

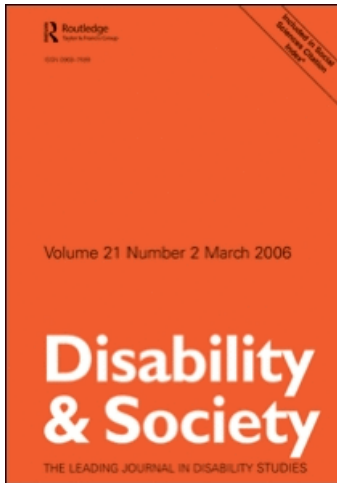
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Mediating self-hood: exploring the construction and maintenance of identity by mothers of children labeled with autism spectrum disorder

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Based on the findings of a qualitative study, this article describes how mothers of children labeled with autism spectrum disorder (ASD) mediate for their children in interactions with those who are unfamiliar with ASD. Data were collected through in-depth interviews and participant observations. Findings indicate that mothers mediate for their children because they perceive hostility and lack of accommodation for their children on the part of unfamiliar others. As they mediate, mothers attempt to construct and maintain positive identities for their children by explaining and reframing their children's behaviors to influence the interpretations and responses of unfamiliar others. I argue that in these interactions mothers function as proxy selves for their children because they are attempting to influence the perceptions others develop of their children, thus shaping their children's social identity in the process. The findings of this study demonstrate the active, interpretive role that many mothers of children with autism play as they continually sort and assess information in order to determine what is in the best interests of their children. Further, the findings presented here demonstrate the social nature of self-hood and identity, that all people involve others in the performance of their self-hood. In this way and others, people labeled with ASD have much in common with those considered normal.

Keywords: autism spectrum disorder; mediation; interaction; proxy self-hood; marginalization; normality; identity

Introduction

In this paper I explore how mothers of children labeled with autism spectrum disorder (ASD) facilitate their children's sociality and the accommodation of their needs by mediating between them and the broader world. Read (2000) documented the importance of mothers' mediation for the well-being of children with special needs, and further that mediation is something that mothers (and in some cases fathers too) of non-disabled children also do. However, it may be argued that the stakes are higher in the case of disabled children because their behavior and bodily comportment may differ significantly from what is considered normal and may result in their being misunderstood and excluded (Ryan 2009). Because of the gap between neurotypical (NT) expectations and ASD behaviors, interactions between them may be strained and mutual understanding thwarted. People classed as NT not familiar with

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the condition – referred to as ‘unfamiliar’ hereafter – often see a person with ASD as ‘weird’ or threatening, and research demonstrates that people with ASD and their families may face lives in which misunderstanding, social isolation and exclusion feature prominently (Barnard 2001; Read 2000; Krauss 2004; Gray 1997). Bagatell’s (2007) gripping account of Ben, a high functioning autistic teen trying to define his own identity, revealed the social challenges people with autism face as they struggle with the often disempowering discourse of disability and the profoundly negative effects it can have on their lives.

In order to bridge the social chasm between their children and unfamiliar, many mothers act as mediators, decoding the self-expressions and communicative gestures of their children, translating them into terms that unfamiliar can better understand. Read (2000) argued that mothers of disabled children witness ‘unacceptable, exclusionary or devaluing responses to their children’ and that it is this hostile social context that makes mediation necessary (p. 107). Furthermore, Read suggested that mothers tend to serve in this role because there are few others available to act as mediators, and mothers have the most comprehensive knowledge of their children. As mothers:

modify and augment their views about their children, their children’s place in the world and the need to safeguard their interests, they find themselves increasingly and irrevocably drawn into the role of go-between. ... Many do not take the role easily but feel that they have no alternative. (Read 2000, 115)

Evidence suggests that some mothers extend their activities beyond their immediate families and into the wider community, becoming activists who campaign for greater understanding and accommodation of ASD (Ryan 2009).

Similar to the women in Read’s study, the mothers of children labeled with ASD that I interviewed for this study also reported frequent ignorance, lack of accommodation and outright hostility to them and their children by unfamiliar, and they too mediated for their children. These mothers were concerned about helping their children construct positive identities, and ensuring that their children can get on in the world. A significant part of mothers’ efforts involved educating unfamiliar about ASD and the particularities of their children, reframing their children’s behaviors in ways that highlighted their individual abilities and needs and encouraging unfamiliar to see the world from an autistic person’s perspective. In doing so, they directly challenged and resisted stigma and the foundations of the hostile context itself, the hegemonic norms of embodiment that produce the lack of understanding and exclusion of those with embodied differences. Mothers’ mediation aims to increase inclusion and acceptance of their children as people who understand and interact with the world in sometimes fundamentally different ways, but whose existence and personhood are fully valid nonetheless. To the extent that mothers attempt to influence the understanding and treatment of their children on the part of unfamiliar via their mediation efforts, I suggest that mothers perform a proxy self-hood for their children.

Self-hood and identity

Mead (1934) argued that the self develops in a long-term process in which individuals exchange meaningful symbols (e.g. language and bodily gestures) with others. As part

of this process of symbolic exchange an individual's self-concept emerges as they and their behaviors are subjected to the responses of others. In turn, these responses allow individuals to assess their own behaviors and the way they are viewed by others. In this view, once an individual has internalized the norms of the community into their own world view they have developed what Mead referred to as a 'generalized other' and can discern the meaning of various situations, assess their place in them and adjust their behaviors to produce the desired responses from others. In other words, having developed a generalized other, individuals can reflect on their own actions from the position of the other and imagine the reaction of others to them in a given situation. For Mead, this ability was fundamental to self-hood.

In his analysis of the ways in which individuals are shaped by the broader society Goffman (1956) wrote:

for a complete man [sic] to be expressed, individuals must hold hands in a chain of ceremony ... while it may be true that the individual has a unique self all his own, evidence of this possession is thoroughly a product of joint ceremonial labor. (84-5)

Linking self and identity, Goffman (1959) extended Mead's analysis, arguing that individuals in society were like actors on a stage. As individuals performed their self-hood in social encounters they acted to create impressions on their audience. These impressions were aimed, wittingly or not, at enlisting the audience in constructing and validating the individual's identity. Thus, one's identity depends greatly upon the reactions of the 'audience' to one's performance of self. As Schwalbe (1993) noted, identities are produced in interactions and are ascribed to individuals by others, and derive from the meanings attached to the social positions, roles and statuses individuals occupy. Further, identities often strongly reflect dominant discourses and categories (Holland 1997), yet, as Kondo (1990) suggested, people actively construct their identities, and in the process sometimes challenge cultural constraints.

According to these theorists identity is linked to the self and its embodied performance and, further, the cooperation of others. Fundamentally, self-hood and identity are products of social interaction that depend on others for their realization. It is in the sense of the terms as used above that I suggest mothers' mediation is the performance of proxy self-hood for their children that is aimed at the construction and maintenance of their identity.

By suggesting that mothers of children labeled with ASD sometimes act as proxy selves for them it is not my intention to imply that their children have not developed selves. On the contrary, Tito Mukhopdhy, Amanda Baggs, Lucy Blackman and many others labeled with ASD have provided ample evidence that they do indeed have selves. The mounting evidence of autistic self-hood provides the opportunity for scholars to critique dominant models of the self as reflecting only normative self-hood to the exclusion of the diversity of self-hood that humans may embody. What I argue in this paper is that mothers of children labeled with ASD often perform a proxy self-hood for their children in interactions with unfamiliar not because their children do not have selves, but because unfamiliar are typically not equipped to understand what mothers believe are the self-expressions of their children. Further, framing mothers' mediation practices as the performance of proxy self-hood acknowledges them as active agents who interpret the raw and real time information available in a given interaction context and who use this information to frame a plan of action in the best interests of their children (Read 2000).

Methods

Data for this study were collected using qualitative methods to foreground the subject's narratives, thereby illuminating the lived experience of caring for a child labeled with ASD in contemporary America (Clandinin 2000). The participants in this study were drawn from the families and school personnel in the Special Education Department of Mountain Valley School District (MVSD), located in a medium sized southwestern city in the USA. All names used in this paper are pseudonyms to protect the confidentiality of participants, except when I refer to public figures. Although I interviewed mothers and school personnel, this paper focuses on the narratives of the former, as it is they who perform the work of mediating self-hood that I discuss below.

To recruit participants I used snowball sampling (Biernacki 1981) and a formal invitation to participate sent in a letter to families and therapists by MVSD that described the purpose of the study. Most of the participants in this study were white, suburban and middle class. Several families were white and low income. It is possible that greater ethnic and class diversity might alter the findings of this paper. Nearly all of the families had more than one child. Most had only one child labeled with ASD, although several had two with this diagnosis.

One cannot help noticing the gender imbalance of the participants in this study. All of the school personnel I interviewed were women and all but two parents were mothers. In every case it was mothers who responded to the letters that I sent to families informing them of my study, and it was they who were interested in participating. Mothers continue to be the primary caregivers and advocates for their children in daily life, and this is perhaps even more likely in the case of children with disabilities (Read 2000; Ryan 2009; Traustadottir 1991; Cole 2004). Thus, the gender imbalance in this study is a local reflection of broader cultural practices and views regarding childrearing, which are intensified when the population needing care are children with special needs.

Because the vast majority of participants in this study were women, I must call to attention here my position as a man interviewing women and acknowledge that my gender was probably a salient factor in many of the interactions I had with participants, and thus shaped the data I was able to collect. Further, I cannot discount my own gender in the analysis and interpretation of these data. I can say, however, that I approached these data with an ethnographic sensibility, taking seriously mothers' experiences and knowledge as I attempted to understand their practices from their point of view. To check the accuracy of my transcriptions, I regularly gave participants copies of interview transcripts. This afforded them an opportunity to amend any errors I had made, clarify statements they had made and add information that they had not thought of at the time of the interview. Further, I circulated drafts of papers I had written to participants so that they might have a chance to comment on my interpretations of their narratives, as well as on the arguments I was making. In this way, this project became a conversation about their lives and a process in which they played a vital role (Skeggs 2001).

Data were gathered through in-depth, semi-structured interviews and participant observation. Most of the interviews were conducted in families' homes, while the others were conducted in local establishments or at school. Each interview lasted at least two hours, with several taking much longer. Rather than proceeding with a preconceived agenda and list of questions, I followed the interests of interviewees in order to jointly explore the meanings they attributed to the events in their lives

(Spradley 1979; Heyl 2001). In addition to interviews, I also collected extensive participant observation data in school special education classrooms, parent support group meetings and outings in the local community. Participant observation data provided vital context for the lives of these families, as well as the opportunity to check the correspondence between mothers' narratives and actions.

Analysis of the data was inductive, proceeding according to the grounded theory and constant comparison method (Glaser and Strauss 1967). In this method of analysis the theory emerges from the data, rather than being imposed upon it. Thus, the researcher begins categorizing the data using thematic codes based upon the narratives of the interviewee. Thus, some early codes focusing on mothers' experiences were labeled 'advocate', 'needs', 'unfamiliar' lack of understanding', among others. When these early codes were further examined sub-categories emerged which revealed further nuances about the mediating role of mothers. Taken together, these codes demonstrate the complicated negotiations mothers engage in to meet their children's needs, to construct and maintain positive identities for them and to foster their inclusion.

Explaining their children to others

Because the behaviors associated with ASD can be so contrary to commonly accepted behavioral norms, mothers frequently find themselves explaining their children's behaviors to others to increase the possibility that their children will be afforded respect as people and that they will be included and accommodated by others. Most mothers discussed the difficulty of explaining ASD. How does one describe such a diverse condition? Several mothers suggested that people unfamiliar with ASD would have to immerse themselves in the autistic community to really begin to understand the peculiarities of the condition. Katherine illustrated this view.

They'd have to go to the meetings [of the local parent support group she attended], read about people like Temple Grandin, talk to a bunch of people – but most of all, they've got to experience it. That's the only way you can ever really know about autism.

Katherine's quote implies an additional question that mothers face: does the unfamiliar person warrant an explanation? If the person is someone they are unlikely to encounter again, mothers often say nothing about their child's autism. However, if the unfamiliar person is someone with whom they or their child will have continued contact mothers will try to gauge their level of interest – effectively trying to read their willingness to interact with their child – and tailor their explanations accordingly. Joan, the mother of a four-year-old boy named Trevor with little verbal language illustrated this point.

If they seem interested, I'll say something like 'a good way to interact with him is to get down at his level. And if you say hi, then he'll say hi'. I just try to anticipate what they might be willing to do. And then other people, I know they don't care. They're not going to do anything, so I don't bother. It's kind of at peoples' level of interest.

Joan encouraged people to interact with Trevor in ways that might be more suitable or interesting for him, rather than attempting to interact with him in ways with which they were more familiar, but which might alienate or fail to elicit a response from him.

In most cases explaining their children was a practical matter for mothers. They tended to emphasize their children's needs and odd behaviors, rather than discussing the ontological question of what autism is. Katherine illustrated this practical emphasis in the following quote.

I just explain what types of behavior they may encounter and what to avoid. Things to avoid that might upset him, to make sure he has his medicine at a specific time, you know, just little quirks that any parent would have to explain about their kid. So I don't explain autism. It's just too big a subject and I don't even understand it, after all these years, so how could I possibly explain it to somebody else? All I explain is behaviors to look for and be careful of.

With every new person and situation mothers must assess when and how to communicate their children's needs and unusual behaviors in such a way that ensures they will be understood and accommodated, due to the incongruence of autistic embodiment and the normative behavioral expectations of others.

Explaining others to their children

Because the norms that guide the behaviors of people classed as NT can appear arbitrary, irrational and confusing to people labeled with ASD, mothers must also explain the world to their children. Renee, the mother of an 11-year-old high functioning boy named Ricky explained:

He doesn't completely understand the difference between what's acceptable and what's not. So he comes to me a lot with questions, and I explain them to him, but he doesn't always understand. I just hope that if I keep explaining it over and over and over, and as he grows older and experiences more, he'll understand what it all means. ... I usually explain certain things to him that aren't socially acceptable. And generally I say, 'you cannot do this, don't do that. And if you want to do this, ask me first'. He asks me lots of questions. He looks up a lot of stuff on the Internet that's appropriate – I mean actual research type stuff. And I've gotten him manuals, one's about the human body and he looks up all kinds of stuff. He's got the Merck Manual. He loves that.

Parents also rely on others to help explain the world to their children, especially when they feel they do not have experience or expertise with particular issues. Katherine, whose son Taylor was 15 years old, recognized that she could not answer all of his questions, especially as he grew older and his concerns became increasingly complicated. She recruited people with whom Taylor has established relationships to address questions about which they might have greater knowledge.

I've had his doctor explain sex to him. He's had a whole session on that. If he asks me something and I don't want to answer it, I'll say, 'Dr. Sanders can answer that question for you, and you can ask him any time. Do not talk to anyone else about this'. So I give him a list of three or four people, 'you can ask this person questions'. For instance his Big Brother Pete, through the Big Brother organization, has been with him for five years. I said, 'you can ask Pete, you can ask me, you can ask Jim, your special ed. teacher, you can ask Dr. Sanders, but you can't ask anybody else'.

Katherine had established a network of trusted people upon whom Taylor could rely to help him navigate the complexity of social relations. Aside from noting the irony presented above that a teenager labeled with ASD may have a more developed support network than many teenagers classed as NT, it is important to note here that

this delimited list of people with whom Taylor could speak about potentially sensitive or socially awkward topics such as sex was necessitated by earlier social missteps and misunderstandings involving Taylor. As the following excerpt illustrates, Taylor had transgressed a normative boundary during an e-mail exchange with a girl he knew from school. In the e-mails Taylor had brought up the subject of sex with the girl. Katherine continued:

And he does get in trouble with certain things. Like, he emailed this little girl about sex stuff. He had a crush on her and I had to tell him, 'this is not right, she's too young. You can't be doing this'. They [the girl's family] wanted to do an intervention. But he's very honest and upfront with any problems he has. He tells me everything, to the most embarrassing. ... But it's not been fun. He's 15, so he's right in the thick of adolescence, right? He's very aware of that, and I notice he's got these urges and I'm not quite sure he knows what to do with them, right at the moment.

Taylor's overtures to the girl were viewed as threatening by her parents, rather than the result of his being unaware of the inappropriateness of such a discussion. For Taylor he was simply following his sexual feelings for the girl unaware that he needed to be careful how he expressed them to her. The sexuality of adolescents with autism is a sensitive issue that parents must grapple with (Newport 2002), and one that requires delicate handling given the prevailing cultural attitudes about the sexuality of adolescents and children. Katherine knew the limits of her own ability to mediate for Taylor in this situation, so to help her navigate this difficult episode she relied on Taylor's doctor, an expert she presumed would have greater knowledge than she about how to constructively advise and guide her son's emergent sexuality.

Constructing and maintaining positive identities

In addition to their practical concerns, the above examples point to a vital dimension of mothers' mediation efforts: managing the uncertainty that may be produced in unfamiliar by their children's unusual behaviors. Anne, the mother of 16-year-old Aaron, considered high functioning, described the uncertainty of meaning that is sometimes produced in interactions between people with ASD and unfamiliar.

Aaron's actions say one thing – if it was out of some other 'normal' kid, it would say one thing that everybody knows, that's universal. But from Aaron, it's a totally different thing; it could mean something totally different. People get angry, like he's stolen things a few times. He'll take things when he's mad, but he's not really stealing. It's not about wanting the item per se. He knows it's not right to steal. He may be mad at someone and he's expressing himself in that manner. But people don't know that, and they interpret it as, you know, a kid just being precocious, getting in trouble. But that's not his purpose, to steal. It's his only way of expressing his anger or frustration. That's the way he does it.

Anne had available to her an alternative understanding of Aaron's behaviors, so that what appeared to others as a willful act of stealing, Anne understood as an expression of anger or frustration that Aaron has little control over. Meredith offered another example of the uncertainty that is produced in others as a result of her 22-year-old son Reed's unusual behaviors in public.

One day Reed and I were in the grocery store. He's usually really great in the store, and pretty independent. He'll kind of wander off and look at the videos or whatever, and I find him and we continue shopping. But this day I was checking out, and I think he had

gone to put a penny he found in one of the [mechanical] horses, down at the other end of the checkout area. He finds money everywhere we go. I call him my money magnet. Well, it must not have worked, because I had already checked out and I was walking toward where I thought he was, and I saw his shoe go flying up in the air. I was just like, 'Oh, God'. So, the horse didn't work, and he just went like that with his foot and the shoe went flying. It came down right between two of the checkout lanes. Luckily, it didn't hit anybody. Everybody was so startled; they didn't know what was happening. I just grabbed the shoe, grabbed him, and got out of there.

In this example Reed's behaviors do not seem to match his appearance, and the uncertainty that results is partly because of the common assumption that outward appearance is indicative of the self 'within'. In other words, people do not know how to interpret the behavior of someone who looks normal but whose behavior contradicts the common expectations of behavior for their age (Gray 1993).

There are no physical signs or visual cues that a person is autistic and unfamiliar are often confused or draw the wrong conclusion about the meanings of their behaviors. To control the meanings that unfamiliar may attribute to these behaviors parents attempt to reframe them as the result of neurological differences, rather than signs of unpredictability, deviant morality or immanent danger. Below, Katherine explains how she tried to influence how others viewed Taylor.

New neighbors just moved in across the street and they have a 13-year-old son. So I went over and I introduced myself, and I brought Taylor with me to introduce him too. When Taylor left I said, 'by the way, he is a very high-functioning autistic, so there are some little strange things you might see him do, just so you're aware'. I don't say much more than that, because they won't quite understand. I just give a brief little explanation so that whatever he does they're not going to be like, 'what's wrong with that kid?'

It is important to note that Katherine mentioned that she did not want her new neighbors to think that Taylor was strange, that there was something 'wrong' with him. She provided an alternative set of meanings for unfamiliar by using the term 'high functioning autistic', linking Taylor's potentially unusual behaviors to an increasingly available discourse about autism in popular culture, so that they might define the situation in a way that was more favorable toward him. There was an implicit moral concern in Katherine's narrative: she wanted the neighbors to realize that Taylor sometimes did 'strange' things because he was autistic, not because he was a bad, unpredictable or dangerous kid. In doing so, she was engaged in self-work for Taylor that may have made his behaviors comprehensible to the unfamiliar neighbors, attempting to preempt future confusion in order to maintain Taylor's identity.

Parents also reframe behaviors in terms of their children's strengths. Meredith provides an example in the following passage.

Once while Reed was using sign language, a younger child asked me, 'why doesn't he talk?' I replied, 'He is talking, with his hands'. The other child said 'that's cool!' and her entire demeanor changed. She seemed to become more interested in paying attention to what Reed was doing instead of judging what he was doing as worthless or senseless.

Had Meredith not reframed Reed's behavior the child would likely have left the interaction with the idea that Reed could not communicate at all and that his hand movements were just random, rather than symbolically significant. Instead, Meredith highlighted a skill of Reed's that the other child did not possess, offering an alternative way of understanding him. In addition to expanding the potentiality of Reed's identity

in this interaction, Meredith may have expanded the girl's notion of what counts as communication, and thus her view of Reed as a person.

Research on parenting children with disabilities demonstrates that unfamiliar commonly respond to the uncertain meaning of the behaviors of children with disabilities by presuming that the behaviors are the result of 'bad parenting', rather than the disability (Gray 1993; Read 2000). The following paragraph – taken from my field-notes – describes how Tammy negotiated this presumption during a routine visit to a new doctor.

Tammy described a visit to the family doctor's office with her son Nathan. Nathan had been having a difficult day, and was having difficulty sitting quietly in the waiting room. At one point, Nathan began to cry quite loudly. Tammy described the others in the room becoming 'visibly uncomfortable' as evidenced by their furtive glances at she and Nathan, and their efforts to ignore them. Tammy also noticed the receptionist looking at her several times with an increasingly severe look on her face. Finally, the receptionist walked over to Tammy to ask her if she would please control her child. Tammy, holding back a flood of anger at this question, explained to the woman that Nathan was autistic. Upon hearing this explanation, the receptionist reacted visibly, showing surprise and exclaiming 'oh!' before apologizing.

In this example the receptionist had defined Nathan's behaviors, not unreasonably, as those of a 'spoiled child', perhaps on the basis of her previous experiences with children in the waiting room. She assumed that the reason Nathan was crying was because he was not getting 'his way' and that the appropriate solution was for Tammy to discipline him. When Tammy provided autism as an explanation the receptionist was forced to reassess the situation, and arrived at a different conclusion. Tammy mobilized the signifier 'autism', which today is more available than ever before, in an attempt to redefine the situation contrary to the definition reached by the receptionist. With this new information Nathan's behavior made different sense. It became more acceptable that he was crying and inconsolable because, among other things, in the popular imagination autism connotes the inability to control oneself.

The potential for people to perceive someone labeled ASD as a threat can also be seen in more mundane circumstances, such as when a person with ASD has a so-called 'meltdown' – a common label used by caregivers to describe someone who appears severely agitated and to have lost control of themselves – in a public setting. As they attempted to reframe these 'meltdowns' in their explanations to unfamiliar parents often emphasized their children's need for sameness and predictability. If routines were interrupted, parents explained, their children have difficulty readily adapting to or accepting that their desires will not be met. Parent's explanations located this need for sameness in the disorder itself, a feature of autism that was 'hardwired' in their children. The term 'meltdown' conjures up nuclear imagery and the notion that the processing capacity of a reactor – in this case the ability of a person to manage themselves in the face of unfavorable or undesired circumstances – has been exceeded and that the reaction has got out of control. The 'out of control' behaviors are said to be the result of some internal inability to handle a rapid change in inputs, and the over-abundance of stimulation that results. Meredith provided an example of a 'meltdown' in which Reed's job coach explained to an unfamiliar Reed's need for predictability in his routine.

Reed really wants things to go like he thinks they should go, or he's used to them going. He rides the [local bus], and he has a bus pass, but he's never ridden unassisted. One day he was riding the bus, and it stopped at [a nearby school] and our house is the next stop.

And for some reason, the bus was ahead of schedule. It had gotten ahead of another bus and shouldn't have. So the driver was going to stop there and let the other bus go past. And he said to Reed, 'You can get off here and walk, or you can get off here and get on the other bus'. And Reed could not handle that. He went crazy. He sat down and took his shoes off – he always takes his shoes off when he's mad. And, luckily there were no other people on the bus, and the job coach – she was with him – told the driver, 'You have to understand, he can't handle this kind of change. Can you just drive up to the next stop?' Luckily, he did. But had there been other people on the bus, he probably wouldn't have. It was just that kind of thing where some little glitch happens and it's out of his schedule, out of the ordinary, and he just totally falls apart. If he isn't with somebody who can explain for him, then I don't know what would happen. It's hard, having to have an assistant who can be your communication – not just verbally, but behaviorally too, to interpret that.

Meredith emphasized the importance of Reed having someone with him who can interpret his behaviors that might result from a disruption of his routine. Had Reed's job coach not been with him to explain to the bus driver why Reed had become so upset, and what might be done to help him, the situation might not have been resolved so easily. Framed in terms of an embodied inability to readily adapt to changes in his routine, Reed's behaviors lost their threatening quality and the bus driver could simply drive to the next stop and let him off, without feeling that his safety has been compromised or his authority challenged.

While the above example demonstrates the successful reframing of behaviors and resolution of conflict, not all misunderstandings end so happily. The killings of Kevin Colindres (Diaz 2006), Michael Clement (National Association of Personal Injury Lawyers, <http://www.napil.com/PersonalInjuryCaseLawDetail34346.htm>) and Raymond Lee Mitchell (Burge 2007) and the repeated taserings of Sir J. Millage (Davis 2007) are just a few examples that demonstrate the grave danger of misunderstandings based on unfamiliarity with autism in encounters involving the police. Moreover, these examples illustrate the importance of both successful interpretation and reframing practices on behalf of autistic people, and the need for increased awareness and understanding of autism in the police force and society generally.

In the process of reframing their children's behaviors to unfamiliar some parents attempted to directly engage unfamiliar's feelings about their children's strange behaviors, anticipatorily empathizing with and comforting the unfamiliar person. In the following passage Joan discusses how she would explain Trevor's unusual behaviors to a new neighbor such that he would appear non-threatening.

I might say 'this is Trevor; he has autism. And what that might mean is that you might find him in the back of your pickup cab, or on top of your car'. I just try to make it kind of light hearted. I try to very proactively tell people, to anticipate that they might be uncomfortable because he's doing something weird or not looking at them, so I'll say 'you know, autism has these funny things'. I guess I am just consciously trying to anticipate what somebody might be uncomfortable about, and help them get over that. He's gone and eaten other people's food in a restaurant, in the past he's taken his clothes off in various places, and sometimes it's really embarrassing. I know that the average person is going to feel sorry for me thinking, 'that must be hard', and I want to meet that and say 'this is autism and this is what it's about. Isn't it a weird thing, or isn't it a funny thing?' It just makes it a lot easier.

One can read the above example in multiple ways. Joan's anticipatory feeling management aims, on the one hand, to reduce the discomfort experienced by unfamiliar because of Trevor's strange behaviors by offering an alternative, non-threatening

explanation. By identifying Trevor as autistic, and casting his actions as a curiosity – as a benign quirk – Joan hopes to reduce the fear and uncertainty in others that Trevor's behaviors might evoke, thereby enhancing the possibility that others will have a positive view of him.

On the other hand, one can also see that Trevor's behaviors produce social discomfort for Joan, a courtesy stigma (Goffman 1963), as shown by her saying that Trevor's behavior can be 'embarrassing'. Because children are extensions of their parents, parents are often blamed for their behaviors. Thus Joan's emotion management is also an attempt to manage her own identity. She is attempting to protect herself from stigma at the same time as she is helping the unfamiliar manage their own feelings. Joan's emotion management is effectively an attempt to redefine the situation for the unfamiliar such that Trevor's identity remains intact. Understood in terms of identity, mothers' mediation efforts aim to increase the possibility that their children will be understood and accommodated by others and that, despite the fact that they may at times offend normative sensibilities, they are afforded respect as people.

The behaviors of people labeled with ASD may appear odd and cause confusion on the part of unfamiliar. Left unmediated, their meaning is open to a range of interpretations, most of which would likely be inaccurate and unfavorable. Crying inconsolably in the doctor's office or throwing one's shoes into the air may connote a 'spoiled' child, whereas an adolescent or adult labeled with ASD might appear threatening, potentially resulting in escalating tension and fear in situations involving those unfamiliar with ASD. Durand (1991) suggested that these types of 'behavior problems' are not pathological, but rather 'reasonable behavioral adaptations necessitated by the abilities of our students and the limitations of their environments' (6). In other words, many of these behaviors are communicative attempts that suggest a deep frustration by people with limited or just fundamentally different forms of communication. By providing alternative explanations for these sorts of behaviors, parents hope to affect the interpretations of others such that their children might be better understood and accommodated. Moreover, to the extent that they are successful in reframing their children's behavior in terms of frustrated needs and disrupted routines, parents will have negotiated hegemonic normality and ultimately facilitated the construction and maintenance of positive identities for their children.

Conclusion

The findings presented above confirm previous studies (Read 2000; Ryan 2009) that suggest that mothers of disabled children act as mediators for their children in a variety of ways and settings. These data extend previous research by suggesting that mothers' mediation practices are vital for the formation and maintenance of positive identities for their children and themselves in the context of the lived experience of disability. I have argued that mothers' mediation might best be conceived as the performance of proxy self-hood for their children. Mothers and their allies actively seek to define the meaning of their children's behaviors so that they may be better understood and their needs accommodated. Viewing their children as intelligent, fully formed persons who have embodied differences that sometimes make normative modes of communication difficult, mothers see their children's behaviors as communicative gestures and learn to read their meanings. As they translate and mediate for their children, mothers decipher these meanings for others in an attempt to advocate for their children's needs and frame their identities positively in social interactions.

Mothers also decipher the rules of social interaction for their children, helping them to understand how to function in the world. Further, mothers attempt to reframe the actions and behaviors of their children such that unfamiliar will better understand the reasons underlying their children's unusual behaviors and be better able to interact with them in the future. If their attempts at reframing their children's behaviors are successful, mothers will have widened unfamiliar's understanding of autism and thus will have chipped away at hegemonic norms of embodiment that lead to fear and exclusion of people with autism and other differently configured and performing bodies. Thus, mothers' performance of proxy self-hood makes possible social identities for themselves and their children that may not otherwise be available.

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