Documenting the Experience: Creating a Non-Fiction Film as a Resource for Siblings and Parents of Autistic Children

A Senior Project submitted in partial fulfillment of the requirements for the Bachelor of Science Degree in Psychology

By

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Winter Quarter, 2010

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Chapter 1

Introduction

Autism is on the rise. As a result more and more parents and siblings will have begun to live with a relative with autism. Disorders such as Autism and Asperger's exist on a scale. Because this serves a range of other disorders for the purposes of this paper any person referred to as having been diagnosed with a disorder on the scale will be referred to as having an ASD. According to the Diagnostic and Statistical Manual of Mental disorders (DSM-IV-TR 2000):

> An autistic disorder is characterized by the presence of markedly abnormal or impaired development in social interaction, communication and a markedly restricted repertoire of interests. Some behavioral symptoms may include hyperactivity, short attention span, impulsivity, aggressiveness and self injurious behaviors. There may be odd responses to sensory stimuli such as high threshold for pain or oversensitivity to sights, sounds, touch, light exposure and odors. Abnormalities in diet, sleep and fear response may also be present. (p.70-75).

According to the Center for Disease Control and Prevention the latest data, collected in 2006, has indicated that 1 in 110 children have an autism spectrum disorder. The growing prevalence of this disorder presents an obvious challenge for both educators, doctors, counselors and others in the field of psychology who are still in the process of identifying the exact causes

of the disorder. At the same time the approaches necessary for care of a child with an ASD is just as important for the both the child and families future. The focus of the research and science on the children who are diagnosed with an ASD has extreme significance and therefore should have a large priority as the field continues to look for new and evasive techniques to treat autism. However, in the face of this growing disease the family unit can often get little attention. This can especially be the case in the wake of a recent diagnosis where the introduction of a child with an ASD can drastically change the family dynamic. For both the parents and siblings adjustments must be made. Although the resources for families are becoming larger with non-profit organizations, and school programs it has become evident there should be a resource available to these families and the public which highlights what types of interactions are shared between the parents and siblings of children with autism.

In the spring of 2009 I set into motion the proper means of creating a 20-30 minute documentary film highlighting the dynamics and interactions of family members of a child on the autism spectrum, through video recorded interview. The purpose of this film is to both cinematically and educationally present the lives and interactions of these families who have multiple children who are both typically developing and children who have been diagnosed with an ASD. This Senior Project will provide an in depth look into why the film may be an important resource for families. In addition, this Senior Project will present the proper instructions for making a documentary film as a student while also providing my personal method and experiences during the course of creating my documentary film. Chapter two will examine the current research regarding parents and siblings interactions with an autistic child. The chapter will also discuss the current research on the psychological and emotional states of

such family members. Chapter three will discuss the role of non-fiction film in education and the use of new media to raise autism awareness. Chapter four outlines the steps necessary for making and producing a film from a college student's perspective. Chapter five expands on the method of documentary film and conducting interviews with families and educators in the field of autism. Chapter six discusses the ethical issues surrounding documentary film and controversial subjects in autism research/history. Finally, chapter seven will re-examine some of the noted topics in the previous chapters while also providing my personal thoughts on my experiences making the film, and the film's future.

Chapter 2

Effects of Autism on Sibling and Parent Relationships

Considering the types of symptoms of an ASD I set out to document family experiences through interview of the parents and siblings. Studies have attempted to investigate this topic. One goal of the study done by Altiere and Kluge (2008) was to "compare mothers and fathers ratings on cohesion, adaptability, satisfaction with family functioning, family coping mechanisms and perception of social support" (p. 89). According to the results of the study there was no significant difference in the level of rating by either parent for family coping mechanisms, cohesion, adaptability or satisfaction with family functioning. However, there was a significant difference in the level of perceived social support where "mothers perceived significantly more social support from family and friends." (Altiere and Kluge 2008, p. 89). Differences in perception may play an important role in the family dynamic. If fathers perceive less social support than it could affect how they cope with the possible concerns surrounding a child with an ASD.

Siblings also play an important role in the family dynamic, the amount of play between the parents and children and the siblings themselves may be a large factor in the family units overall functioning during childhood. It is heavily noted in the research that play is an important means through which children develop social skills and interact with other children. (Swindells and Stagnitti 2006). Due to the social deficits autism creates in young children the typical form

or amount of play parent's show with their children may be greatly altered. Dissimilarities in play were brought to light in a study conducted by El-Ghoroury and Romanczyk (1999). After observing families on three different occasions in their home, researchers found that play behaviors from parents were exhibited towards children with an ASD more frequently. These results do not come at too much of a surprise especially in autism where social interaction is difficult for the child to initiate. However, this does invoke discussion about the child who is "typically" developing. How much does this child notice that his/her parents are exhibiting more play behavior towards their sibling? In the presence of this disability parents seems to make greater efforts to interact with that particular child. Also interesting in the study, however, is the level of initiated interaction by the "typically" developing child towards their autistic sibling. The study indicates that "siblings do not appear to be compensating for the children's disabilities" (El-Ghoroury and Romanczyk 1999, p. 256). In other words, the typically developing siblings overall, did not initiate nearly the same amount of play towards their autistic sibling, treating their autistic sibling as though they did not have any type of disability. This dynamic resulted in children who were autistic to exhibit a higher amount of vocal-verbal initiations towards typically developing siblings, than towards their parents (El-Ghoroury and Romanczyk 1999). Other studies have confirmed that autistic children with typically developing siblings have more and improved social interaction. Such is the case found in (Knott, Lewis & Williams 2007) who concluded that a child's "ability to engage in collaborative interaction appears to be uniquely enhanced by the role reciprocity inherent in the sibling relationship (p.1994). Differences in interaction between parent and their child were also found in the El-Ghoroury and Romanczyk's 1999 study. According to the results, children with autism made a

greater amount of vocal-verbal initiations towards their fathers than towards their mothers. All of these factors may impact family functioning in multiple ways. For a child with an ASD, having a sibling may come as an advantage in their development however, there is no doubt that autism still creates difficulties in interaction between family members. Other stressful factors become present considering the amount of time and care required for a child with a disability.

Stress is most likely existent in all families and especially families with children. "Caring for a child with Autism Spectrum Disorders (ASD) is demanding and presents significant challenges to parents…" (Phetrasuwan and Miles 2009, p.157). When autism first began to gain attention, parents and particularly mothers were heavily scrutinized and led to believe they were at fault for their child's condition. The baseless scrutiny for which these mothers and parents had to endure was coupled with the fact that "raising a child with an ASD can result in significant psychological distress for many parents" (Benson and Karlof 2008, p. 358). Although it may seem like common sense that these parents are experiencing a family life which is stressful, there are a limited number of studies on the families and particularly the parent's mental health. Because such research is lacking this would undoubtedly affect parents currently raising children with autism who have not been provided with enough study and information about their experiences. Furthermore, future parents of children with an ASD may not be able to fully grasp the similarity in experience they share with other parents. Those similarities may well be the concerns they have for their child. These concerns are the top sources of stress reported by parents such as "challenging and anti-social behaviors, concern for the future, education, attaining support and services, and understanding their child's needs" (Tehee, Honan and Hevey 2008, p. 40). These concerns are especially pertinent to parents whose

toddlers and young children are, for the first time, being diagnosed with an ASD. Given the unique challenges inherent in raising a child with an ASD, in particular during the time surrounding diagnosis, it is not surprising that many mothers and fathers of recently diagnosed toddlers evidence high levels of stress (Davis and Carter 2008). For these parents it is critical that they are given something which can validate their feelings and emotions as they raise a child who is in some or many areas developmentally delayed. Although any new parent may make attempts to educate themselves on a disorder in their child, their access to peer reviewed articles and databases is most likely limited. Not to mention the fact that their time, above all, is limited. Providing parents with information may improve their access to support services, hence improving their ability to cope and effectively reduce stress levels (Tehee, Honan and Hevey 2008).

Keeping with topic of stress, siblings like parents, can also be left out of the conversation when it comes to autism. The psychological health of typically developing siblings of children with an ASD is a little researched subject. Caring for a developmentally challenged child creates expectations and obligations that involve most family members, including that child's siblings (Schuntermann 2007). The expectations a sibling may face can vary depending on their age. Parents may insist or in many cases need their child who is typically developing to help with their older or younger sibling with autism. In some cases although the typically developing child may be younger in age, they may be developmentally more mature when compared to their sibling. Thus they may begin to take the role of an older brother or sister. Undoubtedly, for these siblings', experiences in and outside the home differ far from other children who do not have a brother or sister with a disability. This is not to say that typically developing siblings of autistic

children are not in good psychological and emotional health. Some research findings suggest that most of the siblings of children with autism are "reasonably well adjusted both behaviorally and socially when they have a sibling who has autism" (Pilowsky et al. 2004, p. 861). The addition of a child with a disability, specifically autism, may be a factor in creating greater resiliency and positive characteristics. In a study conducted by Macks and Reeve (2007), typically developing siblings of autistic children were more likely to have a positive view of their behavior, scholastic performance, intelligence and overall personal characteristics when compared to siblings of non-disabled children. It seems that although these siblings are going through hardships at home they have been able to behaviorally and socially adjust which is admirable considering the stressors involved in having a sibling with autism.

Unfortunately, a wide range of stressors and hardships can be placed upon siblings when their brother or sister is diagnosed with a disability that may require constant supervision and money. According Dyke, Mulroy & Leonard (2009), these constraints can greatly limit spontaneous and planned recreational opportunities and "normal" family outings. As a typically developing child grows older these constraints may create a negative effect which may explain why results on studies of siblings are mixed. Other studies have indicated that some siblings of children with autism showed "increased behavior problems compared to typically developing children" (Schuntermann 2007, p. 99). In research conducted by Ross and Cuskelly (2006), children and adolescent siblings of an autistic brother or sister were noted to have several behavior problems. In the study, findings were consistent with others such as, "Gold (1993), who noted clinical levels of depression in adolescent siblings of children with autism, and with Fisman and colleagues (1996, 2000), who identified significantly higher levels of internalizing

and externalizing behavior problems in siblings of children with a Pervasive Developmental Disorder (ASD) over a 3-year period" (p. 83). Mixed results on the findings of typically developing siblings and parents of children with autism point to the need for more research but more importantly an immediate resource for these family members where their experiences can be related to. The creation of resource which highlights their individual family experiences may validate their emotional feelings and also shed more light on the psychological and emotional state of the parents, siblings and family as a unit.

Chapter 3

Film & Media as a Teaching Tool

The world of psychology and autism is dominated by research and experimentation. Although a documentary film is uncharacteristic of more formal psychological methodology, nonetheless I believe non fiction film can be used effectively in educating and presenting psychological issues, creating a resource for families. After viewing many documentaries on various subjects and having a considerable background in digital media and film I felt that using film to highlight a subject which has been relatively unnoticed could do a great amount of good for autism awareness and families who have recently begun to live with a child who has an ASD. Students entering family service careers and counseling could also be given a glimpse into the lives of these families.

As technology advances both inside and outside the classroom it has become increasingly more common that forms of digital medium are being used as a teaching tool. This film will

have a large element of educational value which I believe all nonfiction films are striving for. Short documentary films such as "A Class Divided," in which a teacher attempts to conduct an experiment with her grade school children have become famous for being used as a window into psychological subjects. The teacher suggests to her class that certain physical characteristics (eye color) make one child better than the other. Due to the teacher's suggestions, "blue eyed students experience responses ranging from incredulity, self-conscious amusement, sense of futility and sometimes rage" (Infinito 2003, p. 69). This film is now shown in introductory psychology and sociology classes across the country to highlight how segregated institutions and feelings of superiority may come to exist in society. Without going into further detail the film also suggests how easily stereotypes and labels can be made or reversed through manipulation by those in authority positions. This film has been shown in two different curriculum classes I have taken at Cal Poly. Short film specials are not the only tools which are being used for educational purposes. The internet and portable digital media has become a huge contributor to awareness on certain world and medical issues, including autism. This can be seen on organization websites such as autismspeaks.org (official website of Autism Speaks Inc.) which contains a video glossary for "parents, family members and educators highlighting subtle differences between typical and delayed development" (ASD video glossary 2005-2010). Even major Hollywood films such as, "Rain Man," and low budget documentaries have featured autism as a theme or subject impacting autism awareness. Interestingly enough, in two of the interviews I conducted parents claimed that upon learning of their child's diagnosis the only frame of reference they had for autism was the movie "Rain Man" (United Artists 1988). The movie "Rain Man" is the story of two brothers one of whom is an autistic savant the other, played by

Tom Cruise, is a typically developing man. An autistic savant has "exceptional skills in some normative context (i.e. calendar counting, massive memory recall capability), but is accompanied by a severe broad intellect deficit" (Miller 1999, p.1). In this film Hoffman portrays his character as having many of the archetypal traits of autism showing lack of social awareness, limited verbal communication and in some cases self harm from over stimulation. In both interviews parents used the example of this film as both their lack of knowledge in autism and to highlight the fears they had for their child. In many ways the character in "Rain Man" has accuracy considering he was based off of a meeting between the film's screenwriter Barry Morrow and Kim Peek. Kim Peek is an autistic savant well known for having skills of phenomenal memory. (Treffert and Christensen 2005). However, it should also be made clear that Hoffman's portrayal is not what every parent is dealing with in terms of a child with an ASD. It should also be stated that the film can lead the audience member to falsely assume certain characteristics are present in all children and families living with an ASD. The movie "Rain Man" may have led many audience members to believe that all people with autism or an ASD may have some type of savant trait. However, this is not the case; about one in 10 people of the autistic community come to show savant characteristics (Treffert D. A. 2004). However, it does point to how powerful the film medium can be in terms of influence. As I filmed and directed my non-fiction film I had to be constantly aware of how each testimonial in the film may influence the audience because of the film possibly being presented in an educational capacity to other families. As I have interviewed seven families and two professional educators the theme of vaccination has made itself present in several interviews. Later in this paper I will

discuss in detail this occurrence in my interviews, how it may affect the film and the controversy surrounding the subject.

Chapter 4

The Student Documentarian

"At its very simplest, cinema verite (documentary film) might be defined as a filming method employing hand-held cameras and live, synchronous sound. This description is incomplete, however, in that it emphasizes technology at the expense of filmmaking philosophy" (Mamber 1974, p. 1).

I believe it is always in the best interest of the filmmaker do a comprehensive amount of research on the particular subject before they start to film, especially when making a documentary. In a film such as this it was important to know and understand what past research

has come to discover about the particular population being filmed. Novels, biographies and memoirs about families with autistic children were and can be a great resource to understand the experiences of these families. Doing a thorough amount of background research on your subject may allow you to improvise during filming, maximizing the amount of footage you capture.

Beginning and Planning the Film

Making any type of film first and foremost requires planning. In this particular instance, when making a documentary, planning is crucial because you are trying to work around peoples schedules that are volunteers. There is no monetary, tangible or any other financial gain for the participants. You are at the mercy of their schedule and when you are trying to film multiple interviews, especially when those interviews call for an entire family which may include young children, organization and scheduling must be an essential component of your process. A documentary film such as mine is using a population whose children in many cases require a special service. Considering my film's subject falls into such a category I began to contact an Autism Spectrum Center located in a close by area. Finding these organizations are not very difficult, the internet and faculty should be enough to get into contact with at least one organization involved in any film's subject. In my case I was informed of a special event/fundraiser for autism being arranged by the organization I wanted to work with. At this event I began to speak with one of their Chief Executive Officer's. Introducing yourself early on to those who are crucial in helping you make your film is very important. This took place approximately 9 months prior to any filmed interview which is why I think it made it much easier to get back into contact with her, discussing more in detail my project. Once she agreed that she would help me in contacting families the entire film process truly began.

The method used for contacting families/clients was by using a general email/advertisement, through the organizations database, explaining who I was and the general details of the film. Using this method allowed for every family who wanted to participate to contact me through email. I was then able to gain a list of all those who wanted to participate along with their contact information. Subsequently, I contacted each family who replied to the advertisement and began to schedule interviews. All of the participants were made aware of the film's subject and that prior to any filming they would have to sign a release agreement form. The release forms for this particular film were created by using a template of another documentary film release form. The forms are designed first and foremost to protect the filmmaker from any participant attempting to own any rights of the film. Each family member over the age of eighteen who participated in the film signed this form. Parents of any participant under eighteen signed the form giving legal consent. Though there were questions from parents about where exactly the film would be shown and to whom, I never had a parent or family member unwilling to sign the form. There was one minor who stated she did not want to participate and subsequently the parental guardian did not sign the release form. However, this was one isolated instance and while each family member began to read over and sign each form I began to set up film equipment for their interview which was filmed in their place of residence.

Film Equipment

As a student, expensive film equipment is not usually something we often have, but some equipment is necessary when making a documentary. Some universities, such as Cal Poly do not have a film program and equipment can be scarce. Although resources may be limited the beauty of non-fiction film is that production cost of the film is, if anything, not an important part

of your film. However, film equipment is available at Cal Poly University's media services. There are two locations for media services, building 10 Agriculture and building 2 Education, one of which, (Bldg 2) usually houses more of the larger equipment. Tripods, DV (digital video) camcorders, hard drive camcorders, lighting kits, and microphone recording systems are all available and were all used in the making of my film.

Style & Non-Fiction Film Aesthetics

In some cases, use of the aforementioned equipment was for stylistic reasons. Often it is thought that aesthetics are not involved in documentary film. Most people's idea of documentary film is an approach in which the director finds people, confronts them with a camera crew and begins to ask questions. Such style seems to be more journalistic and in many ways realistic. The hand-held and shaky movement of the camera creates the effect of realism and factual experience. However, there is still the question of whether or not what is being filmed is actual truth. Does the simple fact that there is a camcorder in front of someone make them act differently? The answers to such a question could be argued for yes and no, but this is not the real issue. If you are to make a documentary the question of whether presenting actual truth is something you will have to move past or else you will never have a film. The priority should be about presenting what you have filmed in any way possible. Once I accepted the possibility that the presence of the camera may or may not influence how people will react when I filmed, then I was able to ask the more important questions and concerns. Namely: How do I want the people in my film to be portrayed? This is also something you will have to decide for yourself, but the ability and resources for different emotional and aesthetic portrayals do exist. One of the main types of tools for aesthetic portrayal is lighting. Interviews in documentary are

much more controlled and create the ability to greatly influence the environment because it allows for the use of enhanced sound and artificial light.

Lighting

Because interviews are the bulk of my particular, film lighting and arrangement of the environment greatly influenced the emotional and cinematic presence portrayed in the film. Though I am not advocating that in a film such as mine any person be portrayed as dark, evil or devious there is the possibility that lightning can be used to portray a certain emotion or experience as dark. In situations such as these back lighting is what would typically be used. Backlighting is when one or two lights are place right behind or behind on both sides of the interviewee (Rabiger 1998). This posture of the lighting literally makes the interviewee a darker image on the camera. Less light is being placed on their face and body thus a less bright image of the interviewee is seen by the audience. Lighting is a very useful tool which in some ways can be used as narration of the emotional experiences in the film. In general for my interviews I used what is called frontal lighting. In frontal lighting the light is placed near the camera, shining light on the entire participant. This technique "throws all shadows backward out of the cameras view." (Rabiger 1998, p.88). I used this technique for two reasons. The first being that lighting equipment, especially the lights I was given, are large, hot, and take time to set-up whenever they are moved. Thus the lights were rarely moved throughout the interview. The second and more important reason was for the footage captured on camera. These interviews were designed to give families a chance to tell their story and subsequently I wanted everything recorded by the camera to be illuminated. Whenever I was shooting inside, light was often scarce and participants became very dim in the film footage. I did not want for there to be any

harsh or dark shadows which may or may not have made the participants hard to see. The brightness of the room and families were something I wanted to highlight and although the content would be able to portray it, sometimes I literally needed light to brighten up the shot. Ultimately, the audience needs to see what is happening.

The Camera

For the audience it may always seem that one camera is doing all the work. For my film I did not have a budget, crew or access to several cameras. But during the interviews I conducted I used two video cameras. One camera was placed directly on front of each participant, the other in a particular location in the room filming the interview from a different angle. Once again it is important to mention that these interviews were done solely by me. During each interview I had to be aware of each camera and what exactly it may or may not have been filming. It may seem odd that I had another camera on a tripod in some other location during the interview; however, upon looking over the footage it becomes apparent how useful two cameras can be. In many cases during each interview parents had to leave or were interrupted by their children. Obviously during these times I especially wanted to get footage of how they interacted with their child. As I could not leave the other parent to go and film, the camera which was set up at a distance often was able to capture certain moments between the parent and child. Even though I had never moved from my chair and I was still conducting the interview with one parent I was able to get footage of a parent-child interaction without stopping the interview. In several occasions I was also able to film sibling interaction which took place in front of the camera which was placed in an obscure area. Even though all family members were aware of each camera it was often the

camera which was not placed directly in front of them that they often forgot about and subsequently interacted in front of.

Using more than one camera also has its aesthetic applications as well. Presenting different angles during the film may make keep it from becoming monotonous or repetitive showing more than the same perspective (as far as the camera is concerned) in every interview. At the same time I had to consider the interviewees as well. It would be hard for them to keep their concentration on, me the interviewer, and the questions if in front of them was a camera operator constantly moving around a camera in order to capture footage of varying angles. Using multiple cameras allowed for the ability get more than one angle of a single shot without destroying the integrity or composure of the interview/interaction.

Chapter 5

The Art of the Interview

As a filmmaker, I wanted to have as much knowledge as possible about the type of families I was interviewing. However, I also wanted to enter any type filming session with an open mind. Each family and subsequently each interview needs to be treated with a sense of novelty, because the fact is, regardless of the family's situation, all families are different and as a filmmaker and especially as an interviewer you must be able to improvise with various questions as to completely capture the spectrum of thoughts and behaviors exhibited by each family and

family member. In other words, no documentary filmmaker should assume what is going to happen or what people are going to say during filming. Such a mindset might make you miss or not ask something which could be crucial to the film. However, you are still bound to miss something in the process as I have in many interviews. There are countless times when I should have kept the camera rolling, or asked one more question. This is the nature of the process. You will not get everything on film, but you have to make the most of what is captured.

Knowing what needs to be captured starts long before any footage is taken. It starts with the questions you plan to ask. All of these questions in some way should be meaningful either for their possible answer or the questions which may arise later. The questioning which takes place in each interview is not always for the film itself, sometimes it is for the participant. Many of the questions which naturally occur in the interviews are a guide to help the participant tell their entire story. Each question must relate to the individual in some capacity as well as their personal story.

Interviewing Families

Even though I did tailor questions towards the participants during the interview, prior to the interview I sent a sequence of the same 9 questions through email to each family. These questions, as I explained to the families, were designed to give them an idea about the subject of the interview and the depth of questioning I would use. The questions ranged from "At what age was one of your children diagnosed with autism?" to "What is a typical day for you and your family?" I also sent the questions prior to the interview as a method of creating some comfort for the families who, prior to meeting with me, expressed their uneasiness about doing an

interview without having thought out the answers to the questions before being on camera. However, even when asked questions, which were specific to the family and were not in the prior given sequence of questions, families appeared to have little trouble in answering.

Interviewing Professionals/Educators in the Field of Autism

Although the focus of this film is primarily on families themselves, I feel it pertinent to include professionals and educators in the field of psychology and autism. These are also people who have had much experience in dealing with families similar to those I interviewed. Interviewing professionals and educators not only gives another perspective on what the families are dealing with, but can also enhance the message to the audience. It helps show that although many of the family interviews are edited, and subjective to that particular family's viewpoint, professionals in the field can help validate the stories which are told by each family. Using an academic or professional interview is a way to show that your film is not just conjecture. For audience members and families who see the film I think it is important they see people in the film who are similar to them, but it is equally important for them to see someone who is experienced and educated in the field of autism. These types of academic interviews were conducted much differently than those which involved families in that there was not much question improvisation during the interview. The questions were sent prior to filming and for the most part were the only questions asked. These interviews were not designed to get their particular views on autism or families, but to present a general feeling among professionals about autism and the experiences of autistic children's parents and siblings. Presenting both the views of the families as well as professionals and educators in the field presents a more broad and inclusive view on the subject of the film.

Chapter 6

Ethics

"One of the core free speech principles specifies what is the only acceptable justification for limiting expression. The core of this principle is that speech may be suppressed only if it would inevitably cause danger." (Strossen 1998 pg. 53)

As mentioned earlier in this paper the theme of vaccinations came about in parent testimonials. Several parents firmly believed that after showing normal signs of development,

once their child was vaccinated, they suddenly changed showing odd behaviors and delayed development. Other parents mentioned vaccinations as a possible cause, yet were clear that they felt the cause was irrelevant to their family and that their focus was on their child's future, in the context of development and societal assimilation.

Controversial Issues: The Vaccination and Autism

Vaccinations and regressive autism has been an intriguing subject among the science and research community for the past few years. Childhood vaccinations are administered as early as possible to assure that infants are protected against diseases that occur in early childhood (Miller and Reynolds 2009). Vaccines have been one of the major breakthroughs in medicine, saving a catastrophic number of lives. To date vaccines have been created to fight a number of diseases including measles, mumps, rubella, chickenpox, pertussis, diphtheria and tetanus (Miller and Reynolds 2009). For the few parents who did mention vaccinations as the probable cause, in their opinion, it was not necessarily due to any particular vaccination or the vaccination itself, but from the combination of vaccinations. Much of the controversy regarding vaccines and regressive autism has focused on the MMR (measles, mumps, and rubella vaccine). Numerous studies and cross cultural research have discounted the MMR vaccine and a possible link to regressive autism ever since a relationship was suggested by Wakefield et al. (1998) (Uchiyama, Kurosawa and Inaba 2006). However, even with the current research parents still seem to be fearful of vaccinations for their child especially multiple vaccinations in a short period of time. At the present time vaccination programs offer vaccinations for nine different diseases (Hilton and Hunt 2006). For many parents the fears of overloading the immune system from multiple vaccinations have continued as autism diagnosis and awareness has risen. At this point in time

the science is heavily weighted towards vaccines, especially the MMR vaccine, not playing a role in the onset of autism symptoms. This was the finding of Richler et al. 2006, in the study 351 children with ASD (163 autistic regression, 188 no autistic regression) and 31 typically developing children were analyzed through parent interview and documented vaccination. It was concluded the experiment "provides no evidence that regressive autism is associated with MMR vaccination" (p 313). Such research has to be considered when making the film.

Because the film is designed to present the families story the subject of vaccines raises an interesting question for me and other student documentarians. Though the research does not support the views of these parents, should this still be presented in the film, knowing it could potentially influence a viewer? This question can only be answered by the filmmaker. It is the filmmakers' and will ultimately be my decision to edit certain information which could be seen as false or misleading. As a filmmaker you must make sure that the film highlights a family member's own experiences and thoughts, but not let anyone's personal agenda become a focus. As mentioned earlier this film is not about the cause of ASD or how best to treat an ASD. The film is about families who are going through a taxing and unique experience and ultimately my hope is for that theme to be what the viewer leaves with. In order to do this it is my feeling that a filmmaker similar to a researcher must always remain ethical and honest to the film's purpose not necessarily the audiences or in this case the participants wants. Instances such as the one just mentioned did not make me stop recording or stop the interview. As a filmmaker I chose to remain objective and make sure that no matter what the participant began discussing, it was captured on tape. You must be ethical in how you choose to present the subject, but this does not mean that a controversial issue should not be recorded or presented in a film. Ultimately, the

filmmaker has artistic freedom of expression. However, artistic freedom should always remain moral and should not be used in excess.

Protecting the Film Participant

Each family who participates in the interview has willingly accepted that their stories may be edited in any type of form for cinematic use. However, as both a student and filmmaker you must not abuse this right and the family's willingness to participate. It may seem like an obvious comment or suggestion, but I do believe one must constantly remind themselves why they are making their film and how each individual in the film must be portrayed. This is particularly pertinent to films such as mine which involve minors from a very young age (from 4 to 19 years of age) Children at any point in time may say a number of things. The important thing to be aware of is when a child is saying something they don't mean rather than something they mean but don't fully understand. For example, I conducted one interview with a seven year old girl. Her brother, aged ten, had been diagnosed with both Down syndrome and autism. Her brother's speech was non-existent, the extent of his communication being only as she said, *"babbling."* When asked about how her brothers absent speech affected her she replied by saying, "*it's sometimes like I don't have a brother even though I do."* The point of this excerpt is not to highlight the resonating emotional power of the statement, but rather to examine what purpose the statement may play in the film. She is well aware that she has a brother and the description of how she feels indicates her inner struggle. She is attempting to understand and characterize her experiences. The statement however, can be construed as her saying she feels as though she does not have a brother. This is not the case; her characterization is only a reflection of her young development and language skill, her inability to not yet accurately describe the

experience of sometimes being “lonely”. But, it must be clear that she does in fact mean what she says. Her description has no mal-intent and therefore is something which should be used in the film in order to highlight an emotional experience a child in a similar situation may be going through. Her inability to use words like “loneliness” should not discount the statement or keep the original statement out of the film. One must hope and assume that her testimonial is not misconstrued as saying a sibling with autism is like not having a sibling. She was very clear throughout the interview how much she “cares” and “loves” her brother. Those accounts should also be in the film to give the full spectrum of her feelings.

Chapter 7

Conclusion.

All families deserve the chance to tell their story. However, the growing prevalence of autism and its affects on the family give the film a large priority. It is obvious from the research and the interviews I conducted over the past three months that both parents and siblings of children with an ASD are going through a unique experience and need as much support as possible. It is my hope that this documentary film can provide some support and be used as a resource for these families. Unlike certain Hollywood films accurate accounts of autism, its characteristics and the families of people living with an ASD need to be made aware to the public. This film will hopefully join a multitude of other non-fiction films which have attempted to document both autism and how the family dynamic has changed in attempting to adjust to the disorder present in a child. However, this film can not join others until it is made. The final step in the completion of the film is the editing process, which I have yet to finish. Within the coming months I will review every hour of footage and begin to edit the footage into a final 20-30 minute film. Though the editing process will undoubtedly be taxing I believe I have completed the hardest part of the project, which was to actually organize and conduct each interview.

There was a point during the making of this film when I did not think it was ever going to happen. All of the effort and preparation I had put into the making of the film seemed as if it was going to waste. However, this did not happen. Every interview and piece of footage I got was the result of persistence belief and support of the faculty who have supported me throughout this whole process, mainly Dr. Laura Freberg and Dr. Mary Garcia-Lemus. Without these two I would have no footage and therefore no film for which I am looking to finish in the near future. However, I must stress that this also took a lot of my own hard work, planning and dedication.

At one point I was conducting four different interviews with families and professionals in the San Jose area in one weekend. If there is one thing I can say about making a film as a student it is that you must decide early on that you want to make it and once you make the decision do not hold or look back, continue as if you had no choice and you will be satisfied when you are done. The final product of this film is still prospective and there is a long process ahead in terms of actually finishing the film. Yet, I am confident it will be finished and soon seen by the people who were apart of it.

As mentioned earlier more and more projects like this are using film as a medium to reach families, educators and the public. Though documentary film is hard to make, especially by oneself, it is worth the time and energy once completed. I know this because every family, after I conducted their interview, told me how much they were appreciative of the project, stressing the need for such a film and the possible resource it may be for other families. Even in the three interviews which became deeply emotional, accompanied by tears from the parents, I was met with the same comments once the interview was finished. The comments of these families are what keep me motivated to finish the film and possibly continue as a documentarian, highlighting other psychological issues present in today's society.

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