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A Mother's Story about Raising Children with Disabilities

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Abstract

The purpose of the study was to understand a mother's perspective about raising children with disabilities. This was a unique case study because the mother was a highly educated advocate in the special education profession and the process was very educational for the researcher. A detailed description of the methodology is provided to encourage new researchers and doctoral candidates to study the area of parental perspectives in special education using participant-observer case studies.

Interview Experience

The interview process was a real eye-opener for me. I found it overwhelming and exciting. Before the first interview I was nervous and unsure about the procedure, and about my ability to conduct an adequate interview. However, most of my anxieties disappeared during the first interview with Diane. We met on campus because it was a convenient site for the both of us. We chose an empty classroom to

sit in. Diane said that she “could talk for hours” because the topic of disabilities was very close to her heart. As the first interview began, it became apparent that Diane indeed was passionate about the topic. She was also very emotional at different times during the interview. At one point she cried, and I was so moved that I cried with her. This incident made us both feel comfortable with each other and Diane did not feel awkward opening up to me after that. I also felt very comfortable during the interview, and the interview seemed more like a conversation between two friends. We had established rapport within the first half-an-hour of the interview.

The questions I asked Diane focused on two different areas. Firstly, I wanted to gather data related to the focus of my study, and secondly, I had a personal interest in some of the issues. For example from the beginning, I was curious if having a child with disabilities affects a parent’s relationship with the other children in the family. When I asked Diane if Laura had affected her relationship with her other children, her answer surprised me, and at the same time provided me with substantial data for my study.

Case Study Participant

Before I delve into Diane’s story I would like to introduce Diane as well as I can. This case study is Diane’s story, and I hope to retell that story in Diane’s voice.

Diane as My Instructor

In the spring of 1997 I enrolled in a class called Families of Children with Handicaps. Diane was the instructor. I had decided to take the class because it is in my area of interest and also because Diane was teaching it. Since Diane and I were enrolled in a course together during a previous semester, during that time I discovered that Diane had a teenage daughter with disabilities. I did not know what the disability was because Diane did not bring it up in the setting of the classroom. Towards the end of the class I found out that Diane was going to teach a class, and I knew that I had to take it. One reason was my interest and the other reason was the way the class would be structured. Diane told me that she had planned to invite a number of parents of children with disabilities, because she wanted the students to understand the plight of these parents by interacting with them and “listening to their stories.”

So, in January 1997, I was one of the fourteen students enrolled in the class. All of the students were in the Special Education Master’s program.

Diane began the class by describing her background. Diane said that her daughter Laura was the reason she had decided to advocate for parents of children with disabilities. “It’s important to me to let teachers know that when a parent comes to a conference table, they’re coming with a lot of history behind them. That has to be considered.”

Diane’s selection of books for the course reflected her feelings about having a child with disabilities. These books dealt with the issue of parents’ plight in dealing with a society that is non-inclusive of the children with disabilities. Her choice of videos also dealt with the idea of inclusion, and how parents have to struggle to advocate for their children. A video titled “Sean’s Story” dealt with a mother’s struggle to give her child the opportunity to be in a regular public school. Shaun had Down’s Syndrome, and his mother had to fight the system to give him a chance to be with regular children. While watching the video, I glanced at Diane who was in tears. It was evident that she knew what the mother was going through.

The class assignments also challenged the students to understand the feelings of parents of children with disabilities. We were asked to locate services that the parents could use for their child. Diane tried

to instill in us a sense of responsibility for parents. She said that as professionals, it was our responsibility to help and empower parents, and become advocates for their child.

Diane as a Peer in the Ph.D. program

Diane and I initially met in a graduate seminar titled Inclusion. This course was designed to give an in-depth picture of what the Inclusion movement is all about. We were instructed to read research showing the pros and cons of the Inclusion philosophy. There were six doctoral students in class and Diane was one of them. Each of had ideas on what Inclusion meant in terms of teaching. However, Diane brought forth a unique perspective. She had been a special educator, and was a parent of a teenager with Cerebral Palsy. While most of us viewed Inclusion only in terms of the classroom, Diane viewed it as a basic human right. She was adamant about her believe that children with disabilities have to be included in all walks of life, beyond the classroom environment. She talked about her struggles with the school system because she want Laura to be in the regular environment with all the other children.

Diane was very approachable both in and out of class. Since she was ahead of me in the Ph.D. program, I was able to learn from her. She was very resourceful when it came to understanding the rights of parents of children with disabilities. I did not hesitate to ask her questions related to the doctoral program, and the issue of Special Education in general.

Description of the Methods

In the following section, I will discuss the procedures I used to conducting this case study research. I will elaborate on the research method, the data collection procedures, the methods of data analysis, the ethical considerations taken, and what methods I employed to ensure the credibility of the findings. The aim of this case study to understand an issue in as much detail as possible. I do not propose to generalize the findings in anyway. However I will address the issue of transferability.

Focus of Study

The focus of my study was to understand what it's like to be a mother who has a child with cerebral palsy. I had no preconceived ideas about this topic because I had little knowledge about cerebral palsy. The daughter was a senior in high school and I had never met her. I know the mother as a fellow student and as an instructor. The mother was teaching a class that dealt with parents of children with disabilities. We had a professional relationship and she was willing to talk about her experiences.

My reasons for working with this mother had to do with her availability and her willingness to share her story.

For the purposes of this study I am using a pseudonym for my participant and all he children, so that she will remain anonymous. She told me that I had her approval and permission to use her real name, however I feel that it is my responsibility to protect her identity.

Interview Questions

In the questions that follow, I intended to collect relevant data about the focus of my study. To understand her feelings, I had to develop open-ended questions to give her the opportunity to describe her story as she saw fit. I wanted to understand what it has been like for her to have a teenage daughter who has disabilities.

My primary objective was to make sure that the mother was comfortable with the interview process and that it was a positive experience for her. Since I did not want her to feel judged by me, I had informed her that I was interviewing her for the purpose of the case study and not for any other reasons.

The interview questions were general in the beginning, but became more focused towards as the conversation progressed.

1. Diane tell me something about all your children.

I wanted Diane to feel relaxed. This question gave her the opportunity to open up and give me some understanding about her family.

2. Diane what is your relationship with your children.

I did not want to start talking about disabilities right away. I wanted her to focus on all her children and in the process talk about her daughter with CP (cerebral palsy). This helped me understand the uniqueness of her relationship with each of her children.

3. Diane tell me something about Laura (daughter with CP)?

This was a direct question. However I did not think that it was out of place since it was a follow up from the previous questions. It is also very open-ended and it let Diane tell me what she chose to. She decided what she wanted to share with me since I was a stranger.

4. Diane I want you to focus on different stages of Laura's life. Describe what impact these different stages had on you?

This question gave Diane an opportunity to open up and describe her situation in detail.

5. What has your role been at each stage of Laura's life?

This was a sensitive question, but it was non-judgmental since all parents play a role in the lives of their children with or without disabilities. Since it was open-ended, Diane was able to elaborate. This question also opened the doors to further questions because it was a broad question.

6. What are your dreams for Laura?

I wanted Diane to share with me what she wanted for Laura. I also got a glimpse of her feeling about what has been like to have a child with disabilities. This question also showed me that her dreams for Laura are the same dreams that Laura has for herself.

7. Diane what advice can you give to parents who are in the same situation as yourself?

This question is designed to let Diane reflect and focus on the needs of others and at the same time share her feelings about her situation.

8. Describe what the prom means to you.

During the first interview Diane mentioned that Laura wanted to attend the prom, and how important that is for her. I wanted to understand the significance of the prom from Diane's perspective, and how it has impacted her.

Ethical Considerations

Several ethical considerations were taken in conducting this case study. I obtained informed consent from Diane before starting the process of collecting data. I approached her with an exact explanation of what I wanted to know and what I was planning to do with the data. I did not want her to feel intimidated about the project. I wanted to help Diane feel like my partner in this study, and therefore I had to show her that I had no set agendas.

I met Diane in the education building for the interviews, and she gave me her official consent to use her first name during class discussions and in writing up the case study. There was some information that she did not want me to share with the class and I strictly followed this. I also told Diane that if she wanted a copy of the case study, I would be more than willing to provide one.

I informed Diane that although I was tape recording the interview, at the end of the data collection process, I would not share the tapes with anyone. I feel that the tapes contain a lot of private information that has to be guarded. I did not use certain sections of the tape because they were not useful for my purposes, and Diane was reluctant to share some of the information about her personal life. I did not make any extra copies of the tapes. I also assured her that I would not share the tapes with the instructor.

Methods of Data Collection

Interviews

Interviews were the primary method of data collection. Four open-ended interviews were conducted to gather the pertinent data. The first interview was used to establish rapport and to answer some basic questions related to Diane's family structure and her relationship with her children. This interview took place in one of the empty offices in the education building.

During the follow up interviews, which were conducted in the education building and the biological sciences building, specific ideas were explored in depth and clarified. These interviews were conversational in style to promote partnership between Diane and myself. The time duration for these interviews was an hour to an hour and a half each.

I audio-taped all the interviews and transcribed them. I took down some notes during each of the interviews, but most of the time, I simply listened to Diane describe her story. Although my questions were open-ended, I asked the same question in different contexts to ensure that the answers I was obtaining were consistent. In doing so, my objective was not to interrogate Diane, but rather check to see if she understood the questions the way I thought she would.

Class Observations

Since I was a student in Diane's class, I was able to take in-depth note in class. I used these notes to gain additional information about my topic, and to develop further questions. The class observations also provided with an opportunity to gather information that gave me further insight about my topic.

During the lecture Diane would talk about certain issues that she had not mentioned during the interview. For example, she mentioned how important inclusion is to parents of children with disabilities. I made a note of her remarks and later approached her for clarification. She desperately wanted her daughter to be included in all the mainstream activities. Diane invited several guest speakers who were parents of children with disabilities. They also mentioned the need for inclusion. Diane used their stories to describe what she had gone through. During follow-up discussions Diane gave the class insights into her feeling about her daughter, and why inclusion was a basic human right of every child with a disability. She compared her own experiences with those of her guest speakers, and thus I was able to relate better to her ideas and feelings.

Articles

Diane also mentioned articles that described her experiences with her daughter Laura. Diane mentioned that the grieving process that parents of children with disability go through is similar to that of those of parents who are mourning the death of a child. It is the death of a normal child. I examined these articles that made this comparison. I sought these documents to corroborate data that I had collected from the interviews. Since I had also completed a literature review before the study, I had a framework to evaluate her responses with.

Analysis of Data

I employed the constant comparative method of qualitative data analysis in analyzing my data. After I transcribed the interviews, I printed out my transcriptions. In the margins of the transcripts, I made single-word notations for the themes that emerged from the transcripts. After I had completed this process I was able to see the emergence of certain key themes.

I saved the original print out of the transcripts. On the computer, I began reading the transcript to find the units. As soon as a unit was identified, I hit the enter key so that each unit would be separate. After all the units were identified, I saved the document and printed it out. Since I had clearly identified units, I simply had to cut them out. I listed the page number of the transcript behind each unit.

As I began grouping units into themes, I started typing the themes on the computer. When all the themes were typed up, I started cutting and pasting the units into the category. I was able to pull up the exact unit from the transcript because I had the page number listed on the back. When all the units fit into the themes, I began reading the new document. If I sensed that some units did not fit adequately into the existing themes, I moved them around. At the end of this process I was able to work on the organization of the case study.

The themes that evolved centered around not only what Diane's relationship is with Laura, and how Laura's disability has affected her, but also around what her relationship is with all her children.

While writing up the case study, I used the themes as the titles for introducing different aspects of Diane's life.

Ensuring Credibility of the Finding

Trustworthiness

Several criteria exist in qualitative research that ensure the credibility of the finding. In qualitative research, standards of trustworthiness have to be adhered to. For this case study I have taken the following measures to ensure that my findings be given serious consideration.

Peer debriefing

Peer debriefing is a term that means inviting others to review and discuss the research as the researcher proceeds along. This method ensures trustworthiness. It helps to build credibility by allowing an informed peer to analyze the questions asked, listen to the researcher's ideas and concerns, and to raise concerns that might arise from the research. I met with three fellow students from class to review the questions that I proposed to ask. We had in-depth conversations in person and over the phone. We discussed my interpretations of the themes that were emerging from the transcripts of the interviews. I met with one student three times outside of our class. With the other two participants I met during class. As a result of collaboration I clarified some of my questions and eliminated some questions that appeared to be leading.

Member checks

In order to present an insider's view, it becomes crucial that the participant agree with the interpretations of the researcher. The interpretations presented need to be verified by the participant. I made a point to retell the different sections of the story before conducting the follow up interviews. I also gave Diane the completed account of our interviews, so that she could make changes where needed. She verified or negated interpretations and conclusions. I made an effort to use as many quotations as possible while telling Diane's story, so that her voice could be heard clearly. After Diane completed her analysis of what I had written, I made the changes that she suggested by rephrasing or rewording certain sections of the case study, and confirmed the changes with her. I emailed the entire case study and Diane had a chance to read it. She told me that I had fairly and accurately represented what it is like to be a parent of a child with disabilities.

Time

There was a prolonged engagement with the respondent. This helped me develop an emic perspective. I was able to establish rapport with Diane because of the time I spent with her during the course of a semester.

Triangulation of Data

Triangulation is a method of increasing the trustworthiness and the credibility of the study. I triangulated my data using interviews, documents, observations, and audio-taping Diane's son during class. He was a guest speaker and he talked about what it has been like for him to be a sibling of a child with disabilities. He made several references to what his mother had to go through because she had a child with a disability. I clarified this information with Diane.

Transferability

Transferability of a qualitative study is dependent on the thick description that the researcher provides. For example, the researcher should try to describe the chosen topic of research in as much detail as possible. The aim is to demonstrate the applicability of the findings from one setting to the next similar setting. The researcher, however, does not state the applicability. Instead through rich, thick description, the reader should be able to see the applicability.

I have attempted to describe my participant and the topic of my case study in detail. Through this, I hope to convey to my readers a sense of what parents of children with disabilities feel. I have covered several aspects of Diane's life that show how she feels, being a mother of a child with disabilities. Her story can be the story of any parent in her situation.

Dependability

Since there is a chance of researcher bias in research, it is important for the researcher to be object during each stage of the research. From the beginning I used outside sources to confirm the truth of what I was learning. I made an effort to stay focused on my topic, by asking questions that were relevant. I also used articles to confirm what I was hearing from Diane. I was an objective listener during the interview, and after the interview, I clarified with Diane what I had understood.

Confirmability

Confirmability deals with the question, "Do the data help confirm the general findings, and lead to the implications?" (Marshall & Rossman, p. 145). I kept all the audio tapes of the interviews, and all the transcripts. The notes that I took during the interview were separate from the actual transcripts. The summaries of all the transcripts were shared with the respondent for confirmation. I also used peer-debriefing as a means of critically evaluating my research questions, and data-analysis. I checked the data (transcripts) several times against my own notes, to make sure that I was not misrepresenting my respondent.

Limitations of Study

There are some limitations to this study. Since Diane was my instructor, and the fact that she was also in the doctoral program made me feel intimidated at times. I was wondering whether I was doing an adequate job of interviewing, and if my questions were as insightful as Diane said they were. I tried to remedy the situation by preparing more carefully for the interview. I made sure that I listened to the tapes of the interviews several times before asking questions. Also, I made a serious effort to ask Diane to let me know if I was doing a poor job.

Although Diane's story can be any parent's study, it is not the story of a minority parent. It is also not a story of a parent from a low socio-economic background. These are some of the limitations. However since having a child with disabilities is a unique challenge for any parent, in some ways this issue transcends the cultural and economic boundaries.

Diane and Her Four "Great" Children

Diane's most defining role is that of a mother. She has a unique bond with each of the children. She told me about each of them with great enthusiasm. The birth of each child was exciting and unique, and brought forth with it new challenges. Diane also discussed her relationship with each of them and what impact they have had on her.

Tom: The Athlete

When I asked Diane to tell me something about her children, she seemed excited and eager to talk. She began her discussion about them by saying that "They are great!" She chose to talk about them in their

birth order, but elaborated on Laura after she had discussed all of them. The discussion began with Tom, her eldest. It was evident during the conversation that she admires Tom immensely. She is extremely proud of his achievements.

Tom is my eldest, and he is twenty. And when he was born he did everything according to the book, and you never worried about any of the milestones. As a matter of fact I thought he was a genius. And I remember going to his three-year conference, and the teacher told me that she always gauged everything by Tom because she thought of him as being sort of normal. And I was just appalled, because I just thought that he was incredible. Anyway. He really taught me a lot about parenting. I had been a teacher for years and years and from him I learned how exciting it was just to watch those different stages and respond to him, and all that stuff.

When I asked Diane to discuss her feelings for Tom, she smiled and said:

Since he is my first born, for some reason there is a hook. And because it is a mom-son thing. They all pull my heart strings, but he can really jerk them! But he was a great kid to raise. He was very athletic, very popular, and so we experienced a lot with his high school, because a lot of our social life was around the things he had done. He is pretty much a star in terms of what he was able to do athletically.

In terms of the current relationship, Diane expressed some concern.

With Tom, hopefully my relationship will be improving. In his last couple of years in high school, he rebelled a lot. And got pretty angry at me. And really rebelled against our life style, parenting and all that kind of stuff. And since he has gone away to college, he turned to the family for support. He struggled a lot in college. Right now that relationship is tentative. Part of what is happening is moving from parent-to-child to more adult-to-adult. And trying to help, and guide, and give the benefit of your experience. But yet not be over parenting.

He is at UCLA, and, although “he got away as far as he could go,” Diane felt that it was very healthy for him.

Oliver: The Entertainer of the Family

Since Laura was born with a disability, Diane decided to wait before having the next baby. They waited quite a while. It was six years after Laura before they had their next child. According to Diane, Oliver was just an “absolute treat.” She said that he was her hardest baby to deliver, and he also had a disability, but it is not as profound as Laura’s. At his birth they were aware that something was wrong, but they did not know what it was. According to Diane, when he was born, his soft spot was big at the top of his head. With a huge smile on her face, Diane recalled what Oliver looked like at birth.

He had this heart-shaped head, and curly red hair. And so he just came out looking like this little imp! And he has sort of maintained those characteristics all along. He is the joker of the family. He is into theater, and that sort of all about what he is.

Diane described her relationship with Oliver as the best relationship. She referred to him as an “open” child who says the most “outrageous things.” For example, Oliver approached Diane to find out what the rules were about having his girl friend in the basement. When Diane asked him what he thought the rules were, he said, “Why don’t you yell downstairs ‘are you having sex?’” Both of us began to laugh and she said that she told him that she was going to be with him in the basement with his girl friend.

He is the one who asks Diane how her day is and how she is feeling. He is twelve years old yet he cuddles up in her lap.

Mary: The Youngest

The fourth baby was born five years after Oliver. Diane did not talk about Mary in great detail. She mentioned with a smile that Mary is “exhausting,” and that she enjoys reading Dr. Seuss.

And that was just wonderful. Mary must have known that she had to come out with a very strong character and she did. From the minute she was born, she has let her presence be known. She screams, she yells, she demands, with hands on her hips and that’s the way she is. But she is delightful.

In terms of her relationship with Mary, Diane felt guilty.

I probably feel the guiltiest about Mary. I am not in synch with the parents of kids that are Mary’s age. I am also at a stage that I am looking at a second career, and I’ve been gone, and so the play group and the swim lessons, and the long bike rides are just not there as much as they were there for the other kids. And so a lot of my relationship with Mary is guilt. It might not be as natural as it was with some of the other kids. There isn’t that sort of a normal routine of hanging around and cooking dinner. But the kids are real close. So you see that when you have families the size of our families. And so she gets the benefit of other experiences that I am not able to give her.

Laura: Committed to Succeed

Laura was born almost two years after Tom and Diane described her birth experience in more detail after she had completed talking about the other siblings. Diane took a deep breath and began her story. She stated that “from her birth on, it was just a very different experience.” Diane was absolutely overwhelmed at having two children, both in diapers. But she was thrilled to have a boy and a girl. When she and her husband were in the recovery room, they cried because it was just so incredible to see a baby that had just been born. She described what had occurred at birth and what life was like after she and the baby came home. Diane described Laura’s birth as “very quick.” “In fact, we barely made to it the hospital. And there was something very scary about that, and I did not know what that was about.” But for a while at least, everything seemed fine. Her APGAR score was between 7 and 8. Diane recalled that there were some reason for concern but “everybody said it was fine.”

With a lot of love and jubilation, the new parents brought their baby girl home. However, at about three or four months, they realized that her development was very different from that of the other children. Her muscular development was very tight on one side, and quite loose on the other side. “But the thing we keyed into the most was that her left hand was fisted all the time, and contracted to her chest. And she had very low affect.” So they went to the doctor and raised these questions.

Finally, at about seven months, Diane went into a panic. The parents decided that they would take things into their own hands, and consult with a neurologist and an orthopedic doctor to see what was going on. Diane made an appointment with the pediatrician to discuss her concerns. When she went in to see him, he gave her a file on Laura. What he had been doing was consulting with a neurologist and an orthopedic through letters. They had diagnosed that Laura had Cerebral Palsy. “And that’s how I found out about her diagnosis. I was alone because we did not know that anything was going to come up in this meeting. I went to a friend of mine, and we both cried.”

This was the beginning of lots of hard work and perseverance for Diane and her husband Dave. As soon as they got that diagnosis they were immediately introduced to the medical system. Laura was hospitalized for about a week. She went through extensive neurological testing, which confirmed the label of Cerebral Palsy. The doctors explained to Diane that Laura had had a stroke during the pregnancy, and that they had never been able to detect it. Nor could they ever give a reason for why it happened. Diane remembered a doctor who was trying to help her, explain that the stroke could have been caused by a sneeze, or a hiccup, or even when Diane had walked up the stairs.

It could have been anything. But the “anything” he said was the stuff I had done. And that was very difficult, because I held the responsibility. There was a lot of guilt thinking about the glass of wine I had had, that I probably shouldn’t have. And the time I went water skiing when I was pregnant. You go back through everything you might have done.

While the parents were grappling with the medical diagnosis, they were also plunged into the educational system. They were told to get Occupational Therapy services, Physical Therapy services, Speech and Language services, and Social Work help. Diane remembered feeling “clueless.” She had never known anybody with a disability, and she had no idea what it meant to have Cerebral Palsy. She remembers vividly the reactions of members of the community. People from her church called her up and told her how sorry they were, and that the disability would impact Laura’s life expectancy. “The way people responded to me was difficult.”

We started into a 0-3 (zero-to-three) program, and it was every single day. I had to drag Tom to Laura’s therapy all the time. And from those therapies you were supposed to do certain things at night. The doctor told us he did not know if she would ever walk or talk. The prognosis that we were given was just horrible. There was this constant struggle to enjoy the baby but then feeling you were not doing enough, and you had to do more. On one hand you would see the kid as a kid. And on the other hand it was medical. It was very confusing.

One of Diane’s strongest memories revolves around a social situation at a park where a woman exercised her freedom of speech!

I remember taking Laura to a park. A mom and a kid came up to me and asked, “what’s wrong with your child?” I said she had Cerebral Palsy. And I really needed to say those things, because I needed to let people know that there was a reason. And I needed that for a long time. But when she heard those words she picked up her child and left the park. So there were things that kept telling me from professionals and community people that having a disability was not acceptable. That it was bad and it was a burden. It was hard, because she was my baby and I wanted to enjoy her. But there were these other messages.

The messages that Diane received from her family ranged from pity to no concern at all. Diane’s mother responded with incredible sympathy. She would get angry at Diane because Diane would push Laura. Laura had a high chair that was crafted for the purposes of therapy. She was supposed to hold on to it for therapy. Sometimes she would cry and the parents would push her to hold on to it some more and for a longer time.

I remember my mom getting real angry at me for pushing her. It was really the poor and pitiful, and “lets take care of her” attitude. And my thing was to get the most of it and it was hard to keep pushing Laura.

Diane's husband's family, on the other hand, reacted as if nothing was wrong, and that Laura was just fine and "we were making this all up, what's our problem. So we had these two responses that were totally different."

Moving on to her current relationship with Laura, Diane expresses some concerns. She worries a great deal about her relationship with Laura for many reasons. She feels that often-times she has had to play the role of teacher.

I don't think that Laura and I have had a chance to just be playful in our relationship. And she is big in teenage stuff right now, and so there is that push pull. You know people say that, before you go away, you dirty the nest. She is rebelling, and there is some of that push pull kind of stuff. One minute she is that little girl, and one minute she is really screaming that I am bugging her and that she is not a baby. So I say that in this relationship I have had to be much more guarded with. Much more distant and even more objective. I think that much of the guardedness is because if I would allow myself sometimes to get so much into it, it would overwhelm me.

There were tears in Diane's eyes, although she tried to laugh it off by reminding me that she had told me that she would cry.

Laura is aware of her mother's sensitivity and she has told Diane that she does not like to tell her things sometime because "you have too much sentiment Mom." Diane admits that she reveals her emotions. Diane realizes that it is hard for Laura sometimes because she feels responsible for "keeping me happy."

It's hard, because she is cautious with me. Sometimes I think that to protect myself in all this is to protect her from feeling like she has to take care of me. I am more guarded in that situation.

The Impact the Disability Has Had on Diane

Attending to the needs of Laura's siblings

I was very anxious to find out if having a child with a disability had impacted Diane's own life in any way. Diane confirmed that it had affected the ways in which she responds to her other children, and the way she feels.

From my perspective, I feel that there have been times when we have had to give more attention to Laura, especially when she was little, and there were so many things we had to do in terms of therapists and doctors. But even as she is growing up, the expectations are clearly different for everyone in the house. There have been times when the kids have complained that Laura doesn't have to do that much.

I was curious to find out how the siblings felt about their mother's treatment of Laura, and whether it had had an impact on them. Diane had only eluded to the feelings of her other children towards her treatment of Laura, and I wanted triangulate her story with that of her other children. Diane had scheduled her eldest son Tom to come and talk to the class about what it has been like to be a sibling of a sister with Cerebral Palsy. I recorded the lecture, and found him to be an amazing person. While talking about his feelings about his sister, he also talked about Diane's treatment of him.

Tom began his discussion by introducing himself and his family, and proceeded to talk about Diane:

I don't exactly remember when I realized that my sister had a disability. I don't remember when I came to the realization that there were things that I can do that she couldn't, or that she was different from me. I don't know that I ever came to that realization entirely.

He proceed to talk about the way he was treated by his family. He said that as a young child he was annoyed when he would have to do more physical work around the house than his sister. He mentioned that his father was “really into chores,” and that Tom would have to mow that lawn in the heat, while Laura had to empty the dishwasher. “It made him really mad.” He said that when he realized that Laura had a difficult time doing physically demanding tasks, he stopped complaining. He also pointed out that he realized how hard his sister worked in school while he “hardly finished his homework.” She would spend four or five hours a day trying to finish her homework, and she would get very angry that he was watching television. “So things balanced out.”

When I asked him if he felt that he was treated unfairly, he said “Not really. Because Laura had to do some things that I didn't have to.” However he voiced one concern: “I wish my parents had told me why Laura did not do certain things. I wish I had known that she had Cerebral Palsy when I was younger.”

Diane had mentioned several time during class that her children had a very solid relationship, and Tom confirmed this by telling the class that he really loves his sister. He also read a letter Laura had written for a project.

My brother influenced me by telling me that I could do a sport even if I had Cerebral Palsy. My brother's name is Tom. He is seventeen years old. Whenever I would try to play a sport, and do it with my left hand, he would encourage me, and not be a kid who would put me down. I liked that, because it would give me a lot of courage. He has changed my life over the years, because he is kind and a wonderful brother, and I won't change him for anyone else. At times he can be mean, but he tries not to hurt me. He tries to make me see if I am doing something right or wrong. He's a cool guy, once you get to know him.

Diane mentioned that she had tried to instill in all her children a sense of responsibility for each other, and after meeting Tom, I think she has been very successful. Diane is also very cautious of the needs of her other children.

I think sometimes I flip the other way. You know Laura could really hang out with Oliver's friends who are in 7th and 8th grade, and I won't let that happen, because I don't want Oliver to feel that he has to take time to entertain, or always be with his sister. So sometimes I think I go the other way. It is a hard balance.

She as a mother wants her children to be responsible for each other on one hand, but on the other hand tries to respect their needs, for privacy and independence.

Diane felt that Laura has had an impact on her siblings because: they felt a need to explain for whatever reason Laura's behavior. They have seen Laura through a fit. By that I mean get out of control and not being able to talk through it and stuff. I know Tom had to and Oliver probably had to defend her in front of his friends.

Diane has also set a high standard for all her children because of how hard Laura has worked. Laura's level of determination is used as an example for the other siblings.

I think that since Laura has such determination, that sometimes my frustration level is higher with Oliver and Tom, who are so capable and when you see them not working to their full potential, in contrast to Laura, who gives it her 150% all the time.

Although Diane admitted to treating all her children differently, she is not apologetic about why she has chosen to do what she does.

Everybody is who they are, and their needs are different at different times. So one kid will get more one time, and another kid will get more another time. It's that way with Christmas presents, it's that way with attention, and it's that way with our time.

When I asked Diane if her treatment of her children would have been any different if Laura did not have a disability, she said:

Maybe. But Laura taught me because of who Laura is. I am more sensitive to it. I want each of my kids to recognize their gifts and use those gifts wisely. Laura has served as a model for me, and as a model for the kids. The impact of having her there has made it more meaningful to them, and to all of us.

The Grieving Process

Several times during the course of the semester, Diane referred to the grieving process. During class she showed the students videos that described the grieving process.

Although Diane made comparisons between herself and other parents who experience this process, she did not describe why she was grieving. I asked her to describe to me what the grieving process has been for her. Diane described it as:

It has been on-going, and there have been different periods where I have been really aware that this is about grief, about acceptance, although I don't like the word acceptance. I don't feel that there is non-acceptance. It's a deeper understanding of what it is like to have a child with a disability.

Her strongest memory of when it really “hit” revolves around a time when she had an exchange student. Diane and her family have exchange students who come yearly, and the family fosters them. They are usually graduate students, but one year they had an eighteen year old girl from Paris. She was “absolutely lovely.” She was there to understand how an American family worked. She would “hang out” with Diane in the kitchen and she would stay up and talk. She wanted to understand what parents’ expectations were in terms of boys and girls and she would talk about her mom and dad. She was also home sick. She spent a lot of time with Diane. “There was something that hit me in that relationship that I think I got very sad realizing that I probably wouldn’t have that kind of a relationship with Laura.” However, Diane, upon reflection concluded:

Now that I have raised two teenagers, I think I never would have had that kind of relationship (laughs), just because she is my daughter. But at that time it really hit me because Laura was about eleven years old, and Tom was twelve. And it hit me that that was what I had lost. I had lost the daughter that would be real connected and would be cognizant enough to ask me all those “what if” kinds of questions, futuristic kinds of questions.

When Laura was younger Diane remembers going past playgrounds and it would “grab” her that “she (Laura) was not part of the group.” “You know that this is not the kind of life she has. She does not have a group of kids that she hangs out with.”

Diane was also grieving the loss of a close friendship that she had with her sister growing up.

The loss was that I grew up with one sister, and the loss was replacing that sister relationship, and that closeness, and looking to Laura as doing that. I think I am more realistic now that I think that some of these things might have happened anyway. But it is exaggerated for me because she does have a disability.

Grieving has been “sort of cyclical.” For Diane it has been more profound at the transitional times like junior high and high school. Also knowing that Laura’s career is not like that of Diane’s or “even close to it, or like that of her brother,” has caused Diane to grieve.

Diane’s Role in Laura’s Life: An Advocate

In Diane's own words, she described what her main role has been in Laura's life:

I think that probably the biggest role that I've had to play has been that of an advocate for making sure that things were on track. We have done it through a couple of ways. We've done it through the school and we've had outside resources to help us help Laura stay in the mainstream as much as possible.

She also stated she would not be getting her doctorate in Special Education if it were not for Laura.

There is that personal side of it too that changes you. When I saw her schooling in a segregated environment, I knew that would not do, and so I got my Master's in Special Education.

Early school years

I asked Diane to describe what it was like for her when Laura began school. After the struggles with the early childhood programs it was time to deal with the public school system. Laura was placed in a Special Education school although she lived in a neighborhood where the school was practically in her backyard. All she would have had to do was walk through her backyard with Diane and arrive at school. However, she could not go to that school. She was bussed for forty-five minutes to the Special Education school, and she was bused with the same kids that were in her class. She was one of two girls, and one of two whites. The other girl was a minority student. Laura went there for three years and had the same teachers for three years. The parents watched their daughter's school experience patiently. She had no social life. The family of the other little girl wanted nothing to do with Laura, and therefore there was no social life after school either. Diane kept looking at Laura's educational experience and comparing it to Tom’s, and it drove Diane "absolutely crazy.”

This awful experience resulted in Diane fighting for her daughter and becoming an advocate for her. She made a commitment to get Laura out of the Special Education, and Diane decided to go back to

school and get her Master's in Special Education. She had always believed that one had to change the system from within.

Changing the system was going to be an uphill battle. Her first encounter with the system set the stage for what Diane had to face later. Since Laura was in the Special Education system, the parents had to call a meeting to discuss their plans for a different placement. The first IEP (Individual Educational Plan) meeting was a nightmare for the parents who were so proud of themselves. They felt that they had experienced what they thought was a horrible school experience. They thought that they had "really done their homework." Without any help from the school system, they went and looked in the district and found the perfect school. They were very excited, because they thought this was the perfect school for Laura.

Their happiness did not stand a chance at the meeting. At the meeting, they requested that Laura be transferred to this school. The reaction of those around them was that of outrage.

It was just horrible. We had the principal tell us that what we were doing was immoral, because what it meant was we would have to change her label from LD (Learning Disabled) to DD (Developmentally Disabled). But we were not going for the label, but for the environment. Even though she was going to be labeled DD she was going to be in a least restrictive environment. We wanted a better educational experience. We were told we were immoral. That we were unethical, and that it was illegal. People were standing up in this meeting and yelling at us.

As terrifying as that experience was, it did not stop Diane from fighting back. Diane and her husband had to threaten a lawsuit to get Laura into that school. Diane was convinced that Laura received the placement in the Special Education school because the school needed a white child, and the fact that she was girl was an added advantage. Recent research confirms Diane's speculations. There is an over representation of minority students in Special Education for several reasons including mislabeling, and sometimes the system is criticized for that.

By the time they were able to get her into the regular school, she was in fourth grade. Diane recalls

How absurd the entire situation was and when you look back on things like that you feel really stupid. We should have known better, but you have professionals telling you that this is the way things should be.

She did conclude that since it was the early 1980's, the idea of inclusion was unheard of, and they were going against the grain.

The Middle School Years

From grades six through eight, Diane felt that she could take a break. The advocacy piece was still present, but the school's philosophy coincided with Diane's philosophy of education. Laura was thoroughly involved in the process of attending IEP meetings and advocating for herself. She gave a presentation in her social studies class, on what it means to have Cerebral Palsy, which was so well presented that the teacher called Diane to congratulate her. Laura was understanding what her rights were and she was taking the initiative in demanding what was rightfully hers. During a school assembly the principal honored all the students who had received A's and B's on their report cards. However he failed to call Laura's name and this prompted Laura to approach him. He told her that since she was a Special Education student, the criterion was different. However in the process of telling her that her A's

and B's were not the same as those of students in a regular setting, he realized how absurd his explanation was. And so Laura and the principal changed the school policy. As a Special Education teacher in Chicago Public Schools, I could relate to this experience. On my first day at my job, I was told the I could not give my students A's or B's, or F's. When I questioned my supervisor, she told me that my students were not performing at the same level as their peers, and therefore all they could get was a C or a D. I was not allowed to give out F's because I cannot retain Special Education students. Diane described these middle school years as a "time where I could sit back and watch."

The High School Years

Although the educational setting was under control for Laura, the social arena presented problems in high school. Diane found it difficult to see that Laura did not have a social life. Because of the lack of social opportunities available to Laura, another role that Diane had to play was that of a social network coordinator. The parents have created a social network around Laura, and a lot of it has been with the church. Diane and her family are extensively involved with their church, and, through this involvement Laura has been able to get in touch with young adults. Many of the connections she has made are with the young adults in the church or youth group leaders who are in their early twenties. Also, Diane has always presented a picture of success to of Laura by giving her the opportunity to meet successful individuals who have disabilities.

To facilitate the process of socialization further, birthday parties have been family parties. For example, Laura's sixteenth birthday party was a huge bash. Her parents and other family members made an elaborate album for Laura and everybody gave Laura advice. The family transformed the birthday into a ceremonial occasion.

Diane credits Tom for playing the biggest role in Laura's life. When he was in high school and as popular as he was, he brought "tons of friends around and since he was older he was sort of able to see what was going on." He included her in everything. But since he has been gone for three years, that network of friends has disappeared. Laura tried to pull some of Oliver's friends and that has been hard for Oliver. Laura invited Oliver's girlfriend to go shopping and she agreed to. However that made Oliver upset because he wanted to be with her. Diane expressed her concerns by telling me that:

Whenever Oliver's friends are there Laura is there. Sometimes it really isn't appropriate because Laura is a teenager and is very hormonal. She does not have a boy friend and wants one more than anything in the world. She talks a lot about boys and what she would do if she had a boyfriend. And it is not appropriate around these seventh and eighth graders. That has been that hardest thing to watch.

Attending the Prom

Diane began talking about the prom by saying that "more than anything right now she wants to go to prom." Both Mom and daughter have gone out and looked at dresses. But Laura does not have a date. Laura has compiled a list of three or four people whom she would like to invite. They are Tom's friends. And Diane is "so afraid that they will say no, and watching her go through that is real painful."

Since I grew up in a culture that did not create the pressure about having a date for the prom, I was curious to find out what the prom meant for Diane. Since I went to an all girls high school, I looked forward to having a huge girls' party. Since we hated our principal, we had our own graduation

ceremony without her. However after listening to Diane describe the significance of the prom, I realized how painful it was for her to watch Laura not get that opportunity.

According to Diane, the prom is the culmination of the senior year of high school. There is the sense of getting over the hurdle of high school. Teenagers go a little crazy, and they drive their parents crazy worrying about them for a night. Diane sat back in her chair, and with a smile described the purpose of the prom.

It is sort of the rite of passage. It is the biggest dance that they really have. And they make it sort of spectacular. The date becomes important because people usually go with a date. Sometimes a group of kids go together but Laura does not have that group.

There was also a personal aspect of the prom that Diane described. She wants Laura to share the same positive experiences that Diane had growing up.

What it has brought out for me is how prom was for me, and how special it was, and all the activities, and the guy that I went with. I mean all the stuff that she doesn't have. So that sense of loss is there.

Dreams for the Future

College

Diane told me in her first interview that “the doctor told us that Laura was never going to walk or talk, but now Laura is going to college. I never dreamed that Laura would ever go to college.” This is a big moment in Diane’s life.

And probably the most important thing in the world is that she is going to college. We are so excited. We applied to ten places. What we have basically gone for has been the environment. We had some good experiences and we had some bad experiences. Our first experience was really horrible.

Diane described the first experience in detail. She pointed out with pride that Laura’s resilience beams through in that experience. The family drove up to Milwaukee to see a small Christian school that had an LD program. Diane had a very frank discussion with Laura about what kind of program Laura wanted to pursue. Laura said she wanted to try for the next level of programming which demands a 90 IQ. Since this is what Laura decided she wanted, Diane wanted nothing less. They were welcomed and taken around the college. They talked to the dean of education because Diane wanted to be very frank. She did not want to set Laura up for failure. After the tour of the campus they went back to the main office. The admissions officer asked Laura if she had a good time. She asked Diane if she would like to talk to the a financial aid officer. Everything seemed to be going as planned until the admissions officer turned to Laura and said “We will not even consider your application.” She went on to say:

I want you to know that you did the right thing by coming here, and we are so glad you came up here, but given your grades and the classes you have taken we are not even going to consider your application.

Laura was shocked but kept her composure. However Diane who has “too much sentiment” started crying. While telling me this story Diane started to laugh and she said:

But to show you Laura's resilience, we were getting out the door and Laura said "that's the rudest thing that anyone has ever done," and we both started to laugh. That is who Laura is. She has been hit with a lot of crap all her life. She has been to places where she hasn't been accepted because of who she is. Yet she has this determination and persistence.

Independent Living

I asked her what she expects for Laura, and she said that her goals for Laura were Laura's goals for herself. Laura desires what we all do. She wants a family of her own, a loving spouse, a home, and a career. Laura wants to be an aide in an early childhood center. She has worked very hard, although school has not been easy for her. She is determined to do what she wants to do.

Well it's what Laura wants to do. She wants to live in an apartment by herself or with a roommate. She wants to be an early childhood aide in a classroom. She definitely wants to be married. She wants to have kids. She clearly sees herself as a Mom. I think she sees herself living close to family. She wants to be part of a church. And if those are things that Laura wants, I want her to have those things. Those are my expectations for her as well.

Diane added that she wants to make sure that Laura is safe, and that she doesn't get into a vulnerable situation. She wants to place her in situations where her strengths can be enhanced. Diane sees her role as "working frameworks around her, so that she can do what she wants to do." She has "had an impact on an incredible amount of people, and people have rallied behind her wanting to help her reach her goal." Diane informed me that Laura just got a summer job. She described what "frameworks" she and her husband had to build to help Laura reach her goal.

In order for her to get that job, we had to make a grid for her. She wanted to work at a summer camp. We broke it down to the name of the camp, the contact person, the phone number, follow up and a what happened column. When she sort of had the structure, and we listed all the things that needed to be done, she kept walking through, we provided that structure that allowed her to get the job. She sent resumes.

Diane does not see those structures being removed, and she feels that Laura will always need someone to check on her financial situation on a regular basis. Diane and her family hope to help Laura figure out what supports Laura needs in order to reach those goals that she has set for herself. Diane firmly believes that Laura can be independent the framework of structures that the family provides.

Socialization

Socialization has been an area of ongoing concern for Diane. In the future, Diane wants to create "some sort of social life around her." She pointed out that it is easier to create a social life for young children. But as the child gets older, the job gets tougher. Diane has some ideas on how she plans to create the social structure for Laura.

Maybe that's being part of a volunteer group or something. Maybe being well-connected to a young single group at church. But I see us as figuring out resources for her to be able to plug into. So we are sort of this net. But they wouldn't be things that she would initially instigate on her own.

Conclusion

The struggles that have arisen from having a child with a disability have clearly impacted Diane. However Laura is not a burden on Diane. There are changes that she has had to make, but having any child changes a parent's life. Diane wants all her children to succeed and Laura is no exception. She admires her daughter and credits her for giving her a focus in life. Diane knows that Laura will succeed in life because of her determination and a strong desire to succeed. Diane's admiration for and awe of Laura were evident in her voice:

I admire her incredibly (started to cry and so did I). She has been very clear about what she wants in life. I am learning a lot from her. The doctor told me she would never walk or talk and then she walked. She did things much slower than everyone else but I was so surprised. You don't have to predetermine anything. She will let you know. Just watch.

Laura has taught Diane how profound ordinary life is. Diane considers herself to be Laura's student. Laura has taught her about people and human relationships, and how important it is to include all sorts of people. Laura has been able to instill in Diane the value of relationships. For Diane, life is "really about relationships and about supporting one another, and I don't think without Laura I would have learned as much about myself." Having Laura has made Diane look at people differently. She has the need to "get to know people better and in a different way, than I might not have otherwise had."

In conclusion, Diane believes that Laura has changed her life in many ways.

I don't know if I would have taken the time to do some things had it not been for Laura. I know that there is much more than meets the eye. And clearly Laura is the catalyst for why I am doing what I am doing.

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