit his brother at school [age 9].

Interview 11, *because of the differentness involved in having a disabled brother*, is worried that the brother "is different" [age 6].

Interview 13, *about the future*, (worry x anxiety) is worried about the brother's future, "I have always worried very much, even if he was fine, even if he was with my mother, I start turning it around in my head and it worries me terribly, he is the person that I most worry about in the world. I worry that he might be taken advantage of". Worry because she/he wants to take charge of the brother when they are older, but feels that this is incompatible with forming one's own family [age 19].

Interview 17, *about the future and about making life plans that might mean abandoning the brother*, (worry x fear), "I've always worried a lot about him, even now there are nights that I don't sleep" (complicated family situation, sense of protection). When thinking

about making personal life plans, has the doubt: “that I might be leaving him all on his own” and “you know? Then maybe I go to bed and start to think, dammit, this son, when he gets older, can he have a life, will he have a girlfriend? you know? And the truth is that sometimes I have a hard time (...) I’m very worried about the whole idea of his future” [age 28].

Interview 20, *about caring for him*, “when I was small I was with him a lot, when he started going to school, then whenever anything happened to him, I was always keeping an eye on him during recess, always” [age 23].

Interview 24, *about the future*, the brother’s lack of autonomy, the family situation, the mother’s relationship with the disabled child, the lack of discipline [age 26].

Interview 26, *because of discrimination*, “that they might do bad things to my brother” [age 11].

Interview 28, *about the future*, “I worry about what she’s going to do when she finishes school (...) she’s very lazy” [age 26].

Interview 32, *about the future*, “since when my mother gets older, we’ll see what I can do with xxx, because I can take care of him for a while, but not too long, because I will have to work and if I get married and all that, well, I can’t be in charge of him all the time and if my mother some years from now gets older she is not going to be able to take care of him (...) my mother has told me that she wants to keep him always with her, but she won’t be able to, because when she’s 60 years old, she won’t be able to do anything, because if she squats down or something she might hurt herself.” [age 14].

Interview 33, *about a future occupation (worry x fear)*, “what most worries me is that she can always be occupied, I would like her to always have something to do (...) that she would always have a job, I would feel afraid and sorry if she were to stay at home (...) that she would have a social life” [age 35].

Rage

Interview 4, *over the disabled person being teased*, mixed with powerlessness and *embarrassment* “when they teased my brother and imitated him” [age 21].

Interview 6, *over differential treatment in favor of the disabled sibling*, because my sister is scolded less when something unfair happens (she has taken something away from him/her) [age 7].

Embarrassment

Interview 2, *because of the sibling's inappropriate behavior in public*, the sister embarrasses him/her in public [age 26].

Anxiety

Interview 18, *because of the sister's distressing experiences at school*, some of her sister's troubles affected him/her seriously, when she changed schools and was able to overcome them, the sibling notes how she/he has relaxed [age 25].

Conclusions and suggestions for intervention

1) It is important for the family with a disabled member that the sibling relationship take on a positive, constructive, harmonious role, in order to build a positive future for the family members.

2) Toward this end, it is positive to work through stressful situations and for siblings (and parents and all the family) to (1) incorporate in their identity aspects of resiliency and strengths that are fostered by having a disabled member of the family, and to (2) work through psychologically the more arduous and difficult aspects.

3) The following aspects found in the literature are examples of the more arduous and difficult: getting mad, inhibition and concealment of angry feelings, irritability, social isolation / loneliness, aggressiveness, deprivation of parental care, stress, tiredness from increased responsibilities/ overprotection, unease, frustration from reduced social and after-school activities, resentment, guilt, indifference, depression/sadness, fear/angst, jealousy, confusion/perplexity, worry, anger/rage, embarrassment, insecurity (lack of self-esteem), anxiety, hate/hostility, rivalry, pressure to compensate for the sibling's limitation. Of these 24 emotions found in the research, 13 are indicated in our study. Of these, worry and unease stand out, with the most frequent motives being: the sibling's future, differential treatment in the home in favor of the disabled sibling, and conflicts due to discrimination and insults toward the sibling at school or in the social context.

4) Support groups or workshops for siblings can be – for those siblings who need it – a forum for expressing emotions, for being recognized, for integrating and working through the more difficult aspects (“turbulences”, says Lefebvre, 2008) that are brought on by this specific sibling relationship, protecting siblings from inappropriate resolutions, seeking to protect them more than pathologize them (Basquin, 2003; Cagigal & Prieto-Ursúa, 2006; Ponce, 2007; Yeh-chen Kuo, 2000).

Support groups for siblings are a protective element for the sibling, and a predictor of better psychological adjustment, in the opinion of Giallo and Gaviria-Payne (2006). Several reasons are offered for promoting these; for Korff-Sausse (2003) the sibling’s encounter with another adult outside the home can “give him some psychic space”, a place that allows them to “no longer be forgotten children”, “children who are erased from their mother’s psyche”, in the words of the author. For Dew et al. (2008), support groups can come to mediate and modulate relationships, smoothing over negative aspects and facilitating harmonious and positive ones. Lefebvre and Sarfaty (2008) consider that the main role of these groups is to facilitate the expression of positive and negative emotions; in the latter case, to be able to work on certain feelings such as hate, embarrassment or isolation, which cannot be shared with others or in the family. With a less clinical perspective, Ponce (2007) considers the active role of the sibling (she/he is not the patient, is not a passive subject) in the quality of life of the disabled siblings, and in their family, proposing that sibling workshops be held as a “recreational” and “occasional” activity. These encounters between siblings serve to provide information and to detect whether they are having any difficulty in their experience with the disability, and then be able to offer this orientation to parents so that they can be the ones to work on the matter or make a referral².

² Ponce (2007) takes as his basis the *sibshops*, sibling workshops launched by Mayer in 1990, and which can be explored in the website (www.siblingsupport.org). Since 2004, Ponce and Gordillo have carried out sibling workshops with children ages 4 to 10, where children meet with other siblings in the style of clubs, where they spend the whole day doing recreational activities led by volunteer siblings who have received specific training in this model (Ponce, 2007, p.19). This document describes in detail their experience with the initiation and functioning of these workshops.

In closing, we offer some brief input that can guide practical work with siblings. First, we indicate objectives, provide a picture of the siblings' reality, and suggest topics to be addressed with siblings in these types of groups, by content and by age.

Regarding objectives, Ponce (2007) and Scelles, Boutheyre, Dayan and Picon (2007) indicate the following:

- 1) With regard to the child participating in the workshop
 - Avoid feelings of loneliness/differentness.
 - Create the conditions for exchanging neutral information about the disability in a context where the children can express what they know and can take their time to ask questions.
 - Promote self-esteem and personal growth in the members of the group.
 - Encourage sharing between the siblings (experiences, emotions, desires), away from the judgment of adults, but under their protection.
 - Acquire new knowledge and skills that are useful for daily life.
 - Encourage parents to find time for their non-disabled children, helping parents listen to them and consider what they are living.
- 2) With regard to the disability
 - Improved understanding of the disability.
 - Recognition of the full range of characteristics of the sibling with mental disability (both abilities and limitations).
 - Exchange of information about the disability.
 - Clear up questions and confusion.
 - Ensure that siblings feel recognized and supported in the specific experiences that they are going through.

In order to *further explore the most common worries* of siblings, we recommend reading in Orjales and Polaino-Lorente (1993); pages 86-88 of this article include over 120 detailed questions with regard to the most common *worries* of siblings: a) *regarding the disabled sibling* (cause of the limitation, disabled sibling's feelings, prognosis, services required, how to help him/her, best place to live, the future, parental expectations, communication with parents, parents' feelings, parents' time, helping parents, participating in the sibling's education; b) *regarding themselves* (feelings, health, relationship with the sibling); c) *regarding friends* (informing friends, acceptance on the part of friends, relationships with the opposite

sex); c) *regarding the community* (the school, acceptance from the community, life in community) and d) *regarding adulthood* (guardianship, one's own family, commitment).

Regarding topics that can be addressed in the groups:

Topics relating to parents (Germain, 2008; Lefebvre & Sarfaty, 2008):

- 1) Parental suffering.
- 2) The sadness of being unable to comfort one's parents.
- 3) Resentment toward parents.
- 4) Fear of losing one's space of parental care.

Disability-related topics (Benderix & Sivberg, 2007; Germain, 2008; Ponce, 2007):

- 1) Understanding the handicap (diagnosis, prognosis, decision making).
- 2) Improved understanding of the disability.
- 3) Recognition of the full range of characteristics of the sibling with mental disability (both abilities and limitations).
- 4) Exchange of information about the disability.
- 5) Clear up questions and confusion.

Topics relating to social life (Benderix & Sivberg, 2007; Germain, 2008; Lefebvre & Sarfaty, 2008):

- 1) Work on exposure to strange, provocative, or even physically violent behaviors that make siblings uncomfortable and embarrass them in public.
- 2) The feeling of having a poorer social life. Work on social isolation.
- 3) Other people staring.
- 4) Prejudices and mocking.
- 5) Angry feelings that elicit inadaptive and turbulent behavior from the disabled sibling.
- 6) The embarrassment of being seen by schoolmates.

Topics relating to personal aspects (Benderix & Sivberg, 2007; Germain, 2008; Lefebvre & Sarfaty, 2008):

- 1) Offload guilt with respect to a premature sense of responsibility in trying to protect one's brother or sister.
- 2) The feelings of pity and sadness.

- 3) The feeling of empathy, working through such feelings when they perceive frustration, sadness or fear in their disabled siblings.
- 4) Sibling rivalry that turns into concealed aggressiveness.
- 5) Jealousy.
- 6) The feeling of being forgotten.
- 7) Not being an object of love.
- 8) Guilt on account of negative feelings toward the sibling, guilt for being normal, or for not being able to look after their sibling sufficiently.
- 9) The need to speak very confidentially about certain negative feelings such as hate, resentment, hostility and ambivalent feelings.

In *APPS (2005)*, topics are broken down according to age, in terms of the needs of siblings at each stage in their development (Table 3).

Table 3. List of topics drawn from the opinions of siblings who work in support groups (APPS, 2005)

Childhood	Adolescence	Adulthood
Perplexity Unease Angst Jealousy Desire to cure the disabled sibling Protection Feeling of differentness Embarrassment Rage	Differentness Loneliness Rage Protection instinct Embarrassment Guilt	One's mate One's offspring Worry about the future

In conclusion, although Núñez and Rodríguez (2005) do not directly present a list of topics to be addressed in a group of siblings, we offer the following points for reflection, inspired in the reading of their book. Since the book is advocating for the condition of brother or sister, we write from this position:

- 1) I the sibling also want to be the center of attention, and want my parents to meet my needs.
- 2) I the sibling want my parents to defend me, to take care of me and protect me. I the sibling often have the feeling of being unloved.
- 3) I the sibling ask my parents: do I mean something to you? is my brother or sister the one who means more? or the one who means everything? is my existence not enough of a motive for your happiness?
- 4) I the sibling want to spend time with other siblings who tell me how *they* are living.
- 5) I the sibling sometimes cannot stand my disabled brother or sister, I feel jealous, angry, I cannot put up with it.
- 6) I the sibling need to be able to express negative feelings toward my brother or sister clearly, the way I would if she or he were not disabled.
- 7) I the sibling demand that my brother or sister have limits and requirements placed on them. They cannot systematically get their own way, be the privileged one, the boss, the fussy one.
- 8) I the sibling want all the brothers and sisters to be treated with more fairness and equality.
- 9) Do I the sibling always have to place myself in a passive position, of endurance and obedience, so I don't lash out at my brother or sister and then feel guilty?
- 10) I the sibling get tired of having to take care of my disabled brother or sister.
- 11) My parents think that since I have no disability, that I am mature, autonomous, and grown up, able to understand and reason, able to take care of and protect by brother or sister.
- 12) I ask my parents not to expect from their non-disabled child what the disabled one cannot give them. I am not here to compensate you for the dissatisfactions that my brother or sister may cause you. I cannot get an A in everything.

We wish to indicate, together with Scelles, Boutheyre, Dayan and Picon (2007), that intervening with siblings in support groups improves their adaptive ability. Behavior problems decrease both at home as well as at school, feelings of loneliness are lessened, and anxiety and guilt also diminish, through working out one's own positioning and a new, personal perspective on the disability.

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APPENDIX 1

Table 4. Negative emotions drawn from 33 interviews with siblings

	1 Con. Ang.	2 Irrit	3 Lone	4 Aggres	5 Care	6 Stress	7 Tired	8 Unease	9 Frustr	10 Resen	11 Guilt	12 Ind	13 Dep	14 Fear	15 Jeal	16 Con	17 Worry	18 Ang	19 Emb	20 Ins	21 Anx	22 Hat	23 Riv	24 Pres		
1 Getting mad / Inhibition and concealed angry feelings	* 10 29														2											
2 Irritability		*																								
3 Loneliness / social isolation			* 4 24 25 29 32																							
4 Aggressiveness				* 13																						
5 Deprivation of parental care					*																					
6 Stress						*																				
7 Tiredness from increased responsibilities / over-protection							* 4 20 13 22 25																			
8 Unease								* 6 7 11 16 18 21 26 30 33							24											
9 Frustration over reduced social or after-school activities									* 7																	
10 Resentment										*																

	1 Con. Ang.	2 Irrit	3 Lone	4 Aggres	5 Care	6 Stress	7 Tired	8 Unease	9 Frustr	10 Resen	11 Guilt	12 Ind	13 Dep	14 Fear	15 Jeal	16 Con	17 Worry	18 Ang	19 Emb	20 Ins	21 Anx	22 Hat	23 Riv	24 Pres
11 Guilt											*													
12 Indifference												*												
13 Depression													*											
14 Fear / angst														*										
15 Jealousy / envy	3														*									
16 Confusion / perplexity																*								
17 Worry														17 33			*			8 13				
18 Anger / Rage																		*	4					
19 Embarrass- ment																			*					
20 Insecurity (lack of self- esteem)																				*				
21 Anxiety																					*			
22 Hate / hostility																						*		
23 Rivalry																							*	
24 Pressure to compensate for the sibling's limitation																								*