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## Siblings of the Mentally Disabled

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## **Abstract**

The objective is to determine the effects that are found in the siblings of intellectually disabled children. Previous studies, have concluded that there are certain effects that intellectually disabled children have on their siblings. The effects that are considered in the paper are stress; anxiety levels, internalizing and externalizing behaviors; how they deal with problems, and lastly self-perception; whether they are mentally stable and confident. Negative effects are going to be the focus of the study, however, there are certain positive effects that are exposed. Levels of warmth and affection are higher when a child has a sibling with a disability. There were various forms of instruments used through the different articles: Personal Information Questionnaire , the Rosenberg Self- Esteem Scale and the Trait Anxiety Scales; Wechsler Intelligence Scale for Children-4<sup>th</sup> Edition, the Vineland Adaptive Behavior Scales, the Sibling Relationship Questionnaire, the Social Skills Rating System-Secondary Level, and the Achenbach Child Behavior Checklist; Semantic Differentials. An interview was also conducted on a single person, who proved the hypothesis of all the articles.



## **Problem Statement**

This literature review will provide insight into the effects that are caused by having a sibling with a mental disability. This means that people who are perceived as “normal” and “healthy” can be affected by the qualities their siblings possess. The studies conducted will help families be aware of what the effects a child with a mentally disability can have on their other children. It’s an important aspect to be aware of in order to be on the lookout of problems arising in the future of said children. If these negative influences are caught early on, action can be taken to prevent the child from developing any disorder. This could help parents look for support groups or professional help before anything occurs. The main point of this research is to aid children from the negative effects that may come from having a brother or sister with a mental illness. If left alone these children could grow up to become anxious, stress ridden, and depressed adults with self-esteem issues which in turn cause even greater problems. Many research papers and personal stories revealed that having a sibling with a mental disability leads people to gain mostly positive aspects. This includes empathy, patience, along other qualities. However, there are more research studies discussing how having a sibling with mental disabilities hinders how parents see the rest of the family especially their other children. In this context, the studies that were used demonstrated children developing both positive and negative mental and emotional states. However, for this review the focus will be negative aspects which can cause difficulties to the child’s mental state.

The main focus of this literature review is to prove that there is a connection between having children with intellectual disabilities and the siblings mental/emotional state. The negative states of mind in these children can lead to depression, anxiety disorders and problems



overall with self-image and stress levels. This will be proved by using personal stories, and studies done using professional tests. Before any study is analyzed the hypothesis is that having a sibling with a mental disability has a negative effect on their brother's or sister's state of mind and of emotion.

### **Personal Statement**

The main reason I wanted to do this study was because I have a sibling with a mental disability. In the past I have battled with panic attacks and had to be taken to a psychologist to receive professional help. I wanted to know if others had gone through anything similar to what I have, or if they have ever felt like they have had any other type of disorder. Even to this day I do not speak to anyone about my problems and tend to hold my emotions in. Because of my newfound knowledge in psychology I am slowly learning that holding back our feelings can lead to various emotional and mental issues. That is why I sought out studies to see if there is a connection between one's emotional state and having a sibling with a mental disability. I want to prove that individuals who have tried to lessen their families burden tend to feel the effects of anxiety, stress, depression and self-image problems.

### **Self-Esteem and Anxiety**

Fatma Saban and Duyhu Arikan wrote the article titled The self-esteem and anxiety of children with and without mentally retarded siblings, which studied the factors of trait anxiety and self-esteem between siblings who had mentally disabled brothers and sibling against those who did not. Trait anxiety means the proneness of experiencing anxiety. This study was conducted in Turkey in 2013. Although, the article is from a different region and culture this could help influence similar studies to be done here in America. The main purpose of this article



is to investigate the self-esteem and anxiety states of children with and without mentally disabled siblings as well as to determine what are the effect factors (Saban 2013).

The study was cross-sectional which looked at children ages 15-18 that have at least one sibling with a mental disability and those with none. There was a total of 108 valid participants whose data was used. In order to gather data, Saban used a Personal Information Questionnaire, the Rosenberg Self-Esteem Scale and the Trait Anxiety Scale. The Personal Information Questionnaire was prepared by the researcher using prior knowledge from literature. This questionnaire consisted of two sections. The first section was comprised of common questions relating to the sociodemographic characteristics of the test subjects and the second section was comprised of questions for only those who had disabled siblings. The Rosenberg Self-Esteem Scale is a four-option Likert-type scale that measures self-esteem in adolescents. The Trait Anxiety Scale is a 20-item, four-point Likert-type scale which measures the anxiety level of an individual. The higher the score, the higher the level of anxiety the individual possesses (Saban 2013).

Overall, there was no significant difference between the two groups studied when comparing age, gender, occupation of the mother and father, and their birth order. The results of the studies demonstrated that children with mentally disabled siblings had high trait anxiety scores and feelings of embarrassment or guilt came into play. However, according to Saban, the statistical difference was not significant enough. Similarly, there was no significant statistical difference between self-esteem scores. The results of anxiety, due to guilt about a sibling's disability, were significantly different between the two study groups. The anxiety level was higher



and self-esteem was lower when taking into consideration experienced issues in society (Saban 2013). In the end, this study had a negative relationship between the two groups.

The negative relationship that was seen in this research can be the start of pervious negligence. The article written by Barbara Bronson Gray, "Siblings of Disabled Kids May Show Emotional Effects," gives an overview of her findings when researching a similar topic. Gray wrote the following quote,

"It's not that parents aren't concerned about their other children, the researchers noted. But exhaustive, time-consuming and sometimes expensive treatments and tasks associated with caring for a child with such challenges can draw attention, energy and resources away from siblings (2013).

Having a sibling with a mental disability may mean that a child will have less attention from the parents and therefore, this means that they will have less resources. Based on prior knowledge it is self-evident that less attention and resources at a young age can cause future problems such as the development of a mental disorder like depression or substance dependence.

### **Behavior**

Gazi Begum and Jan Blacher wrote the article titled the siblings relationship of adolescents with and without intellectual disabilities, which sought to examine the differences between siblings with and without a intellectual disability and how that relationship is impacted. Four different dimensions were looked at throughout this study: warmth, conflict, rivalry, and relative status/power. In regards to warmth, Begum has concluded that the relationships of



siblings, when one is intellectually disabled, is generally more positive than typically sibling relationships (Begum 2011).

The study in this article used a total of five different tests: Weschslet Intelligence Scale for Children-4 th Edition, the Vineland Adaptive Behavior Scales, the Sibling Relationship Questionnaire, the Social Skills Rating System-Secondary Level, and the Achenbach Child Behavior Checklist. The Wechsler Intelligence Scare for Children was used to measure the cognitive ability in ten core subtests and five supplemental subtests. The Vineland Scale assessed the Intellectually disabled group only. This is a semi-structured interview looking at how the children take care of themselves. Here the mothers became informants. The Sibling Questionnaire was a 48-item measure which was also completed by the mothers. The items represented in this test looked into four subscales: warmth, conflict, rivalry, and status/power. The Social Skills rating System-Secondary Level is a 52-item measure about social skills and problem behaviors which the mothers also completed. And lastly the Achenbach Child behavior checklist was given to the mother to complete which consisted of a 113-item questionnaire to identify behavior problem patterns.

The study used participants from a previous larger longitudinal study which looked for the emergence of behavior disorders in children with and without mental disabilities. Because of this Begum had data about the participants at age 3 to the present. The current study involved 70 sibling dyads in which one of the pair was a 12-year old adolescent and the other was the sibling with or without an intellectual disability. A total of three research questions were asked.

The “Research question 1: to what extent do disability status and constellation variables (birth order, target adolescents’ gender, siblings’ gender, or type of dyad) moderate the sibling



relationship quality of warmth, conflict, rivalry, or status/power,” can help further explain some outside variables that could affect the siblings (Begum 2011). The results revealed that there was no significant interaction between disability status, birth order or gender. However, There was a trend between disability status and the target’s gender. For typically developed adolescents, gender did not matter, but for intellectually disabled adolescents, more warmth was shown for boys (.42). Another significant interaction was between disability status and the type of dyad. Mothers reported that typically developed adolescents had more warmth when each sibling was of a different gender. Whereas, mothers of siblings where one had an intellectual disability “reported more warmth for same sex dyads (.21) than opposite sex dyads (-.44)” which demonstrates a variance in warmth of about 9% (Begum 2011). As for rivalry and status/ power variables, there was no significant interaction between disability status and siblings’ gender or type of dyad.

A multiple regression analysis was used to answer, “Research question 2: to what extent do warmth, conflict, rivalry, and status/power relate to behavior problems for adolescents with and without intellectual disabilities?” (Begum 2011). Typically developed adolescents group (TD) had a variance of 23% in predicting total behavior problems by using the level of warmth, conflict, rivalry, and status/power they showed. Collectively the variables could predict the outcome, with the conflict trend being a statistically significant predictor. Another trend was seen when taking into account the effect of rivalry in the Intellectually disabled developed group (ID). Begum research showed hat “23% of the variance in total behavior problems was predicted by the warmth, conflict, rivalry, and status/power”, however collectively they could not predict a significant proportion of the variation. The trend of conflict was once again the main predictor (2011). Both groups had a similar variance.



As for internalizing behavior problems, 22% of the variance could be predicted using a collection of all the variables: warmth, conflict, rivalry, and status/power. Conflict was the most significant variable when predicting internal behavior and there was a trend for rivalry. The ID group had a variance of 9% in internalizing behavior when using the variables as predictors. However, collectively they did not predict the significance of proportion and no one variable was a significant enough predictor. External behavior problems had an 18% variance within the TD group. There was both a collective trend and a conflict trend when taking all other variables out of the equation. The ID group, however, showed a 42% variance in external behavior problems. Collectively the variables predicted the external behavior problems. While there was a trend in status/power, conflict was the significant predictor.

Begum's "Research question 3: to what extent do warmth, conflict, rivalry, and status/power relate to social skills for adolescents with and without intellectual disabilities?" The TD group showed a variance of 10% while the ID group showed 6% variance. None of the variables is an important predictor.

The results demonstrate that those in the TD groups had more of a display of warmth within the sibling relationship when they were of different genders. The ID group showed the opposite, more warmth was displayed within siblings of the same sex. Begum explained that this positive relationship could be due to sibling of children with ID having to partake in caretaking activities that could be uncomfortable with a sibling of the opposite sex. While status/power affected the relationship of the TD group, it showed no affect within the ID group. This can be because unlike how status/power comes with birth order and causes conflict over goods like toys



and whose turn it is to do the chores, siblings of someone with an intellectual disorder do adopt a caretaking attitude.

The results for behavior problems concluded that the TD group has more internalized behavior problems. They saw conflicts at home as being done in a safe environment and it was seen as a way to “[work] them out”. The ID group however resulted in externalizing problems. This could be because they may feel like they have a limited social sphere; parents have enough to worry about. This prediction is made after reading Lawrence Kutner’s 1 article, “When A Sibling Is Disabled,” which gives her findings of what it is like for children to have a mental disabled child. The quote, “But she couldn’t express those feelings directly to her parents. She was healthy; her brother was mentally disabled and had cerebral palsy along other neurological problems,” gives a sense of embarrassment and guilt.

### **Self-image**

The academic study by Graziella Trubia et al., “Siblings’ Perceptions in Autism Spectrum Disorder Compared with Intellectual Disability and Typical Development,” focuses more on the emotional effects toward self-perception. It demonstrates how the healthy sibling views themselves contrary to his or her mentally disabled sibling. This study also studies the differences based on the intellectual's disability severity. The main point is to explore how the siblings of Autism Spectrum Disorder (ASD) and those with intellectual disability (ID) of different degrees view themselves in comparison to typical development siblings. Trubia et al. expects to find a difference in self-perception between siblings of subjects with disability in general and typically developed (TD) siblings.



The study consisted of a total of 93 individuals. 31 of the individuals, who had a mean age of 21, were associated with a sibling with ASD. The next group with a mean age of 23, also had 31 participants who had siblings with ID. The last group of 31 participants has a mean age of 22 and is composed of typically developed siblings. Trubia et al. used two Semantic Differentials (SD) to evaluate the self-image of the three groups as well as the image they have of their siblings. Previous analyses of the SD have confirmed its reliability and factorial validity when measuring self-perception. The SD Trubia et al. used in this study had “36 opposite qualifiers through which participants had to evaluate the Self-image and the image of their brother/sister on a 7-point scale (e.g., strong... weak; calm... agitated; tender... hard; efficient.... inefficient)” (2016). There was a total of three possible factor scores, Energy (E), Positive Affect (A), Emotional stability (S). These scores allow for different dimensions of self-image to be compared to the sibling.

The three factors come from a self-report and a sibling report. Someone with a high score in Energy had “self-confidence and presents him/herself as vivacious, exuberant and attractive for his/her assertiveness and expansiveness” (Trubia 2016). While someone with a low score can be seen as someone who is unsure of themselves with little to no trust. A high score in the factor of Positive Affect can be someone who can be open to showing their feelings and affects. This person can be seen as open minded, sincere, and warm. Low scores can be characterized as being aggressive and self-centered. These people do not like being open about their feelings and affects. Having high levels of Emotional Stability usually means being calm and inner order. However, the lower scores can have someone who is unstable and emotionally disordered.



The results showed that when being evaluated on Emotional stability, siblings of ID persons had significantly higher scores. Whereas, the group of typically developed sibling has a higher Energy level. This means sibling of mentally disabled persons are calmer and TD siblings have more self-confidence. When looking if severity and adjustment levels of the sibling caused any difference in scores, it was revealed that none had any affect.

In the end, this study revealed that individuals with disabled siblings see themselves as equally able to demonstrate emotions as their siblings even when they did see their siblings as less emotionally stable than they were. Also, based off of previous studies, siblings of children with disabilities tend to grow up adopting roles similar to that of a parent. As seen in the article, “The Unplanned Journey,” by Carole Brown, Samara Goodman, and Lisa Kupper, the parents are not the only one's being affected by their child. Brown’s quote, “They may feel jealous, neglected, or rejected as they watch most of their parents’ energy, attention, money, and psychological support flow to the child with special needs,” shows a few of the emotions that can be portrayed (Brown, Goodman, Kupper 2014). This demonstrates that the sibling is always on the lookout and does not really perceive themselves, but does to the people around them.

### **Discussion**

Future research should be narrowed down to only one aspects. Most of the studies in this review had multiple items being taken into account. Most believed that the birth order and gender could change the results. Future studies should get a testing population that is similar and see if the results are still true. Furthermore, looking into what causes the positive aspects to develop in some can help those who develop negative outcomes understand what they need to overcome them. As well as, providing support groups and seeing if children who could be at-risk



can be helped before they develop anything. More studies need to be done in this field to better understand how these siblings can cope with the disability of their family member.

## **Results**

The transcript of the interview has been discarded to keep the participant's privacy rights. To summarize her feelings throughout the interview, I would say she was guilt ridden. Ms. Medina kept on saying such things as, "you're going to think I'm harsh," and "this is going to sound mean." She was able to express similar emotions to that of the studies I found. She felt embarrassed about her brother but she also felt guilty for thinking that. She also expressed anger that her brother can never be like normal males who fall in love and are loved back. Ms. Medina also expressed high anxiety levels, as well as, self-image issues. She has struggled with both panic disorder and bulimia throughout her life. She is currently 68 years old and has had a lot of experience in her. She has also been the only one to take care of her brother all this time. Her levels of warmth toward her brother are high and she took up a parent-like attitude toward her brother.

Similar to many of the research articles I read, she did state that she tried to get attention by expressing her feelings of seeking professional help. However, unlike the personal stories I read she did not express wanting to have a mental disability. The following quote by Carole Brown, Samara Goodman, and Lisa Kupper in *When You Learn that Your Child Has a Disability*, shows an aspect of siblings of special needs children expressing a side of them most did not imagine they could have, and many, many siblings swing back and forth between positive and negative emotions. Helen, age 10, whose sister has severe intellectual disabilities and seizures, begins by saying that she's glad to have a sister with special needs. "It has opened my eyes to a world of



people I never would have known about.” (14) But she also says, “Sometimes I wish I had special needs. I think that a lot when Martha gets oohed and aahed over and nobody even thinks about me.” (15) And then in the next breath, Helen says, “Another thing is that it really makes me mad when kids slap their chest with their hands and go, ‘I’m a retard!’ It made me so mad!” (2014).

Overall, all articles expressed differences in correlation to normal siblings. The correlation however, was not significant enough or impactful enough to really say if there is any big difference. I suggest further studies with bigger populations. The experience at the end was fun and informative. It brought about new questions that I wish to answer sometime in the future.

### **Conclusion**

In most of the article that I found greed that there is a difference between having a healthy sibling and having a mentally disabled sibling. In the end, the reader was able to see that siblings with mentally disabled children tend to have lower levels of self-image, stress levels are higher and they express themselves to external people rather than family members. When doing my own research, I found that the results were similar to the outcomes of the articles. The person I interviewed also showed low self-esteem, high levels of stress, and seemed to want to talk to someone outside of their family. Children with an intellectual disability does affect out emotional state of mind, expressivity of problems and self-perception of their siblings.



## Appendix

### Methodology

I was able to find one person to answer my interview question. The questions I composed were related to the effects I was researching. Most of the questions are real life questions that can tend to happen in their everyday life. Because the person I spoke too was an elder I was able to see the different emotions she portrayed throughout her whole life. She did not wish to share her name at the end of the interview because she felt like her answers were harsh. From personal experience, I tend to hold back information about my sister or my feelings when asked directly, that is why I spoke to her through the phone only until it was time for the interview. The interview went very smoothly and the interviewee still wished to talk more.

For future studies, I would like to have a much larger sample of people to answer my questions. I could also do an online version which can be sent to those who are eligible for the study. This can both help them feel more comfortable and help get me a larger sample. I would also like to try to do a semi-structured interview with a same sample. This means that I will have certain questions that I will ask but if I believe that there is more to ask on a specific section I could stay on that topic for longer. In end, I want to know more about the negative effects, like depression. A new questionnaire can be made to ask about depressive symptoms.



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