



“My mission”: Life stories of mothers of individuals who type to communicate

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Abstract

In this paper, we share the crucial stories of women who fought for the education and inclusion of their children who type to communicate. The researchers conducted life story interviews with six mothers of individuals who are labelled as having a disability and use facilitated communication. Utilizing life story methods and applying a disability studies framework, we locate these mothers’ narratives within a larger context, taking into account historical, social, and familial perceptions, as well as how these forces influence their personal lives. The researchers analyzed the themes found in their oral units and provided a contextual understanding for their stories. The themes include: issues of care and gender roles, marital and familial life, challenging normalcy in society, the use of supported communication to demonstrate competence, shifting professional identities, and finally, paths to lifelong advocacy. Each of these elements provides insights into the lives of these women, but also how their stories are nested within and mapped onto large and complex social systems. The mothers’ stories overlap with the story of inclusive education and disability rights and show how their lives and roles as women, mothers, professionals, and advocates intersect with educational policies and practices. We illustrate how the women navigate and resist oppressive educational and political structures, as well as how these individual acts of resistance and advocacy can serve as catalysts for changing perceptions and educational opportunities for students with disabilities.

Keywords: disability, mothers, advocacy, life stories

Theoretical Framework

Disability can be understood differently depending on the tradition and model used. The prevailing approach to families of individuals with disabilities comes from the fields of medicine, psychology and social welfare (Wickham-Searl, 1992). The medical model understands disability as a deficit and emphasizes lack of attributes seen as normative by society. This perspective is prevalent in the research literature and influences social and political decisions, as well as individual perceptions. This perspective often presents depressing, problematic (Lalvani, 2008) and professional (Klein & McCabe, 2007) views of families of people with disabilities. Traditional “theories about disability seem to take stigma for granted and proceed to examine how people manage it, whether through... denial, or resistance” (Taylor, 2000, p. 89). Ryan and Runswick-Cole (2008) affirm that there is a growing body of research that examines mothers’ experiences through a positive lens; however, this more empowering perspective remains under-represented in research, as well as public consciousness. The experiences of mothers, as well as the experiences of disability are socially constructed and depend on social values, opportunities, contexts and understandings of difference and norms.

In an ableist society, parents are overwhelmingly exposed to traditional ways of understanding disability: as a deficit (Hehir, 2005). This study understands disability as a social construct, where difference is welcomed as a natural experience of being human. Furthermore, this paper is grounded in the disability studies literature, which interrogates the use of deficit categories to interpret differences (Bogdan & Taylor, 1989; Taylor, 2000). In addition, disability studies describes that families attach different meanings to disability labels, often resisting larger societal norms and viewing disability as a natural part of life. Particularly in familial

contexts, individuals labelled with disabilities are not necessarily stigmatized, rejected, or viewed as disabled (Biklen, 2005; Taylor, 2000). Therefore, parents, like many disability advocates, come to see that disability is not a tragedy, but society's response to it can be.

“American mothers of children with disabilities find themselves at the intersection of competing discourses. They nurture their children in a society that devalues and medicalizes the lives of people with disabilities but is also a backdrop for a vocal and activist disability rights movement”. (Landsman, 2005, p. 121)

Re-writing a narrative for their children with disabilities is an ongoing process within families (Rapp & Ginsburg, 2001). Composing what Rapp and Ginsburg (2001) call “normalizing” narratives creates inclusion of the person with disability within the family circle; “the efforts of families to re-write kinship are crucial to create new cultural [and social] terrain” for accepting and embracing disability (2001, p. 535).

Ryan and Runswick-Cole (2008) added to this idea saying that the positions mothers occupy are complex, contradictory and sometimes marginal. This complexity, among other factors, comes from the status of the mothers as non-disabled and their need to negotiate and provide care in society. Mothers are the ones who shoulder the primary responsibility for care, and often education. “Gender roles and responsibilities within families of children with disabilities reveals a division of labor that follows a very traditional pattern” (Traustadottir, 1991, p. 221). Wickham-Searl (1992) discusses how women who are mothers of children with disabilities are always mothers first. All of the participants in this study stayed home with their children, not working outside the house. Some mothers considered it an obligation, and some as an opportunity, but “none seemed to question the need for it” (p. 257).

When studying employment for parents of children with disabilities, Rupp and Ressler (2009) show how many factors, particularly parents' education, symptoms were associated with a disability and household structure (single or two parent). Overall, Rupp and Ressler contend that married mothers of children with disabilities are likely to replace employment with caregiving. Kittay (2001) argues that care for sons and daughters with a disability is multifaceted by including labour, attitude and virtue. In this complex scenario, to understand caring as employment or labour, a deeper and intersectional examination of disability related research and the participation of women in the workforce needs to be considered (Gordon, Cuskelly & Rosenman, 2008). This understanding also needs to include advocating for their children and for themselves as caregivers (Kittay, 2001). Kittay argues that the role of the caregiver needs to be elevated so individuals, family members or not, will be able to value their work themselves, and fight for justice advocating with the individuals they care for.

Traustadottir (1991) focuses particularly on mothers caring for children with disabilities. The author provides an important account of caring as love and caring as work, and how this develops to an extended caring role of advocacy for other children. Traustadottir explains that this caring is more professionalized than traditional mothering work. These mothers are active participants, sometimes taking leadership roles in meetings, lobbying, organizing groups, planning for services, among other roles. For these mothers, caring becomes an empowering experience for them in their social contexts and serves as a social catalyst for change. These mothers disrupt the social rules and norms and, thus, caring becomes a career.

Issues pertaining to mothers' roles in the care of individuals with disabilities raises issues of interdependence in our society. From a feminist disability framework, there is an intrinsic

inequality in the notion of care, dependency and equality, gender roles, and ability status between parents, women and their children with disabilities. Using this framework to consider these complex intersections is essential in order to move to a dialogue of interdependence and empowerment for both parties in our society (Garland-Thomson, 2002).

Research also considers the meaning of disability within these caretaking roles. Landsman (2005) reports on how mothers deal with their roles in the context of the medical model. The author contends that the story told by mothers of individuals with disabilities rejects the authority of the physician to define their children, and questions the role and right of “professional judgement” in placing children in disability categories. These mothers declare themselves the experts because they know and understand their children, know the particular people they are, and do not give them only the general label of disability. Landsman affirms that these mothers have changed the concept of normal itself and learned to embrace non-normative qualities in their children; the binary of normal versus abnormal becomes an “arbitrary construction” for these mothers. Ryan and Runswick-Cole (2008) also mention how mothers are able to negotiate, advocate, and mediate, particularly in reframing what is “normal” for their lives and family.

Angell, Stoner and Shelden (2009) explored levels and importance of trust between school professionals and mothers. The authors show that school climate, communication and flexibility of teachers, positive school administration, and services provided, are all factors that influence mothers’ trust in their children’s education. In addition, mothers felt collaboration was important, but above all, mothers listened to and observed their children’s behaviour as a reliable indicator of how things were going in school: “child focus guided parent actions and

subsequently affected mothers' trust in educational professionals" (Angell, Stoner, & Shelden 2009, p. 166). Mothers of children with disabilities assume different roles to ensure the quality of education and opportunities for their children that supersede the need to be employed themselves. Klein and McCabe's research (2007) shows that mothers often become professionals in the field, advocating, being resources, and providing support for individuals with disabilities, after caring and advocating for their own children for many years. They get involved in the education system so deeply that they become good resources for other families. Among the reasons cited by Klein & McCabe are the benefits of listening and sharing their own stories, the impact of their personal experiences on this new career, the credibility they have with clients due to this history, the positive impact of the career on the personal and professional growth and finally, the recognition of mothers' expertise by professionals (Klein & McCabe, 2007).

Panitch (2008) coined the term "accidental activists" to describe the stories of three local and national leaders in advocacy associations for people with disabilities in Canada. She describes personal stories as well as their important disability rights work as leaders in this field. Panitch is able to pinpoint with these mothers and leaders, events in their children's lives (institutionalization or lack of educational opportunities, for example) as turning points for them to activism for their children. Furthermore, she found they were "sensitized to injustice," and that is what made them get involved in advocacy for others as well. As the author explains:

"They did not start out to change the world; they started out trying to secure better services for their children... But as they came to view the forms of injustice that

encompassed children with disabilities and their families more broadly, they learned to mother as activists in a more public arena". (Panitch, 2008, p. 5)

These accounts that highlight the roles of mothers of individuals with disabilities as complex and empowered advocates need to be explored; besides being part of social and rights movements and achievements seen today, they are still "hidden from history" (Panitch, 2008, p. 3). Furthermore, the roles and perspectives of families and mothers of individuals who type to communicate, have been even further absent from the public and academic spheres.

Supported typing or facilitated communication is an alternative means of expression for individuals who do not demonstrate reliable verbal speech or whose speech is highly limited. It involves a facilitator providing physical, emotional and communication support to enable someone to type their thoughts and ideas (Crossley, 1994). In the 1990s, the excitement about facilitated communication combined with the use of incorrect techniques (also applied in the research), undermined the field generating a controversy about its use, particularly regarding guidance and authorship of the message. With training, many individuals who once required more physical support demonstrate the ability to type with no or limited physical touch and/or to read aloud their text during and after typing (Biklen & Burke, 2006; Broderick & Kasa-Hendrickson, 2001; Kasa-Hendrickson, Broderick & Hanson, 2009). Such achievements and independence, demonstrate how individuals with autism are generating their own ideas and not being influenced by the physical support of a facilitator. However, despite most recent research and evidence, because the nature of this type of communication requires physical support, discussion about authorship or guidance has been raised and is still a barrier to access to this means of communication.

Supported typing, as well as other alternative means of communication, is not widely implemented in U.S. schools. Therefore, understanding these mothers' stories is essential to understanding the larger historical, social, familial, and educational contexts that influence and affect people who type to communicate, and their families. With a better understanding of these social contexts, this research aims to resist practices that marginalize groups and individuals and to create opportunities to improve support and opportunities for the families of people who type to communicate (Kliewer & Biklen, 2000).

Objectives

The aim of this paper is to give voice to life stories of mothers of individuals with disabilities who type to communicate. Our aim was to listen to and share the crucial stories of women who fought for the education and social inclusion of their sons and daughters whose communication method is controversial and for whom inclusion is tenuous. Individuals whose primary means of communication is not verbal face oppression and marginalization in U.S. schools and communities, with significant implications for the mothers who care for them. This paper aims to empower these mothers and, as a consequence, families that have traditionally not been heard in schools and society.

Methods

The aim of the present study is to investigate the life stories of mothers of individuals who type to communicate. Life stories are not individual productions but are embedded within larger, group, cultural and historical contexts, so “every in-depth exploration of an individual life-in-context brings us that much closer to understanding the complexities of lives in communities” (Cole & Knowles, 2001, p.1). Such methodology allowed the researchers to consider mothers’ narratives in this larger context, taking into account, historical, social, familial perceptions and the influences on their own lives. Life story interviewing is a fruitful methodology, in that it recognizes “the individual as a window into broader social and societal conditions” (p. 12). While different from other traditional qualitative interviewing methods, it allows the researcher to expand the understanding of the interviewees beyond their particular

individual lives, through considering "the relationship, the complex interaction, between life and context, self and place" (p.11).

A life story is an oral and linguistic unit involved in social interaction and connected with the personal and private organizations of past life, the current situation and imagined futures (Linde, 1993). Life stories go beyond personal and individual contexts to place the narratives and oral units within broader contexts to make meaning of these oral units in society (Cole & Knowles, 2001). According to Cole and Knowles (2001), principles of "reflexivity, relationality, mutuality, care, sensitivity, and respect guide the development of questions" (p. 73), as well as the interpretation of data, and the analysis of lives in context.

Participants

The study included six mothers who have been in some way involved with the Institute on Communication and Inclusion (ICI) at Syracuse University, because their sons or daughters use facilitated communication in order to type to communicate. A recruitment email was sent to mothers that were connected with the ICI at the time, either through participation in training events, workshops, or social groups connected to facilitated communication. We sought women whose children had been typing for at least two years and who reflected diverse cultural perspectives. These six mothers voluntarily agreed to participate in the study and signed consent forms approved by the Institutional Review Board at Syracuse University. The number of participants is small because we wanted to consider each story in depth, rather than attempt to make broad claims.

Table 1 below provides information on the mothers, including their pseudonyms, their son's or daughter's pseudonyms, their highest level of education, and their country of origin. All mothers were residents of northeast of the United States at the time of the interview, but their stories cover educational opportunities in other regions in the United States and abroad.

Participant's pseudonym	Mothers' country of origin	Education	Participant children's pseudonym
Kate	US	College/Graduate	Rob
Leslie	US	College/Graduate	Carrie
Maat	Egypt	College/Graduate	Hussani
Sanoja	India	College/Graduate	Sabal
Sheila	US	College/Graduate	Johnny
Tammy	US	College/Graduate	Matthew

Table 1. Participant Information

Procedures

The researchers conducted life story interviews with the six mothers of individuals who use facilitated communication as their primary means of communication. The participants were interviewed once, twice or in some cases three times, depending on the length and detail of the stories, as well as the need for follow-up or clarification. The interviews occurred over a period of two years and ranged from one to two hours, all starting with the same question: "Can you

tell me about yourself as a mother?" After this question the participants directed the interview to topics of relevance to them personally. Unlike other forms of qualitative interviewing, only one consistent question was used across all participants. However, the researcher used further probing questions to flesh out their life stories, often saying things like, "Can you give me an example of that?" or "Can we go back to that story you told about..." Life story methods allowed us to locate mothers' narratives in a larger context taking into account historical, social, familial perceptions and influences on their lives (Cole & Knowles, 2001). The interviews were audio-recorded and transcribed verbatim.

Analysis

After all the interviews were completed, both researchers analyzed the life story transcripts (Cole & Knowles, 2001). We, the researchers, located ourselves within a disability studies framework and brought that perspective to bear as we worked to interpret and narrate the mothers' life stories. The researchers read the interview transcripts individually and sought to understand the lives of our participants, immersing ourselves in their stories: "[W]e must strive to honor the richness and complexity of lives lived... trying to understand in a holistic way, the connectedness and interrelatedness of human experience within complex social systems" (Cole & Knowles, 2001, p. 101).

Our first read revealed insights that helped to outline a profile of the mothers. After a second and deeper reading, some patterns and themes emerged that added shape to our understanding of the individuals and their stories. In other words, the first read provided an outline and the second and further readings added the richness and details to recounting the

stories. All the themes that emerged from the analysis were contextualized in societal moments and within the lives of our six participants. “The researchers look[ed] and listen[ed] for the root metaphors, life-defining themes, central truths, or epiphanies that can provide an organizing construct for the participant’s life” (Cole & Knowles, 2001, p. 120). Furthermore, we were reflexive, self-conscious and attentive to the way we are telling the story, for it to be reflective of the guiding principles and uphold the integrity of participants attaching a “deep level of authenticity to the meanings expressed” (p. 121). In doing so, the researchers do not claim to describe the reality, but the construction of reality within the interviewing process with these mothers (Denzin, 2001). In addition, by describing their stories, we wanted to make sure this paper was reflective of each of the individual stories, while at the same time telling a collective story, without denying our co-constructive and interpretive role as researchers in this process (Denzin, 2001).

Overall, life story methods allowed the researchers to contextualize mothers’ narratives in larger contexts by taking into account, historical, social, familial perceptions and influences on their own personal lives (Cole & Knowles, 2001). This means that as part of the analysis, the researchers connected the events told by the mothers with the historical process of access for communication for their sons and daughters with autism, for example, or the education laws governing access to inclusive education at the time. Lastly, as part of the analytical process, all mothers received a copy of the paper and were able to review, make suggestions, raise concerns, and voice comments. All suggestions for revisions were accepted so the participants had a voice and a role in how their stories were told.

Findings

The mothers' stories intersect with the story of inclusive education, disability rights and the history of facilitated communication. All mothers have at least some college education, which reflects descriptions in the literature of intersections between advocacy, mothers' roles and socioeconomic status (Ong-Dean, 2009; Rupp & Ressler, 2009). The findings are structured by the key themes found in these oral units, including: issues of care and gender roles, familial and marital life, challenging normalcy in society, the use of supported communication to demonstrate competence, shifting professional identities and paths to advocacy. Each element presented in this section provides insights into the lives of these women. These themes are connected and interrelated, as well as reflective of complex social systems.

Issues of care and gender roles

The six mothers interviewed clearly conveyed that their roles as mothers intersect with those of caregivers. Gendered notions of care and the importance of putting their children first were prevalent throughout all narratives. For example, Sanoja described her mission as a mother and caretaker for Sabal:

“I have to take my mission so. I have to do it. I have to look after my son. I am his mother and see he is depending upon me. Who else will do it for him? He has equal rights like any other child and I have to help him. It's as simple as that. It's not very complicated, it's very simple.”

Sanoja articulated the complexities of the mother role as a straight-forward mission focused on ensuring the rights of her son. She demonstrated that caretaking is as simple as

accepting who her son is and ensuring equal opportunities for him. These mothers accepted their “missions,” and described this role positively, without questioning it (Wickham-Searl, 1992). However, they also described a sense of isolation and feelings of being overwhelmed, as Sanoja describes that regarding her first years of care for Sabal: “I was like an island alone. I just couldn’t take it.” She explained that her oldest daughter had asthma, her husband did not directly support the infant because of his job, and she had a prestigious and busy work schedule as well. As many other women do, she tried to juggle it all (Traustadottir, 1991). Sanoja found support outside of the home, in associations for individuals with autism. From there she started to understand her son’s behaviours and learn to support him.

The first years were ones of adaptation to this new caretaking task, and, therefore, required a great deal from these mothers. Because this caregiving was so time consuming, giving it up for school was another step to surpass. Maat explained the complicated lines she had to navigate when she needed to give away part of the care when Hussani entered first grade.

“The first day at first grade I was again all over the classroom. And [his teacher] looked at me and she gave me a card with a tea bag inside: ‘Take the tea bag, go home and make a cup of tea for yourself and put your feet up and sit down and relax.’ I looked at her and I’m: ‘OK, I’m not used to that.’ And she’s like, ‘I will take care of him. Don’t worry.’ I said, ‘But....’ She said, ‘I’ll take care of him. Don’t worry.’ ‘But you don’t know.’ She would not even allow me to tell her that: Hussani can hit, Hussani can bite, Hussani can pinch, Hussani can spit on you, Hussani can do anything. She was like, ‘I’ll take care

of him. You go home and relax. That's it...' So I went home and I actually put my feet up and made my cup of tea and I drank it."

For the first time Maat heard someone else was taking care of him. Being able to relinquish some responsibility and share this care with school personnel, or with other family members, was both gratifying and worrisome for these mothers as they were used to being the primary and perhaps only day-to-day caregivers for their children.

Gender roles in caretaking were very clearly drawn for most of these women because they did the primary caring for their children with disabilities (Traustadottir, 1991), with the exception of Leslie. Those roles were taken for granted in most of the mothers' stories, even leading most of them to leave their jobs. When fathers were described as supportive, they were not usually the primary caregivers, and rarely provided the direct support for the child with autism. Sanoja explained her husband's personality and parenting role with Sabal:

"My husband is very, very down- to- earth and very grounded person. So then I was thinking about this [moving for better resources] and he was very accommodating even though he wasn't much into all that work that I was doing, but he was understanding."

Sanoja's description shows that her husband was supportive, and helped make decisions, even though he was not the one providing direct support to Sabal. Leslie's experience differed somewhat. Her husband was the primary caregiver for their first daughter while she worked for four years. For her second child, Carrie who had autism, she explains: "I didn't want to go back to [law] practice and fortunately I didn't have to. So then I was able to sort of make Carrie my

full-time job.” She added that her husband “felt so much pride that he’s a dad with a child with a disability. He took so much pride in that.” Leslie admits she learned a lot from him, and how he related to Carrie.

Overall, when mentioned in these stories the fathers’ presence was supportive, but never primarily so. However, in schools their presence was often perceived as more impactful. Sheila explains that “when [her husband] came in and spoke up they [school personnel] would really listen and they would then take action.” This was especially interesting as fathers had a much less direct role in child care throughout the stories, and yet their presence at meetings often shifted the course of discussions. Kate had the same experience and explains about the impact of her husband’s presence in a meeting discussing the physical education of their son Rob.

“One of the few times my husband was involved, in any of this school advocacy, was in a meeting with the Special Ed. Director and he said “don’t you have even one good teacher in this school district?” Which he doesn’t say much but that was...and so then he’d match us with this other teacher who really was a better teacher, but still segregated.”

Clearly, that father’s presence and demands carried a different weight in school. Tammy explained that she felt she “didn’t have a voice [in the school system]. And so ironic that I have a...whatever. I think you can be a woman with a voice and not be a bitch.” Tammy found it ironic that she, who is a speaking person, felt just like her son, who does not literally have a voice and types to communicate, in her interactions with his school. She felt that when she

spoke out it carried a negative connotation, and school personal viewed her as too demanding. Tammy also stated that her ex-husband was treated completely differently when he was the one making the demands. Her story exemplifies how authoritative voice is gendered, both in perception and in opportunity.

This mothering role is described as a process. For all the mothers, at some point in their lives, caring was seen as a central role for them as women. Overall, these mothers' experiences demonstrated that while the fathers have a more secondary role in the care for most families, fathers still hold a position of greater power when interacting in social instances. These uneven roles, as well as the needs of the person with autism, interfered in the marital life, as well with relationships with other family members. In the next section, the mothers describe their experiences within their families.

Familial and marital life

Any new child impacts family life; when the child has different needs, all family members need to adapt and establish their places in this new reality. Sheila explained how that manifested in her marriage:

“Such turmoil in our house. I mean Martin and I are honest about this. And the year after Johnny was diagnosed was horrible for us... It just was hard. Martin took on a lot of the stuff, but what happened to us, and Martin will tell you, along the way is we kind of lost the husband and wife connection and I say we stepped out of the

role as husband and wife and our roles were strictly mother and father. So our relationship changed enormously.”

All of the mothers described themes including marital adjustments, changes to the nature of the marital relationship, and the financial impact of the care (Rupp & Ressler, 2009). In addition to the adjustments in the relationships with husbands, all the mothers described the complexities of sibling relationships and care for siblings. Kate says, for example:

“So they [siblings] had to do a lot of caregiving. I mean only at extreme moments did they say ‘well he’s your kid’ kind of thing, that line you know, but they’re all very connected to him now.”

Deciding how much support they were going to allow from siblings seemed to be a difficult decision for the mothers interviewed. Leslie also explained how she did not want [Carrie’s older sister] to care for her sister too much: “I tried really hard not to make [her older sister] the mom. That was like real important to me. So it’s almost like I went the other direction. But to walk her home from school not a big...”

Leslie showed that finding this balance was complex, but overall these mothers found a point where they were comfortable with some support that was provided by siblings, which was different for every family.

The same was true for balance of attention and support for the siblings, and general support for everyday activities of the household, as Sheila describes: “It was to go to bed and get through the day and try to make things as normal as I could for my other two kids and sort of act like everything was okay.” Sheila wanted to make life as regular as possible for Johnny’s

siblings and find this balance of care among all her children. All the siblings learned new roles in the family and in their relationships with their brothers and sisters. Family life was intensely impacted as these mothers looked for ways to improve the lives of all of their children, including the ones directly affected by autism. Sanoja, for example, explained that in order for her son to have a better education they moved to the US, which had an immense impact on the family dynamics:

“We moved to a different country. I mean, it was not easy and it was a big sort of upheaval in our lives so we had to sell so many things and come here and nobody could believe I was doing that. I mean like I had a real comfortable job. My husband had a real nice job. We had our own house and everything. To leave all that and come if we had something lacking we could...there are people who do that like for a better job or something. We didn't have any such inclination but people had some suspicions, there must be something, but they couldn't believe we did it just for our son.”

Besides the intensity of leaving behind a stable and prestigious life to start over in a country as foreigners, Sanoja also described how this move impacted her as a mother to her eldest daughter, and as a wife to her husband:

“It was very, very difficult for us to leave [Sabal's sister] to come so far away and she wouldn't be able to meet us that often so that was big, very heart-rending for me as a mother of course. And I feel guilty also. Like I was sort of neglecting... [but] I had to take

this position because my daughter was...she was the eldest, she was more accommodating.”

My husband was in between [leaving or not the country]... because he wasn't getting a job [in the US]... we weren't really looking for big jobs, but comparable jobs to what he had there, and just to survive, we had to have a job.... my husband was saying 'why don't I move back and you stay here?' I said, 'okay it's your decision if you want to go then go.' But he had this, 'how can I leave them alone and go?' We had that pain, but finally he got this job here and he left that job and came and took up this. So that sort of smoothed our transition.”

Sanoja explained everything her family went through so that Sabal could have access to quality educational and communication opportunities. She described feeling guilty, feeling she was neglecting her daughter, her husband's worries about job security and her pain above it all. Sanoja's story encapsulates a mothers' fight to guarantee her vision for the education of her child with a disability (Panitch, 2008). The next theme expands this idea on how families, and particularly mothers, started rethinking the knowledge and opportunities offered to their children with autism to start creating their own paths.

Challenging experts and normalcy in society

All the mothers extensively described encounters with doctors, and other professionals particularly, psychologists; and their arrogance, pessimistic diagnoses, assessments and

judgements. Tammy described the diagnosis and prognosis the doctors gave for her son

Matthew:

“When Matthew was diagnosed [with autism] and I know we’ve come a long way but the psychologist and how he delivered that message was so horrendous... We went back to him [pediatrician] again and he said to me, you know Sheila, have you ever seen Rain Man? And I go yeah, and he goes well that’s the highest pinnacle anyone with autism could reach... You know Mrs. Brown there are group-homes... Martin [her husband] got up and left... that psychologist who said group-homes. She was just devastating. What a thing to say to parents when the child is three?”

Tammy further explained how this accepted knowledge in society had a toll on her and what knowledge and alternative constructions she wished were available to her at the time.

“I remember just saying to myself it was almost like ‘you get through it and you survive and you thrive and you do all those things,’ but early on it would be just so great if someone just said to me ‘oh sweetie, please don’t worry and let me tell you this about these individuals that have autism and how intrinsically lovely they are and what their souls are made up of.’ I could almost cry just thinking about that.”

Tammy got emotional when discussing all the pessimistic views of autism she was subjected to. Despite some positive changes, these pessimistic views, as described by Sheila about people with autism and their potential participation in schooling and society that were very common in the 1990s when these mothers had young children, are still very much present, particularly for individuals with complex communication needs. For that reason, re-describing and defying

normalcy and traditional assumptions about their children was and still is a daily task these mothers have to face (Landsman, 2005; Rapp & Ginsburg, 2001). Tammy described this need powerfully:

“It’s a society that judges very quickly if you don’t wear the right clothes or you don’t exceed at this sport and my boys are cut from a completely different cloth. Especially being boys in this age in a community where sports and just certain things are the norm and that’s how a lot of families define themselves with their kids and their kids’ sports and there’s nothing wrong with that. That’s just not us.”

Despite the traditional expectations of experts within this context of normalcy, these mothers voiced belief in the competence and capabilities of their children. Maat explained her response to people when Hussani was growing up and they told her he was not aware of his surroundings:

“He knows me. I know he knows me and he knows people coming in and going out. I know when he was a year and a half and he goes to the fridge and gets me the peanut butter and the jelly, the bread, then brings them to me. I know he’s smart. Don’t tell me that he does not understand what’s around him.”

Similarly, Sanoja talks about Sabal’s early years:

“He was small at that time so I mean he’s running around... he won’t listen to what we say. They didn’t understand...even I hadn’t much clue as to what I was saying at that time. But even then I had the feeling that he is capable of things. So that determination was maybe what helped me to do whatever I needed to do for him.”

Clearly, mostly everyone surrounding Sabal did not understand his behaviours, particularly as he was not able to communicate at the time. However, Sanoja, Maat and all the other mothers in this study always believed their children could do more, even if that belief went against the prevailing medical and clinical explanations and understandings of their potential. All the mothers challenged this traditional knowledge offered to them to make sense of their children. Furthermore, they went a step further and tried to provide the conditions their children needed to be able to engage meaningfully in schools and communities.

The use of supported communication to demonstrate competence

Going against all the odds and societal expectations, these mothers saw the possibility in their children – they saw them as smart - so they looked for professionals, other parents, and connections that could provide their children with tools necessary for success. Typing to communicate was one avenue to address this need, and it provided their children with the opportunity to express themselves and demonstrate their competency. Sanoja captured this search for opportunities:

“As a mother I should say I am very determined. I was from the beginning. I felt I had the...I mean deep inside my heart I had this feeling that my son can do all things even though he wasn’t communicating at that time.”

After trying different therapies, methods of communication and supports that were not meeting the communication needs of their children, they found schools or practitioners that

were able to support their children to start communicating. In the following excerpts the mothers expressed their children's first encounters with typing and facilitated communication. Maat described Hussani's first communication.

"The first sentence he typed at preschool was "OPEN CABINET." And they send me that in the communication book: 'Hussani typed today and he said open cabinet. And when we opened the cabinet he looked at it and he was very upset and he would not communicate anymore.' And I said, 'What the heck is that? Why at four years old would he say Open Cabinet? This does not sound right' ... The second day I went and said 'So which cabinet is that? Hussani said open cabinet?' And he pointed to the cabinet and it all came home. Because that's exactly the same cabinet they used to keep the cookies and the stuff in the school in New York City."

From the early stages of trying to express themselves, these children and mothers were always testing themselves and their assumptions so crystallized by the system. Sanoja also described being skeptical in the beginning, and for the first six months of typing with Sabal, they were just "pointing and [doing] fill-in-the blanks." When they were more confident in their pointing and other exercises, they started working on more complex content and open-ended conversations. Sanoja described the beginning of open-ended typed conversations below:

"He was saying things which I realized he already knew like the past, his memories. I was just testing him all the time. I wasn't doing it very obviously but in my heart I was thinking maybe is it really happening. I was asking him things and he was saying so many things of what really affected him, incidents. He gave me the date, the exact date that it

happened. When my father passed away it was a very emotional thing and he started with that, then what happened, and what was his thoughts then. I mean it was sort of all the things he was saying was correct, the actual facts which I knew. He has really gone through a lot of things in his life which without my knowing it. I was unaware of it. I really...that made me all the more determined like to get him what he really deserves.”

Accessing communication allowed Sanoja and the other mothers to see their sons and daughters in ways they did not before, and that made these mothers want to fight for their rights even more. Most of the mothers were the first people to shake up the preconceived notions and believe in their sons and daughters as competent individuals (Biklen, 2005; Taylor, 2000). After mothers described understanding and feeling confident in the ways their sons were communicating, they wanted to show their competence in other environments, particularly at school. Tammy described Matthew demonstrating competence in school because of his communication:

“He started using FC¹ at school as well but not right away. So he had been doing Touch Math and then one night I finally said to him ‘What’s something plus something?’ and he knew it and I was, ‘Okay, we can do everything with this communication.’ So we had a meeting at the school. So I remember having the teacher facilitate him and I asked the questions: ‘What’s six plus three? What’s...’ and I started going through examples. So they were like shitting their pants. I swear to God, they’re like, ‘Are you kidding me?’

¹Facilitated Communication

And I wasn't facilitating, so there was no [doubt], I was completely out of the picture and then I went and we did multiplication problems and division problems and I think you could hear a pin drop. That you could just all of them across the room they just had no idea."

All the mothers in this study found in facilitated communication, a method that provided the support and structure to allow their sons or daughters to communicate. Like Tammy, all of the mothers saw the benefits of this method of communication, so they tried to prove their sons' and daughters' smartness in school by enabling them to use this method there as well. This form of communication access showed others what these mothers knew all along; that their children were competent beings, who needed support to communicate.

Due to the complexity of their children's needs, the mothers become very present in their children's everyday lives, particularly in working with schools, agencies, and other fields in special education. The access to communication was not easy in those places, but this access to successful typed communication marked an important turning point in these mothers' stories because it proved they were right and encouraged them to continue fighting for what their children deserved. Sheila exemplified this impact in the excerpt below:

"I mean when it comes back it's been a huge, huge thing and I think probably we are where we are because Johnny's been successful [in communicating].... We have issues that come along, but the good far outweigh the crappy stuff, you know."

Sheila described how Johnny's success in typing to communicate was responsible for changes in their family life. The huge impact of access to communication for their children, particularly as a

method that requires so much parent involvement, clearly changed these women's life paths. The next theme explores the impact of access to communication on these connections and eventual employment in disability related fields.

Shifting professional identities

The mothers' testimonies make evident their level of investment in their children's future, including leaving employment to be able to dedicate themselves to full-time parenting (Rapp & Ginsburg, 2001; Kittay, 2001). Sheila explained, "I wasn't working. I had retired from the county when Johnny was one to stay home... So what I ended up doing daycare for teachers' kids. I took five and it let me be home." In a society where access to services or educational rights for their children are not easily granted, mothers became very involved in guaranteeing these rights, to the extent that their career paths shifted to disability related fields (Panitch, 2008). Tammy explained:

"I work at an advocacy agency so I've learned all about I think, the tools that will help Matthew later in life to lead a life as independent as we can define at that time and the monetary Medicaid system and all of those things... Well I came up through like corporate America, had these guys, and then I was looking for a part-time job. Who thought I would be a service coordinator, wanting to work with families, which is completely the other side of the brain for me since I am an accountant and a CPA²."

At the time of the interview, Tammy still worked as a service coordinator guaranteeing that individuals with disabilities received services to which they are entitled. Most of these women

² Certified Public Accountant

either completely changed careers, as Tammy did, or added to their knowledge and focused their careers on issues related to individuals with disabilities and special education. Kate explained how she used her training as a teacher to be able to find support for Rob:

“I didn’t know there were going to be any challenges in this part of it [mothering]. So anyway, the teaching does kind of work in there. And it also really made a difference in terms of supporting Rob through his education because... I always had my teacher hat on so I was always seeing it from their perspective. So I’m thinking ‘how can I engage them in this?’... I was trying to come up with a way to try to make whatever I was asking so that it’s easy for them to do. And I would create this little form for his checklist and all this stuff so I could get them on board.”

Kate was able to use her teacher perspective when advocating and getting the school ‘on board.’ In the same way, Leslie was a lawyer working in a children’s rights clinic in a university and explained how her professional life intersected with her personal life:

“What we did there [at the clinic] is a lot of things to do with kids which I had done a lot of before in terms of custody and different kinds of children’s issues. But an issue that I had never dealt with before had to do with children with disabilities... I had to really learn about that. And then I got pregnant. All of a sudden it’s like all this stuff I had been learning about, researching, and teaching students and then I’m in it personally. I was in it professionally and then I was in it personally.”

Leslie was already working in the field, but describes in various instances how having the personal experience expanded her professional role as a lawyer advocating for the rights of children with disabilities.

Sheila and Sanoja also currently work as trainers in facilitated communication. They are able to train other families in the method that allowed their sons to communicate, have a meaningful education and also meaningful lives. While working in the field these mothers surely entered a lifelong pathway of advocacy as the next section elucidates.

Path to lifelong advocacy

All six mothers shared stories of intense involvement in their sons' and daughters' schools and extending into adult services. This happened because access to communication or educational inclusion was not automatically granted for them. Not satisfied with the educational opportunities afforded to them, those mothers became ardent advocates. Sanoja provided concrete examples of how she envisioned a different education for her son:

“It was just this teaching life skills sort of you have self-contained rooms here... So it was not what I really wanted for him... it wasn't enough, like age appropriate.... So I started at home, like bringing the books which were age appropriate for him... I wanted him to do more math, age appropriate math...and he was complying.”

It was very common across their testimonies that these mothers researched and learned different ways to interact, educate and communicate with their children. After learning what else their children could do, they started asking for these same conditions in schools. Sanoja continues, “I used to read on the internet what things you have, you have schools where they

are studying with other children. So inclusion, that's what I wanted." After having a vision, these mothers intensively advocated for the educational rights of their children. Maat explained her involvement with advocacy:

"I had my reputation in that school that here is a pushy mother so if you're going to deal with any of her kids remember that. You know teachers tell teachers. So I became the bad mom and before I went to any classrooms with any of my kids I would visit the classrooms and I said, 'Hussani or Amit or Ackmin even and I are a team. If you have my son, you have me. If you welcome my son in your classrooms you are welcoming me.' Most of the teachers had no problem really."

Similarly, Kate provided an account from the 1990s when Rob was in a segregated classroom and she was advocating during a meeting. "I'm meeting with the Assistant Special Ed. Director and I'm spouting my inclusion stuff and she's like, 'If you want inclusion then I suggest you buy a house in another school district.'" The school where Kate's son attended at that time was clearly not entertaining the least restrictive environment argument she was making during the meeting, and suggested she move. The schools sometimes created less than welcoming educational environments for their sons and daughters. Leslie described this complex, and sometimes adversarial position, advocating for her daughter's education, particularly given her position as a lawyer herself.

"At one point she [the Principal] said to me 'I can't imagine what it would be like in your shoes.' And that just pissed me off so much. I felt almost like this superior attitude that she had like 'I'm better than you, I don't have a kid with a disability, I'm better than

you.’ That’s how I interpreted it and I’m like they should have moms with kids with disabilities in these jobs. That’s what I thought at the time and I felt like that was her sort of subtle way of telling I don’t have a kid with a disability. I’m better than you. I’m sure she wasn’t saying that at all but that was my interpretation at the time.”

As a professional in the legal field, Leslie spoke about the importance of having more parents serve as advocates and get involved in the provision of services for children with disabilities. Aligned with this logic, after seeing the benefits of advocating for their own children, these mothers did not stop there, but started doing so on behalf of other children in their districts, local agencies, and communities (Panitch, 2008). Kate, who is a lawyer, actually stopped working in her area due to her involvement with advocacy: “So I ended up really not practising then because I was home with Rob and [his brother]. I got involved in advocacy really practically from the first minute.” She expanded her advocacy reach and got involved with different groups as an example of commitment to systematic change:

“We got involved very early, I mean immediately, in a local parents’ support group which was a really active group. They were very tied to the national group too and so that’s how we got involved in national advocacy when he was a year old. In those days, pre-internet, that was your only source of information, so from the time he was one we were attending national conventions... [and meetings] and that’s where you would find the experts and people who really did know and were advocates too not just self-labelled experts...then I got exposed to what’s happening all over the rest of the country and you could figure out we weren’t in the best place to be and Missouri has like little

commitment to human services- period. So you find out that a state's culture and history makes a huge difference. So we actually tried to move back here [New York State] in '85 and my husband had a job offer."

At the time of the interview Kate was a practising lawyer and she explains it is still painful when she needs to work for families in special education cases:

"I do some Special Ed. work if people come to me. I don't seek it out because it's still painful and it's like I don't want anybody else re-living this story or any parts of it. And it shouldn't be, it never should have been, and it still is."

The need to be so involved and advocate on behalf of her child had an impact on Sheila as well:

"The ups and downs and the emotional stuff you just get up, put one foot...you just kept going forward. And I think it was that fear-based thing because if you stop and thought too much about it..." Despite the fact that it is hard for these women, they believe so firmly in their role as advocates within this unfair system that they continue to do so. Maat also describes her intensive involvement with advocacy in her sons' school district:

"I became a parent advocate over here, or a parents' rep[resentative], and they told me just read the files and make this decision. I would not take that. I would go to the classrooms of all the kids. I used to travel all over the city to see all the kids. I would be sitting on the CSE³ meeting and I would talk to their teacher. I would talk to their

³ Committee on Special Education

therapists and I would sit in the classrooms and watch the kids interacting with other kids before I go in and say here's what the child needs, or if I'm going to support this or support that, which was unheard of in the district."

Kate admits that, "Rob got things that nobody else got. I mean just because I was advocating."

Similarly, Sheila describes a positive relationship with her school, and how they were privileged as a result. "It wasn't all perfect. I mean I don't want to say it was, but they seemed to listen to us and I think maybe that's another piece for us that other parents didn't have is that they were so willing." As described in the literature (Panitch, 2008), these mothers articulated that their advocacy bids provided improved educational and sometimes social outcomes not just for their children but for others as well.

Discussion

"Being a mother is probably the most powerful, joyful thing that I have ever experienced." ~ Leslie

All the mothers in one way or another articulated the positive impact of being a mother, particularly of a child with disabilities. They all described this in terms of learning what really matters in life. For example, Tammy shared:

"What I am just so amazed at right now is how humble I feel, and how blessed I feel, and I think because of watching both of them challenge in their way, be challenged in their way, that I have such an appreciation just of my own family.... I am so lucky as I look at that I know kind of what my mission in my life is, and it's really in your face when you have a child like Matthew or any child. All of your priorities change but with both of

them they have just really kind of anchored me and so it's nice to watch.... it's been a beautiful journey. I mean I don't know. My two boys and especially Matthew it's like he has forever, forever changed me."

Tammy's description of her learning brings us back full circle to the first theme and how these women talked about their mission as mothers. When they defined themselves as mothers in terms of having a mission, they show they have a goal, and they are ready for any challenge that came their way.

This research exemplifies the power of the mother role in the educational path of children and adults with disabilities. Because the mothers believed in their children's abilities, potential and competencies, they invested time, energy, resources and adapted their lives so that their children had a meaningful education and future. There are evident commonalities across the mothers' lives highlighting stories of exclusion, fights for justice, and attempts at advocacy. These fascinating stories also show how their lives and roles as women, mothers, professionals, and disability rights advocates intersect with educational policies and practices.

The stories reflect gendered notions of care, because as traditionally posed, the mothers are also the primary caregivers of individuals with disabilities (Traustadottir, 1991; Wickham-Searl, 1992). The six mothers interviewed conveyed that caring is complex and multifaceted, however, it is central to their lives (Kittay, 2001; Traustadottir, 1991). Within our predominantly ableist society, the mothers of children with disabilities learn to create their own meanings, labels and possibilities (Landsman, 2005; Taylor, 2000). Describing and defying normalcy and

traditional assumptions about their children was a daily task these mothers had to face (Ryan & Runswick-Cole, 2008) and that is what these women did. They encountered their own privilege, defined their own paths, and paved one new path of opportunities and possibilities for their children by believing in them and advocating for it.

The women did not simply provide care, they learned to navigate and resist the oppressive educational and political structures. They learned to occupy complex and very relevant places in their children's lives, in society, and in the disability rights movement (Kittay, 2001; Klein & McCabe, 2007; Landsman, 2005; Ryan & Runswick-Cole, 2008). The mothers saw potential, abilities and competence in their kids. As a consequence, they pursued inclusion and access to communication against all odds, they became accidental activists (Panitch, 2008).

Being able to put trust in the teachers and schools was a central theme for the mothers. This trusting relationship required continuous collaboration with school personnel (Angell, Stoner & Shelden, 2009). After years of local advocacy and educational work, they were able to provide their sons and daughters access to an effective means of communication. Through typing to communicate, these children confirmed what the mothers always knew, that they should be included as equals in their school and social environments. However, because the access to communication was not well paved, the mothers continued to advocate so their son's and daughter's means of communication was accepted and recognized. Furthermore, the mothers organized, joined organizations and also informally helped other families, teachers and schools to support other students with disabilities (Klein & McCabe, 2007; Panitch, 2008).

Sometimes, they went further and are now in professions related to advocacy, education or service provision.

Socioeconomic status also played into the role of the mothers as advocates. A few of the mothers continued working full-time, juggling their time as professionals and provider of the household with that as caregivers and advocates. However, most of the households had other income sources, so these mothers could dedicate themselves full-time to the empowerment of their children through communication and education, substituting care for employment (Rupp & Ressler, 2009). This is a relevant systematic issue because the current special education system based on laws and advocacy socially reproduces inequalities and privileges specific types of parent involvement (Ong-Dean, 2009). The system puts the burden of advocacy on the parents, which benefits the ones with social and economic advantages. The same is true for access to communication, because the facilitated communication method requires resources, particularly intensive practice and time outside of their educational services that are not yet available for all families. In this still currently unfair system, these mothers are essential family resources and should be seen as school partners for making sure school systems are providing the education that all children deserve and are entitled to. For that reason, the roles of mothers are caregivers, and support for this role as employment need to be discussed further (Gordon, Cuskelly & Rosenman, 2008; Kittay, 2001).

Conclusion

The mothers recalled positive experiences, with a mixture of realism and hope, and experienced challenges and successes. They described how their mission as mothers of a

person with complex communication needs changed their lives. The women wished they had access to these types of stories when they started their own journeys, and that is why it is important to share them.

All the women within their individualities, cultural and temporal contexts constructed one full story of being a mother of a child with autism who types to communicate. The women viewed themselves as caregivers and had to adapt to this new role, which impacted their entire families. In the interactions with society, the mothers did not find a place where they and their children belonged and, therefore, had to challenge society's notion of normalcy. To be able to provide the opportunities their sons and daughters deserved, they found a method that would allow them to communicate and demonstrate the competence that they saw. Because facilitated communication for individuals with significant communication needs is not historically provided in schools, these mothers became very involved with the educational and other service systems for individuals with disabilities, in order to guarantee their children rights. They started shifting professional identities, sometimes stopping work because of this intensive involvement, and then became professionally involved in educational systems and advocacy. The work of advocacy for their children became a path for lifelong advocacy that now benefits many families with their experiences and support.

These important stories have to be heard to provide insight into how these individual acts of resistance and advocacy can be catalysts for changing perceptions and the education of students with disabilities in the future. Individuals who type to communicate need their rights for communication and education granted. This paper tries to shed light on this complex issue,

showing how the personal experiences of these amazing women show the need for a partnership between schools and families; and how professionals in medical and educational fields related to education need to continue to listen to all mothers. These partnerships can narrow socioeconomic gaps of access to services and opportunities for mothers of children with disabilities to allow them to be productive in the job market, which will also result in the educational and service system learning from their valuable experiences.

In search of a better future than what was offered to daughters and sons, these six strong women defied all odds and created a path to success. Their tireless efforts and creative advocacy benefitted not only their children, but created greater opportunities for others. That was their mission. By listening and exposing their stories we should follow their steps, give them opportunities to get more involved in the educational system, and as a consequence allow other students to access communication and inclusive opportunities.

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