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Discontent and Activism Among Mothers Who Blog While Raising Children with Autism Spectrum Disorders

The purpose of this ongoing study is to identify and classify expectations, feelings, and perceptions of mothers who blogged about their experience as primary caregivers of children with autism spectrum disorders (ASDs). What emerged is a subset of data that included expressions of discontent directed at educational, health and social institutions. These challenges emerged as expressions of discontent, reactions from structures of domination in their attempt to sustain the imbalance, and reactions of activism among the mothers. Discontent emerged in mothers when school staff assigned them to restricted social roles which stigmatized them as disease causing agents. The mothers interpretation of professional reactions to maternal resistance varied from welcoming input to enforcing a top-down power imbalance weighted toward professionals and marked with mother blame. These mothers shaped social reform through their activism designed to address their collective discontent in order to bring about transformations that match mothers ideal systems. The mothering experiences of the women whose blogs were analyzed for this study provide an insight into the nature of the "other world" they seek and into their attempts to bring about that world on behalf of their child.

A child with disabilities can have a tremendous impact on the dynamics of a family. This is especially the case when the child's disability is characterized as autistic. According to the *Diagnostic and Statistical Manual of Mental Disorders* (APA, 1994) children with autism spectrum disorders (ASDs) typically display impairments in the following areas: social interaction; communication; behavior; sensory perception; and cognition. There is great variability in symptoms from child to child. Some children may show severe impairments, like repetitive or stereotyped behavior, with considerable ability in another area, like com-

munication (O'Brien, 2007). These traits are usually not understood by the community at large and the behaviors can embarrass parents. The Centers for Disease Control estimates that at least 300,000 children had been diagnosed with ASD in the United States as of 2004 (National Center on Birth Defects and Developmental Disabilities, 2007) and epidemiological studies of the prevalence of autism in Canada indicate that roughly 190,000 Canadians have an ASD (Fombonne, 2003).

The history of raising a child with ASD in the United States is not a pleasant one. The label "refrigerator mothers" was coined in the 1950s to describe the mothers of children with ASD. The prevailing theory at that time was that the mother's lack of affection and bonding was the cause of the disorder therefore, children were best served by removing them from their mothers (Orsmond, Seltzer, Greenberg and Krauss, 2006). This stigma-based theory is most often attributed to Bruno Bettelheim whose studies at the University of Chicago shaped professional and public opinions (Laidler, 2004). Carol Thomas (2007) identified this phenomenon as "disablism," which she defined as "the prejudicial attitudes of others and the failure to provide appropriate assistance." Thomas was referring to mothers with disabilities, but this phenomenon can be easily extended to mothers raising children with ASD since the refrigerator mother label marks their recent social history in the United States and its associated disease causing stigma. The stigma remains despite the fact that the theory of mothers' lack of affection causing childhood autism was disproved by the 1980s. While not as blatantly defined as in the refrigerator mother era, mother blame continues to be prevalent among professionals who work with ASD. The more passive form of mother blame that exists today is consistent with Paula Caplan's (2007) conceptualization of the phenomena as assuming the mother to be responsible for her child's problems. The focus of this article is the experience of mothers raising children with ASD as expressed through their web logs. We are particularly interested in their feelings of discontent, or negative reactions to educationalist school-centric controls, their own actions of resistance, the reactions of professionals, and other forms of mother activism.

Despite the disapproval of the refrigerator mother theory, blame, and alienation of these mothers remains in the United States. Theories that examined blame and alienation of mothers emerged in the earlier feminist literature by theorists like Chawla (1987). Chawla (1987) theorized that oppression of mothers is highest in societies where mother-child unit is viewed as the smallest social unit and where mothers are isolated in the mother-child dyad. She postulates that modern society negates mothers because they are isolated and restricted to social positions consistent with mother-child dyads rather than viewing mothers as independently functioning individuals. Thus as individuals, mothers' discontent emerges along with their assignment to social positions which restrict their equality and freedom. If we were to apply Chawla's (1987) theses to mothers raising children with ASD, we might consider that their social stigma as "refrigerator mothers" reflected a classification as disease causing,

therefore delegating them to an even greater inferior social positioning than that of typical mother-child dyads. Therefore, their discontent may be greater than that of typical mothers, as their position in the social order was more restrictive and lacking in basic equality and freedoms.

Extending the discontented mother thesis further can be helpful for understanding their reactions to the professional paradigm confronted by mothers who raise children with ASD. Thomas (2007) discussed the concerns of disabled mothers who perceived professional helpers as not helpful when assistance is delivered within the paradigm of "professionals know best" despite the desires of mothers. She identified the theme of help rejection, which emerged when conditions existed that professionals overrode mother requests; instead directing services to patient management strategies. The result is imbalances of power between mothers and professionals. This "professional knows best" paradigm parallels the experience of mothers raising children with ASD and is a source of anxiety for mothers and a cause of conflict between professionals and mothers (Boyd, 2002).

These anxieties are confounded by an atmosphere of blame and stigmatization that continues to alienate mothers from treatment and school professionals. Expressions of discontent may be problematic when mothers attempt to engage social systems in redistributing imbalances. Their response may be one of active engagement with social systems to restructure the balance of power to support their mother-child dyad. Frost (2001) extended the argument of discontent in her critique of three essays on maternalism by Clapp, Van Waters, and Freedman. Her thesis suggests that mothers shape social reform through their activism designed to address their collective discontent. In other words, her argument moved beyond Chawla (1987) and Thomas (2007) to suggest that mothers respond with activism to discontent, such as that resulting from social stigma and disabilism. Thus, activism is directed at bringing about transformation of social systems when mothers are limited to oppressive social roles or when they find the system threatens their mother-child dyads (Freudenschuss, 2007).

While there is a growing amount of literature on parents raising children with ASD, much of it examines parents from the point of view of professionals. This article seeks to move beyond a top-down, school-centric paradigm in which schools make decisions regarding who gets what services and how the money follows those decisions. Parents, from the school-centric perspective, must either submit to school authority or they are deemed noncompliant.

That point of view is not presented here. Rather the perspective presented is from the point of view of the mothers. We seek to present a parent-centric view in which the parent holds the schools accountable for delivering services their children are legally entitled to. From the parent-centric perspective, we assumed that insight about how mothers interpret their world would explain, in part, their interactions with professionals. Further, we assumed that such an understanding might help begin to bridge the gap between professionals and

parents and might help professionals develop effective partnerships. Therefore, as the parent-centric paradigm emerges, the educationalist paradigm, which forces distinctions between compliant and noncompliant parents, may become obsolete.

The limited amount of research that examined the mothers' of children with ASD point of view consisted largely of essays written by parents (Qualls, 1997; Maurice, Mannion, Letso and Perry, 2001; Hill, 2002). While that information is useful, we seek to build knowledge from combining multiple interpretations to form a collective meaning. We build on Stoner and Angell (2006) who studied how mothers perceived their relationships with school professionals by adding insight into these mothers' experiences of their relationships and their social environments. We also extend the research of Huws and her colleagues (2001) that found that mothers of children with ASD seek virtual support to help adjust to complicated roles and technical and medical information.

Method

Research Team

Feminist educational researchers, like Patti Lather (2001), Alice Pitt and Deborah Britzman (2003) discuss the tensions inherent in the relationships between researchers and research participants, which surface as researchers seek to expand knowledge to make room for alternative meanings. Among the sources of tensions is the researchers' commitment to their own point of view, shaped by their experiences, which influences their interpretation of data. These tensions exist in the nature of this study, as the primary researcher is also a parent to a young adult who lives with a mild form of ASD. Her family experience includes solo parenting an adopted daughter who was diagnosed with a mild form of ASD approximately 20 years ago. These insights lead to the initiation of the larger study that attempts to add parent voices to policy and program decisions.

In order to create accountability to the voices of the mothers whose journals were included in this analysis, the research team included two people with varying experiences who shared a commitment to present the mothers' experiences from their own perspective. One of the collaborators is a university faculty member and a long-time friend of the principle investigator. Her background is in special education advocacy and educational policy. Over the years, she has supported the principle investigator as an advocate, advisor, and now as a research collaborator. The graduate assistant studied and worked with the principle investigator over four years while she completed her doctoral studies in rehabilitation. She emerged as a leader on the research team on this article by advancing the model, coordinating the analysis, and presenting the initial findings at conferences. Their perspectives and contributions provided balance to that of the principle investigator, and moved the interpretation from the personal toward authenticity.

Sample

We identified single-authored blogs through the Google blog search and livejournalsearch engines. After identifying blogs, we applied our criteria for selection. First, the blogs had to contain eighteen months of existing data (January 2006 through July 2007), with a minimum of one entry per month. We used 18 months of data to examine narratives written over time to capture expressions of ongoing struggles and successes, providing deep meaning to the mothers' stories. Second, the blog authors had to be raising a child diagnosed with ASD. Finally, writers had to focus on their personal experience. We examined over 100 public blogs. The final data set contained all 24 blogs that fit the criteria for inclusion.

Data

We created the analysis file by selecting the reflective statements that examined personal experiences that related to parenting children with ASD. We eliminated statements that we classified as intellectual property, political or social commentary, news articles, advertisements for events on autism, updates on the child without reflection, pictures or graphics, and updates about other members of the family unrelated to the theme of the study. The remaining statements were coded by author and date.

Analysis

These journal entries were printed as text, coded, then sorted using qualitative content analysis to identify emerging themes. Researchers used constant comparative procedures for analyzing qualitative data, which were adopted from Corbin and Strauss (2007) and Miles and Huberman (1994). In order to reduce levels of bias that influence the interpretations of the findings, the researchers integrated Denzin's theories of triangulation by using multiple investigators in the analysis process (Denzin, 2003). The researchers adopted a verification process to assure that there was agreement on the themes by having the two primary investigators analyze the data independently and then compare their findings and reconcile any differences in interpretation. These findings represent their consensus. The findings discuss each theme with corresponding participant quotes that represent the participants' collective insight in their own words. We named the themes discontent, organizational reactions, and activism, and defined them similar to the concepts examined earlier.

Discontent: For discontent, we based our definition on Chawla's (1987) thesis that discontent emerges in mothers because of their restricted social roles that stigmatize them as disease-causing agents.

Organizational reactions: We examined the mothers' interpretation of professional reactions to maternal resistance, from welcoming maternal input to responding with resistance or enforcing a power imbalance weighted toward professionals. The latter reflects the version of mother-blame identi-

fied by Caplan (2007) which attributed perceived deficiencies in the child to inadequacies in mothering.

Activism: We conceptualized activism similar to Frost's theses in which she suggests that mothers shape social reform through their activism designed to address their collective discontent in order to bring about transformations that match mothers ideal systems, as argued by Magdalena Freudenschuss (2007).

Findings

Overall mothers expressed commitment to their children and concerns for their well-being when they integrate into society. They expressed specific fears about the lack of understanding about ASD's that professionals and supporters demonstrated. One mother described this as a frustration that "not everyone is caught up with you" on the latest research or on their child's abilities and needs.

They presented complex views of their place in the world. However, these perspectives appeared to be interwoven with a thread of displacement from others yet with a unique sense of togetherness within the family. One mother wrote this theme as, "That's what a special needs child does to a parent. You climb mountains. Together." Another mother's expression of this theme identified the displacement as being similar to living a dream in which she also feels periods of disconnect from her child as his symptoms cycle. She wrote,

I'm beginning to feel that I am living in a dream—a nightmare—and surely must waken quite soon. I find myself in a strange new world in which I have a son with a strange disability which most people haven't heard of and definitely don't understand and my son isn't sure who's on his side and whoever and whenever and wherever ... one day is up and one day is down except 'down' means not living in my world and 'up' may not mean much more, other than the fact that he is trying to live in my world and meet me in some no man's land between his brain and mine. Who knows what really goes on in his mind. One day I'm his friend, the next I'm someone who never believes him, someone he cannot trust.

They expressed specific conflict with their experience of their relationships with their children and the expectations for those relationships by friends, family, and professionals. One mother referred to this as "living life as others expect us to" and associated this with the source of duress. Another mother wrote this theme in her statement that "we feel like pawns in someone else's game and I'm amazed we've stuck it out so long." She was referring to her ongoing conflicts with schools over services her child required and what she perceived as the school's resistance to provide adequate care.

Maternal Discontent

The theme of maternal discontent emerged as parents reported frustration at finding themselves subordinate to workers who perceive them as “cases.” This theme emerged in journals written when mothers refuted professional care provider’s “expertise” and replaced professional knowledge with intimate knowledge when they defined expertise. One mother explained the difference:

Where does a parent go then, when faced with such a tremendous mountain to climb, that of caring for a child with a disability or illness, when hope seems so distant? Who will be there in the dead of the night when you are alone with your child, faced with dark fears of the future? What will happen to your child? What can you expect now that your new role in life is so drastically different than it was what you expected it to be? What will happen to you now? Are you spiritually, physically and mentally up to the incredible demands of caring for a child with special needs? I know these questions well. I know the feeling of not wanting to get out of bed in the morning as you wake to an avalanche of the day’s tasks and responsibilities overpowering your thoughts before your feet even hit the floor. I know the feeling of blood on your lips as you bite back the tears, holding your precious child’s hand as your dreams of “what could have been” fade away into the dim future.

The theme of discontent was also grounded in a context where mothers found themselves in situations where they believed decisions about their child’s care are made independent of parent or child needs or choices. One mother described her relationship with the schools as being similar to being in jail, “I feel as though we are in ‘time jail’ where the walls were made of school schedules and bus schedules and other people’s agendas for us and our child.”

The theme of maternal discontent also emerged in cases where there were gaps between the services the mother believed her child needed and the services the child was offered. Some of these decisions were experienced as counterintuitive to the mothers, especially when professionals fail to connect their child’s behaviors to symptoms of their conditions. One mother was told that the staff at her child’s school district did not want to continue to provide intensive classroom support for her child. Their position was that his behavior was manageable and therefore not autism. Further, they suggested that disruptive behaviors could be managed if he avoided situations that provoked outbursts. She voiced her anger and explained her perspective in this comment,

What situations cannot be avoided? What skills are needed to get [my child] through these situations? My school personnel are saying he cannot tantrum and be in an inclusion setting. This is bull crap. His classroom may need a paraprofessional to watch for antecedents and help the teacher with teaching coping skills, but these meltdowns are not normal. They are

not intentional. They are part of a disability that should be accommodated, and when he is accommodated properly, they won't happen.

One mother expressed this theme after finding out that the school district cut special education services for children with higher functioning ASDs. Of her reaction she wrote, “I almost couldn’t catch my breath. I wasn’t yelling, I was more in shock. There was a silence.” This theme of discontent was evident across the journals as mothers interacted with professionals. The theme emerged as mothers compared their realities with circumstances that did not mirror their desires for abundant aid delivered by school and community service systems.

Perhaps an issue underlying the theme of maternal discontent was expressed by one mother as “taking the humanity” of her child. Her words were echoed in other journals that challenged the professional paradigm that examined behaviors as adaptive or pathological. Thus, mothers and others considered the professional paradigm as a prejudice that condemned parents and takes away the humanity of the autistic person.

Organizational Reactions

The mothers’ actions were often met with reactions by systems that fostered hostile relationships. The theme of organizational reaction emerged as mothers tried to pressure resistant schools into providing services. Often mothers found that pressure did not enhance the working relationship. One mother spoke about a heated interaction that arose over notes passed between the home and school in the daily logs. She wrote,

They didn't look at what we'd written to discover what they could learn from it, e.g., my son is intelligent and understands what's going on in the classroom. No, they just assumed something negative and personal. They complain that their staff member feels 'criticized, vulnerable, and beleaguered'. But that's what son feels every moment of every day! But if teachers can't come from a place of 'hope' and conviction that things will get better, we will succeed, and we will find the solutions from within, then what message is that giving our children?

The theme also emerged as mothers rejected what they perceived as blaming their disabled children for their learning or behavioral problems. One mother who was trying to convince the district to provide services for her child used federal laws in the United States to argue that failure to provide needed services was a violation of federal laws regarding disability. She perceived the school staff as shifting their reaction to blame her child. She wrote,

They said he is not increasing his time in blended (he is in self-contained) because of staffing issues—no available staff.... When I asked an IEP meet-

ing to increase the amount of time that he'll be spending, I get this surprise email from a member of his team, saying that it wasn't staffing issues, but instead his behavior. This so [angered me]. He does have behavior issues, but that wasn't the reason we were given! Turns out those districts are not allowed to use "staffing issues" as a reason to not provide necessary services, so they backpedaled and used something else. Like [my child]'s behavior issues, which the law states that they must provide aid and accommodations for. And we feel that that has not been taken seriously. So, they just stirred up a hornet's nest.

These latter expressions of the theme of organizational reactions mirrored the disabling or mother blame concepts found in earlier work (Thomas, 2007; Caplan, 2007). The reaction to blame members of the mother-child dyad may have been grounded in earlier professional paradigms advanced by Bettelheim, or they could have been impulsive reactions by teachers that were often portrayed by the mothers as frustrated and overwhelmed with the responsibility of teaching special needs children with limited training and support.

Maternal Activism

The theme of maternal activism closely followed situations where Mothers expressed frustration over what they experienced as a power inequality that influenced their relationships with care providers. One mother expressed this theme in her reflection,

I often wonder when I read the case studies and profiles of families like ours just how much this compensatory behavior of thinking of our children, heading their troubles off at the pass for them, contributes to our own financial problems, our compensation problems: how difficult can it be to function effectively in the workplace and also think of your little [child] who is operating according to an entirely different set of rules?

The activism theme also emerged as behavioral changes. One mother voiced this when she wrote, "I said to my husband that we needed to dress 'smart' for the visit to the pediatrician. I'm fed up of being treated like some ill-educated nonentity." In other cases, the behavioral changes included observing in the child's classroom, sending notes to school to address problems with services, providing resources or training for teachers, sharing daily routines with teachers to establish home-to-school continuity of successful home-based interventions, and volunteering to accompany the child on class trips or school-wide activities, such as field days, as a means of role modeling successful support for the child with ASD.

The theme of maternal activism also emerged as responses to perceived gaps between the services the mother believed her child needed and the services that

the child was offered. One mother expressed this theme as “We’re going to be in a big fat fight with the district.” Their concern was the school’s decision to cut services due to staffing costs. One mother’s comment reflected this theme. She wrote, “The only thing that would make me happier would be if parents didn’t have to sue to secure a free and appropriate public education for their children on the spectrum.” This theme emerged as mothers found the level of services offered to be unacceptable, and they argued that lack of qualified staff, limited or low insurance reimbursements, and limited governmental funding were not adequate justifications for eliminating or not providing necessary services for their children.

An artifact of the data set is that the mothers blogged their experience. Therefore, it is not surprising that blogging itself emerged as an aspect of mother activism. In the following case, the author is thanking the blog readers for their support and their own personal experiences with similar problems. “I’m humbled and overwhelmed by the outpouring of support and the depth of understanding that followed my last post. Thank you all. I’m sorry that you understand so well; but I really am thankful that we’ve all found each other.” The mothers focused their reflections on this theme not just on the support they received from people who responded to their blog, but the importance of the information in helping shape their activist paths.

Implications

Magdalena Freudenschuss’ (2007) argument that feminists “agree on the necessity of another world” in which domination is opposed and replaced with structures that support justice and equality is relevant to the discourse on mothering children with ASD’s. The mothering experiences of the women whose blogs were analyzed for this study provide an insight into the nature of the “other world” they seek and into their attempts to bring about that world on behalf of their child. In particular, the parent voice would dominate the dialogue regarding the care and evaluation of the child’s needs.

[My son] had an amazing week at school. That’s the word they used: “amazing.” It was—he was—amazing. He participated, he transitioned, he talked, he engaged. He played with other children. There is magic happening in that classroom. Without question, [my son] is performing some startling feats himself. And, also without question, the entire professional team is conjuring up great things. But there is a group of smaller, but no less able, players who are also making magic.

For these mothers, justice and equality involves accessing services for their children without overwhelming cost or professionalized gate-keeping mechanisms. It also involves creating future possibilities for their children in which they are accepted as full members of the community. These possibilities present risks to an educationalist paradigm. As a parent-centric paradigm

with multiple interpretations of realities emerges, it renders the school-centric distinctions between compliant and noncompliant parents obsolete.

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