

Case Study: The perceived impact growing up with a special needs sibling
has on academic and family expectations, responsibilities
and relationships of a gifted child

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Focus of Inquiry

In the United States, over 5.8 million children have disabilities and most have brothers and sisters. Throughout their lives, the siblings of special needs children will share many of the same concerns that parents of these children experience, as well as issues that are uniquely theirs. These concerns have been documented in research and clinical literature, including: (1) being prone to extremes of behavior such as "acting out" or becoming the "perfect" child; (2) feelings of resentment when the child with special needs becomes the focus of the family's attention (Podeanu-Czehotsky, 1975; Bendor, 1990); (3) perceived pressure to achieve in academics, sports, or behavior (Coleman, 1990) and (4) increased care giving demands (Seligman, 1979).

In the case where the family dynamic is made up of a special needs child and a gifted child, one might presume the above mentioned concerns would be heightened due to the emotional maturity and extraordinary intellect of the gifted child. For example, research has shown that children with a special needs sibling perceive a pressure to achieve. Is this perception exacerbated in gifted children who may already place the bar high for themselves? Which raises the questions: (1) is that level of success attainable? and (2) what happens if they fail? Research also states that unbalanced parental attention exists in families with special needs siblings. Coupling that with a gifted child's own unique educational and emotional needs, which may require large amounts of time, could that prove detrimental to their academic and psycho-social development? Conversely, could being involved with a special needs sibling increase a gifted child's emotional maturity, sense of responsibility, family loyalty and/or academic achievement? The present case study was conducted to investigate the effects of

having a special needs sibling on: (1) parent/child academic and family expectations; (2) sibling relationships; (3) maturation; and (4) the roles and responsibilities of the gifted child.

Furthermore, the study sets to examine how the gifted child perceives these factors might be affected if his sibling did not have special needs.

Methodology

This research was conducted using the case study method to examine the effects of a special needs sibling on a gifted child. This paper discusses the experiences of a White, gifted, high school age male and the perceived impact growing up with a severely developmentally delayed sibling has on academic and family expectations, responsibilities and relationships. Paul Hoban is a 15-year-old junior at Notre Dame High School in Chicago, Illinois and participates in the school's gifted program. The results of this study are based on a one and half hour tape-recorded interview with Paul, as well as an interview with his mother, Kathy. The information gathered was then analyzed and organized into pertinent themes regarding the specific influences on their unique family dynamic.

Results

Background

The Hobans are a middle-class family who live in a quiet neighborhood in Chicago, Illinois. Paul lives with both parents and one younger brother, who is a freshman at Notre Dame High School and participates in the gifted program, and two older brothers, one who is a senior at Notre Dame and is in the gifted program and one brother who is severely developmentally delayed. Paul's father is an electrician and their mother is a stay at home mom.

She tends for Michael, her eldest, once he comes home from school since he requires constant care. When Michael was 8 ½ months old he began seizing in response to his third round of immunizations. This seizure activity caused severe neurological damage, which has left Michael, age 18, functioning at the mental capacity of less than 2 years of age. Doctors could not give conclusive evidence whether or not the reaction to the immunizations could possibly be genetic and as a result the rest of the boys were not immunized. Paul lives in a very structured and organized home, in which both parents and extended family are very involved in the all the boys' schooling and activities.

School Performance and Extracurricular Activities

Paul was recommended and tested for gifted education in first grade and was “double promoted” after his 4th grade year. He consistently scores in the 99th percentile in achievement tests and graduated 8th grade at the top of his class. He currently has a 3.97 GPA and says, “It should be well over a 4.0 after this semester of classes.” He is extremely involved in extracurricular activities such as volleyball and bowling teams, academic bowl, math club, Irish club and Notre Dame Ambassadors. Last year he was the Vice President of Student Council and is involved in religious activities such as, Youth Ministers and Religious Life. When asked about all of his involvement Paul states, “Yea, between me and my two brothers we pretty much run the school.” He admits to “breeze through classes” with very little studying and likes to “goof off” occasionally in classes. He believes he gets a lot of leniency with his behavior that others don't get because of his academic excellence. He recently took his PSAT, in which he thinks he did extremely well and has high hopes for contention as a National Merit Scholar. He aspires to go to law school and eventually become a politician.

Perceptions of Self

Paul describes himself as “smart, funny, outgoing and involved.” He thinks that he is “good at school in general” and that he is a good speaker. He admits he needs to “work on discretion,” because he tends to “open his mouth at the wrong time.” He believes that his strongest attribute is his intelligence because “it’s going to get him (me) somewhere and secure his (my) future.” Paul is the most outgoing of the 4 boys calling himself jokingly, “the black sheep,” because he is less shy and less mature than his other brothers. He gets in more trouble than his other brothers and laughs about being named “most likely to be a truck driver” in his 8th grade yearbook due to a brief period of using profanity. Paul seems to take pride in this individualism and believes he possess unique talents from his brothers.

Sibling Relations

Paul states that he and his brothers all get along. He spends more time with Danny because he is “older and has a car” and when he goes out they are often together. He and his youngest brother Bob spend time playing football with his friends and he often helps him with his homework. When asked about Michael, Paul says he is “fun to be around,” and that they spend a lot of time together after school and on the weekends. He often watches Michael, takes walks outside with him and pushes him on his new bike. He enjoys the fact that the three brothers are at the same high school at the same time. They have taken many of the same

classes with the same teachers and have established a great rapport with them. He believes they are looked up to, and takes pride in being “The Hoban Brothers” at school.

While interviewing his Mother she stated that all four boys are very close to one another. She believes it is a factor of having them so close together and the importance she and Tom place on family “togetherness” that foster this camaraderie. “They have always been the 4 musketeers ever since they were little, where one went, the other 3 followed. They always include Michael, whether it be wheeling him down to the park for a make shift baseball game, or door-to-door trick or treating on Halloween.” She believes their fierce brotherly loyalty has had a positive impact on Michael’s progress as well as the other boys’ level of responsibility to school and to family. She also revealed that Paul and his two brothers that are at the same high school are “ultra competitive” in academics, and at first that worried her. “ Now I see it as a blessing. The competition is a friendly one; they keep each other in check. There is no way one is going to get lax and let the other get ahead. It’s their way to keep themselves motivated and as long as they don’t hurt each others feelings and it is all in fun I think it’s great.”

Parental Expectations & Family Responsibilities

Paul believes that both his parents have high expectations at school and at home. They expect him to “tow the line and follow the rules”. “They always tell me that it doesn’t matter what my grade is as long at I am doing the best that I can. They know that my best will be an A, the lowest a B+, so if they get a progress report and I am not doing that well, then they will get on me, but it really never happens.” They also encourage Paul to be involved with activities that interest him in school because “it will look good on his college applications.” He believes they expect him look out for all his brothers, watch Michael, make moral choices, get his

homework and studying done, do household chores, participate in the family & church and behave well. It is important to note that what consists of watching Michael is extremely atypical from “normal” child sitting. Paul described activities such as, bathing, dressing, physically moving/carrying, feeding, toileting and physical therapy as regular duties. “Since we were little we have always had the responsibility of taking care of each other and Michael, we were expected to be mature, not goof off and take our responsibility seriously and we have. There really wasn’t a choice.” When asked to explain that further Paul went on to explain that “...being a family with Michael means that some choices are made for you. Michael needs to be taken care of and looked after and my Mom can’t do it all the time. We have always been expected from a young age to watch Michael and when we aren’t doing that we are looking after each other. I don’t think that is unfair to ask, but it is not really a choice, it’s a necessity.”

Paul feels that the responsibilities and expectations placed on him are more than that of his peers, but that has never bothered him because the expectations have always been consistent, “whether it is my responsibilities at home or what they expect from me at school it has always been the same, my best, and I respect that.” Paul’s mother Cathy admits that she has always expected a lot from the boys in regards to academics, behavior, minding each other, being leaders and holding high moral values. “The boys have been little adults since childhood, they have had to in our situation.”

Family Balance

“My parents try their best to give us all equal attention”, states Paul when questioned how his parent’s balance each of the boy’s needs. Paul believes that if there is anything he needs he can always ask his parents for help and they will have the time for him. Paul also has

an aunt and grandmother that live close by and are at his home almost every day for at least a brief period of time. Paul is very close to his aunt and uses her as his sounding board for personal issues. He admits that a lot of the attention does go to Michael but that was “completely understandable.” He has never really felt as if he has been slighted with attention or that his educational or personal needs haven’t been met. “I have been on a lot of teams, plays and activities since I was little, we all have, my Mom or Dad have been to 99% of them. They never let us down and really stay on top of what we are doing.”

Kathy admits she and Tom are “fussy to a fault.” They are both extremely organized and would rather “beat something to the ground than forget about it.” They have a calendar in the kitchen with a color-coded system for each boy in order to keep up with all of their schedules, appointments, activities and events. Kathy is an avid volunteer at the boy’s high school and at Michael’s school for the Developmentally Disabled and has been involved in disability advocacy for many years. She thinks that having all four boys has made her become a master organizer of time. “Attention has to be past around when you have 1 child with a disability who requires around the clock supervision and 3 very active gifted children, there is little time for yourself and even less time for self pity. We manage to get it all done at the end of the day. “

Perceptions of Disabilities

Paul believes that he is much more sensitive to other people who have disabilities because of Michael’s special needs. “If Michael wasn’t disabled, I probably wouldn’t notice it as much or have as much compassion as I do now when I see people with disabilities. I would probably ignore it or maybe even make fun of it, as some people do who just don’t understand.”

Paul sees himself as an advocate for people with disabilities and takes his role as a peer mentor and a youth minister seriously because it allows him to reach other kids and educate them. Paul feels he is a better student because of Michael's special needs and the structure of his family. He spends a lot more time at home and therefore reads and studies more than he would if he had free reign to do what we wanted when we wanted. He thinks he wouldn't take school as seriously as he does now and would probably goof off more if the responsibilities he holds were lifted.

He discloses that he has thought what it would be like if Michael was not disabled and thinks that it would make life a lot easier. He thinks that the expectations of him might be less and his parents would definitely be more lenient. He also believes that his responsibilities would decrease because so much of his responsibility revolves around Michael and his brothers. He is quick to point out that he does not begrudge Michael's needs or his responsibility because of those needs. "He is my brother and I will always be here to help him. Yes, it would be easier if he was not disabled, but he is and that is all I have ever known. I love him and I love being with him and the extra responsibility is ok by all of us I think..."

Discussion

Powell and Gallagher state that children with special needs siblings appear to have more positive and fewer negative behavioral interactions than do those with non-disabled siblings. They experience higher levels of empathy and altruism, increased tolerance for differences, increased sense of maturity and responsibility, and academic achievement. (1993). In Paul's case these assertions hold true. His responses throughout the interview as well as his academic performance are consistent to the argument that having a sibling with special needs fosters

maturity, empathy and responsibility, which in turn has affected Paul's academic and social experiences positively.

The nature of the relationships between Paul and his siblings and parents are enhanced by such factors as: (1) a solid family support system; (2) structured parental child-rearing practices; (3) extended family resources; (4) the close age between children in the family; and (4) the interaction patterns that exist within the family. Paul stated throughout the interview how important his family was to him and how integral each of them was in his academic and social successes. Although he feels that his responsibilities and expectations are higher than other kids his age, he is all right having the bar raised to meet those expectations. He is extremely well adjusted and balances his academic and family pressures in stride. His easy demeanor and jovial nature stabilize his academic competitiveness and drive to succeed. Instead of getting caught up in being the best and being "perfect" his maturity and strong sense of who he is and his place in his family keep things in perspective. An example of this perspective is his reaction to entering high school at the top of his class. "I explained to my parents that I was at the top now, but that I might not be once I was in a different academic arena. I stressed to them the importance of my adjustment into high school (since I was younger) and told them that always being number one wasn't as important to me as the feeling of being academically successful." Paul clearly exhibits the gifted characteristics of academic success, positive self-concept and emotional intelligence. In his situation, growing up with a special needs sibling positively impacts these characteristics.

Implications

In Paul's case, growing up with a special needs sibling has positively impacted his academic and social experiences, increased his level of maturity and empathy and broadened his insights on the human condition. However, we would be remiss if we did not take into account all the systems that have been put in place within his family to foster this achievement: (1) Paul lives in a highly structured, highly supportive home with parents and siblings who reinforce him; (2) his parents are extremely organized and try very hard to balance their time; (3) his parents take active roles in Paul's academic and extracurricular activity; (4) Paul has high expectations for himself and is competitive; and (5) Paul's parents hold high expectations for him and have given him responsibilities appropriate for his level of maturity. I purport that the removal of even one of these systems would result in academic underachievement, poor sense of self and possible resentment of the sibling with special needs. While growing up with a special needs sibling has been positive for Paul, does not mean that it would be positive for all gifted children who may be lacking one or more of the systems that Paul's family has put into place.

General recommendations to parents of gifted children and special needs children that may serve to positively affect both children may include:

1. Gifted children are capable of understanding the specifics of the disability and how the disability will affect their sibling over time. Parents need to explain to their children, field questions and give them resources for more information if they wish to investigate further on their own.

2. Parents should discuss how family roles and responsibilities will change and allow their gifted child to take an active part in the brainstorming and problem solving ideas for family solutions.
3. Structure and organization is key in the efforts to balance time between a gifted and special needs child. It may seem overwhelming, but organization and a consistent structure will make it easier on the parents and the children.
4. Parents, other adult family members, and professionals should realize that their gifted child needs special understanding, attention, support and recognition of their unique contributions. Reinforce to your child that he or she's thoughts, ideas, interests and academics are important. Most importantly stress the idea of an open door policy to discuss any issues he or she may be having.
5. Parents should be aware that the gifted sibling might feel obligated to compensate for the child with the disability, to try to make up for that child's limitations. This may manifest itself in perfectionistic tendencies, unrealistic expectations, acting as a surrogate parent or assuming more responsibility than is appropriate. Effectively educating, communicating and reinforcing your gifted child in regards to realistic expectations and responsibilities should greatly reduce these tendencies.

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