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## Oughtism and Oughtistic Narratives in the Lives of Autistic People and their Families

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## Oughtism and Oughtistic Narratives in the Lives of Autistic People and their Families

### Cover Page Footnote

Final draft - errors amended

# Oughtism and Oughtistic Narratives in the Lives of Autistic People and their Families

Mairi Evans

I would like to invite you to reflect on the prevalence and pervasiveness of *oughtism*. You may or may not have heard of this term, or maybe you first thought I had made a spelling mistake, but it is highly likely since you are reading this particular journal that you too have experienced oughtism, or on occasion may even have been oughtistic yourself.

In this essay, I provide a definition of oughtism and share my understanding of what oughtism is. I offer stories that capture how oughtisms are created and how they influence the lives of autistic people and their families. Oughtism is a social practice that impacts the lives of autistic people and their families. It informs how services are formed and delivered, how autism is named and identified, and how autistic people and their families feel about who they are and how they should act.

This article is presented as a tapestry of ideas woven from stories and examples from my professional and lived experience and I write from a number of perspectives. Personally, I write as a parent and member of a neurodiverse family. Professionally, I am a systemic practitioner who works therapeutically with families where one or more family members has a diagnosis of autism as well as additional emotional or mental health challenges. I have worked as the clinical lead of a diagnostic pathway and am also a researcher currently exploring the maternal experience of autism diagnosis for girls. Where necessary, changes have been made to protect the identity of others. It is my hope that by raising awareness of oughtism, you will become more aware of the oughtisms that inform your life, the lives of your loved ones and those you work with. In turn, you may be free from some of the restraints that oughtisms can have on our lives. I will start with the story of Rebecca.

## Oughtistic Social Behavior: Rebecca's Story

*The party was in full swing: the busy chatting, music and laughter combined to fill the room, and everyone stood close leaning in to hear what was being said. Rebecca had spent almost the entire party in the quiet of the kitchen. She chatted to close acquaintances that came to say hi, but she rarely entered the room where the party was most rambunctious. As she went home, she reflected on the evening. She had enjoyed this party more than many that she had attended in the past. In the past, she would have forced herself to go into the noisy, crowded room, she would have drunk more alcohol to help her feel confident to talk to people who made her feel self-conscious, and after the party, she would have analyzed every word and interaction out of a fear that she had said or done something wrong.*

*This time, Rebecca spent the evening how she wanted to, challenging the dominant narratives of oughtism that had influenced her so strongly in the past. The oughtism: you ought to talk to everyone, that you ought to enjoy the hustle and bustle of the party, and that you ought to be funny and entertaining at all times. In living up to oughtism she had always gone against what made her happy and done what she perceived others would tell her that she ought to do. This often left her feeling exhausted and full of self-blame and self-recrimination. This party had been different; this time she had done what she felt confident and happy doing. She had been herself. She had given herself the permission to allow her identity as an autistic woman to be more dominant than the oughtistic narratives that she had tried to live up to in the past.*

The story above describes how Rebecca, an autistic woman diagnosed in her 40s, overcame oughtism and was able to put her own needs and well-being above what she had previously, sometimes unknowingly, felt she ought to do. There has been much written about increasing rates of diagnosis of autism, which many feel is due to an increase in knowledge or changes in diagnostic processes rather than an increase in the prevalence of autism itself (Arvidsson et al., 2018; Grandin, 2014; Hassall, 2016; Elkington & Jones, 2015; Russell, 2012). In its history and conceptualization, the diagnosis of autism has been informed by many oughtisms: what autism is; what autism is not; who has the power to define, identify and describe autism; and whose voices carry the most weight.

My use of the word *oughtism* combines “ought” and “ism.” The dictionary definition of *ought* is to critically express “obligation, advisability or probability.” You *ought* to do something, you *ought* to act in a particular way, you *ought* to feel a certain way, a certain thing *ought* to happen. In the example of Rebecca, she believed that she should make an effort to join the party and talk to all the other guests because “that’s what you ought to do at parties.” This example highlights how oughtisms can be internal processes as well as those informed by explicit external instructions or narratives, potentially created by years of observation of a perceived norm. The Merriam-Webster Dictionary defines *ism* as “a distinctive doctrine, cause, or theory, an oppressive and especially discriminatory attitude or belief” or “prejudice or discrimination on the basis of a (specified) attribute.” Oughtism, then, is “the practice of criticizing others, telling others how they should or shouldn’t be and questioning their actions and beliefs” (Evans, 2018). If a person tells another person someone who they should be, what they should be doing, and how they should act in order to comply with a set of norms or social standards, or judging them regardless of their needs or abilities, then they are being oughtistic.

Observed through a social constructionist lens, oughtisms are co-created stories and narratives that can differ across time, place, culture and context. Some have more power, depending on who creates and perpetuates them; others will have more influence due to the context in which they exist. They are perpetuated by diagnostic manuals and research articles, shared through news reports, and retold within families and interpersonal relationships. Some will be overt and apparent, and some will go unnoticed despite the power they hold over those who are influenced by them.

Social constructionism takes the view that meaning is created between people in communication, and this meaning influences how we, as human beings, understand the world. The meanings, or stories, that are created can make us feel that we can and cannot do things, that we should or should not do things, and they also impact on how we view and understand the behaviors of others. These meanings are not fixed: each person will experience them in their own unique way due to their own lived experiences and abilities. Still, some of these stories hold more

power than others. For example, the stories told by scientists hold more influence in some cultures, while in others it might be religious leaders.

Taking this perspective encourages us to ask who is telling us how we ought to think and feel about autism. How do they impact on the lived experience of autism and how are we, as a diverse population of human beings, coordinating these meanings with one another? Where do these stories and beliefs “either liberate or enslave us” and where do they “liberate or subvert (our) human values” (Pearce, 1989, p.11)?

The power of these stories should never be underestimated. In 1998, Andrew Wakefield published research that connected the MMR vaccine with an increase in the prevalence of autism. Despite a later retraction of his findings and evidence that his research was falsified, there continues, to this day, to be reluctance by some parents to vaccinate their children, which has led to an increase in measles in parts of Europe and the USA (Boseley, 2018; Glancy, 2019). Wakefield’s legacy, “you ought to avoid the MMR because it can cause autism,” has resulted in an increase in a disease that has far more risks for the health of populations than the condition or difference that it was falsely connected to.

Oughtism can also manipulate how autistic people feel about themselves, how they can and should act (as in the example of Rebecca), their happiness, and their mental health. In their most extreme form, oughtisms influence perceptions about the very existence of autistic people. Oughtistic discourses and narratives about autism are present in all aspects of society: they exist in family scripts about past and present family members; they are in the school playground and at school pick up; they are in the news and in magazine articles; they are in films, television shows, and novels. In all of these spaces there are oughtists who inform how people understand, think, feel and act around autistic people.

## **Oughtistic Diagnosis: Emma’s Story**

*Emma watched her daughter as she played with the other children at the park. She knew her daughter was different in some way but could not put her finger on how. She had read about autism but when she watched her daughter this didn’t seem to fit. Her daughter was in the middle of things*

*with the other children, not playing alone. She was communicating both verbally and used gestures as she took control of the play with the other children. They were playing vets—her daughter loved animals—and this did not seem to fit with the lack of imagination and social play that she had read about with autism. When they left, her daughter hugged all the other children and then came and looked right at her mum to ask about going to the pet store on the way home. No, according to what she had read, this was not what you ought to see with autism. She would try to put to out of her mind.*

The early identification of autism by Kanner (1943) and Asperger (1938) focused strongly on the observation of autistic male children. With this male focus came one of the earliest, and for some, the most significant of the oughtisms: “to be autistic you ought to be a boy.” The result was that autistic women and girls face what is described by Loomes (2019) as “additional hurdles in the form of authoritative discourses detailing how autism is predominantly a male experience” (p. 141). The few girls identified in early studies had significant learning difficulties leading to the additional ought that autistic girls ought to be “more autistic.” Then came Baron-Cohen’s (2002) “Male Brain Theory,” which brought with it the ought that for a female to be autistic she had to be genetically more like a male.

This means that the story of Emma is not an uncommon one, and it is one I have heard on many occasions as both a practitioner and as a researcher. The misunderstanding of autism as a male condition can lead to confusion, and of more concern, it can lead to delayed diagnosis, misdiagnosis, and unidentified need. Research shows that autistic girls are 13 times less likely to be identified by early year’s teachers (Hiller, 2014). Moreover, parents often wait to have their suspicions about autism corroborated by professional before seeking an assessment (Braiden, Bothwell, & Duffy, 2010). It is therefore unsurprising that, on average, autistic girls are identified later than their male counterparts (Hull et al., 2016).

As research into autistic girls and women increases, there is a better understanding of camouflaging and the many ways in which an individual can experience and/or hide being autistic (Attwood, 2007; Dean et al,

2017; Goldman, 2013; Gould 2017; Hiller, 2014; Hiller, 2015). However, it could be argued that we now run the risk of creating an understanding that male and female autism ought to be viewed as different across the entirety of the autistic population, potentially leaving a number of males who camouflage unidentified as they do not fit with either the traditional “male” view of autism or the newly defined “female” one. When I worked in a diagnostic practice, this often led to me asking, “What would we be saying if he was a girl?”

Along with Eisenberg, Kanner framed the initial diagnostic definition of autism in 1956. In this early definition, Eisenberg and Kanner identified what one ought to have for a diagnosis of autism. This has led to various beliefs about autism such as “you ought to avoid eye contact,” “you ought to play alone,” “you ought to lack empathy,” “you ought to speak in monotone,” “you ought not to use any gestures.” Yet, this list of symptoms also created an understanding of what signs or behaviors ought to be excluded from diagnosis, which has resulted in many autistic people being misdiagnosed or being told they “don’t look autistic.” While all are possible indicators of autism, there are of course autistic people who make eye contact, uses gestures, appear very sociable, and empathize well.

Another problem was that Eisenberg and Kanner defined autism based on what the diagnostician “ought to see” when observing an autistic person rather than focus on how an autistic person may feel. This in part is due to the early focus on autism as a childhood disorder and the early “othering” of autism as something to observe, or, in the case of psychologists such as Lovass, correct (Devita-Raeburn, 2016). This early childhood focus led to a limited amount of research and understanding of autism and aging. As a result, the majority of services have been child-focused. Waiting lists for adult diagnostic services in the UK are now on the rise due to the number of adults seeking a diagnosis, often following the diagnosis of one or more of their children. This challenges the early notion that to get a diagnosis of autism “you ought to be a child.”

The change in diagnostic definitions and terminology has led to changes in what terms ought to be used or not used when diagnosing autism. Asperger syndrome was added to DSM-IV and later removed from DSM-V,



the triad of impairments was added and then later changed to a dyad, and a new diagnosis of social communication disorder was introduced. These powerful oughtistic narratives influence how autism is classified and diagnosed. The positioning of autism in the diagnostic manuals also created the belief that “you ought to be a medical professional to have the power to diagnose or not diagnose.” The agency of the individual to define autism and the autistic experience is reduced due to the dominant medical discourse that asserts medical practitioners as those who have the power to decide. Should the manual writers and the diagnostic fashions of the moment have the power to decide how autism is defined, what is in and what is out, who is autistic and who is not?

Furthermore, the language of diagnostic manuals has meant that “you ought to focus on deficit and impairment,” which excludes many of the perceived and experienced strengths of autism. The reliance on medical manuals and the deficit rhetoric used within them challenges the power of the individual to self-identify as autistic or to celebrate their autism. Fortunately, medical manual’s deficit logic is being proactively challenged by the neurodiversity movement and events such as Autistic Pride (Armstrong, 2010; Bhandari, 2016; Singer, 2017). However, for a newly diagnosed person taking a first look on the internet, or a parent wondering if autism is an explanation for some of the challenges experienced by their child, it still is highly likely that dominant historical oughtisms will be the first things they read.

## Family Oughtisms: Sophie’s Story

*Sophie stood in the kitchen and reflected on the evening meal. One of the children, her oldest, had eaten in their bedroom. Her middle child had sat at the table briefly but had finished before her youngest had even started. They all ate something different. Her youngest had been eating the same food for about two months. The oldest refused to eat anything that required a knife and fork, and her middle child seemed to get more on the floor than near his mouth. She knew he would be snacking later. She had not even had chance to eat yet and would cook for herself and her husband later. She felt like such a failure as a parent. She had read articles on family mealtimes, the importance of sitting together as a family, the benefits of a mixed diet, “a family that eats together stays together.” She had tried to achieve this*

*utopian family gathering for years but had now given up. When they did sit together, the combination of different sensory needs, speeds of eating, anxiety and activity meant that everyone got frustrated. Yes, she had read how they ought to be as a family, but with mealtimes and many other aspects of parenting, for her family it just did not seem to work.*

Oughtism is ubiquitous in parenting of any kind. There are endless books, courses and programs that describe what “good parenting” ought to look like. How you should parent, how you should feel about parenting, and how your children ought to behave are all informed by strong cultural and societal stories and beliefs which differ across time and context. For families with an autistic child, or for an autistic parent, the oughtisms are tenfold. Dominant discourses about parenting can cause additional challenges when they do not fit with the individual needs of your family, and dominant discourses about autism do not fit when they wrongly inform others about your ability to care for your child.

In its early days, the autism story was very much one of blaming the mother. Kanner’s early work (1943) referred to the cold nature of the parents of the children he observed, particularly the mothers. This “you ought to blame the mother” theory was later reinforced by Bruno Bettelheim 1975 text, *The Empty Fortress*, which coined the phrase “Refrigerator Mother” and located the “cause” of autism firmly in the behaviors of the mother. Mother-blaming narratives exist across more than one culture but the content of the stories can differ, for example Landsman (2009) refers to women in Mozambique being seen as the source of a child’s disability due to bad spirits brought from her family, and in some Latin American cultures a child’s disability is seen as the direct result of a mother being cursed (Otufat-Shamsi, 2005).

An alternative story for the mothers of children with disabilities is that “you ought to see the mother as a special mother for a special child.” Landsman (2009) suggests that whatever the narrative that surrounds a mother of a disabled child, they are “not construed as morally equal. Either they are worse than others, ‘bad mothers’ or they are ‘better,’ special mothers chosen by God” (p. 89). There has been significant focus on mothers: research that exists about parenting and autism is largely “skewed towards the experiences of mothers” (Cheuk & Lashwicz,

2015). This relative lack of attention to experiences of *both* parents does not allow for an exploration of different experiences due to gender, parental-child relationship, or the social and cultural expectations placed on parents about what it is to be a mother or a father (Evans, 2017). In a systematic review of 48 articles and studies, exploring parental stress and coping in mothers and fathers of autistic children, Flippin & Crais (2011) found that while mothers reported higher levels of stress or anxiety in the majority of studies, the source of stress for mothers and fathers was different. Mothers were most likely to experience elevated stress levels due to their child's "regulatory behavior," such as feeding or sleeping while "fathers reported that their child's externalizing behaviors (e.g., tantruming) were the greatest source of their child-related stress" (p. 40).

An examination of the changing roles of fathers in recent years highlights a move to sharing more of the nurturing role with their children, especially with the increase in dual income families (Cheuk & Lashewicz, 2015). Cheuk and Lashewicz suggest that "disability-specific demands provide impetus for father-child time and part of this impetus is a relatively pronounced sense of the need to work in partnership with their wives, not only to ensure the needs of the children are well met, but also so each parent has opportunity to pursue individual interests" (p. 504). While some services are now working to include fathers and offering dedicated fathers groups, the experience of some fathers I know has been "you ought to be the mother if you want to access support for parenting an autistic child."

Both mothers and fathers will be informed by internal and external oughtisms. Internally they will hold their own stories about what they thought their family would be like, ideals informed by childhood memories or the hopes they had when they started a family. Externally, as with Sophie and mealtimes, they will also be informed by books, films and societal stories about what good parenting ought to look like. They will see other families, hear comments from other parents and family members and at times even get comments from strangers in the street. This will be balanced against supporting the needs of a child who may communicate their distress and frustrations in the home, sometimes in ways that can be destructive to their family, themselves, or the house itself.

The needs of autistic children may differ from the dominant oughtistic discourses that surround them. With the example of Sophie, something as “simple” as mealtimes might be informed by different aspects of sensory processing, the texture of foods, the smells of food, reactions to different tastes, proprioception difficulties, appetites suppressed by medication, anxiety, different needs for communication or quiet, and any number of things that make sitting as a group and all eating the same meal a challenge. The different needs of her children might mean that the best way to get them to eat is to give them different meals in different rooms, very different to the narratives about eating together.

However, due to the oughtisms surrounding mealtimes, Sophie felt that she had failed at getting things right rather than succeeded at meeting the needs of her family. As a therapist, I have found that this is a constant pressure for families, as they strive to meet the individual needs of their children while feeling that they are being judged or perceived as failing due to their inability to conform to oughtistic narratives. Farrugia (2009) and Gray (1993, 2002) suggest that it is the “normal” appearance of autistic children that can lead to the biggest challenge for parents. This is potentially even more so for girls who are believed to mask their anxiety and behaviors in school, while communicating their distress in more aggressive and concerning behavior in the home (Hiller, 2014; 2015; Sarris, 2015). This combination of challenging or misunderstood behaviors and the “normal appearance” of the child can lead to a multitude of oughtisms, such as:

- You ought to leave him with me, I would sort him out.
- You ought to make him look at you.
- You ought not to seek a diagnosis for her.
- You ought to tell her off more.
- You ought to make him eat it. You ought to make her wear what you bought her.
- You ought to make him use a knife and fork.

- You ought to keep him at home.
- You ought not to keep him at home.
- You ought to stop protecting her.
- You ought to make him do more.
- You ought to listen to the professionals.

These oughtisms, and many like them, often position parents between what is perceived as “good parenting” and being the parent that their child needs. For autistic parents, particularly mothers, this is made significantly harder due to additional oughtistic narratives about how autism may influence a person’s ability to be a good parent, such as stereotypes about lack of empathy or emotion.

Stories and beliefs can enable and inform us, but when they contradict each other, or when they do not fit with our needs they can cause us to feel stuck, or overwhelm our emotions. For parents of autistic children, oughtisms can impact the ability to make parenting choices, self-esteem, spousal relationships, and ultimately, their relationship with their child. Societal stories about what behaviors are correct and how their children ought to act may also lead parents into trying to change or shape their child’s behavior an attempt to protect them from potential bullying, ridicule, or lack of acceptance. This was highlighted in my conversation with one mother about mealtimes. She was battling to get her son to use a knife and fork for fear he would be stigmatized by others if he did not. Her desire to protect her son from ridicule for not conforming to the oughtism, “you ought to use a knife and fork” was in conflict with her efforts to get him to eat a meal. The use of a knife and fork is a culturally dependent oughtism: there are many cultures that do not use them at all. Helping families to name and identify the oughtisms that constrain them can in turn help them to break free and make choices about what works for them, rather than what others make them feel they ought to do.

## Re-authoring Oughtism through Neurodiversity: Simon's Story

*Simon watched the news report silently. The reporter was describing the outcomes of a recently published study about autism. The researchers claimed that they were close to detecting indicators of autism in utero, with the suggestion that parents could then choose if they wanted to continue with the pregnancy or not. After feeling different for most of his childhood, he had recently, at age 15, received a diagnosis of autism. His initial response to the diagnosis had been relief: now he had an answer to why he struggled with things his peers seemed to be able to take in stride. Now, as he watched the news report, he could not help but think about his parents and how they might have reacted if they had known he would be autistic when his mother was pregnant. Would they have continued with the pregnancy, or would they have made the decision that they ought to get rid of him?*

The largest percentage of autism research is focused on cause, prevention, and cure, and a significantly small percentage of research aims to learn about and inform “lifespan issues and resources” (Pellicano, & Stears, 2011; Pellicano, et al., 2014). The dominance of research around causes and cures suggests that people ought to be more focused on preventing autism than making the lives of autistic people and their families better. Alongside the focus of research, many traditional autism awareness campaigns “focus on the importance of normalizing and curing autistic people” (Gillespie-Lynch, 2017, p. 11). If this is the normative culture of autism campaigns and research, what narratives are being created about autism for those who have recently received a diagnosis? How does it inform how they ought to feel about themselves and how they are viewed by the society in which they live their lives?

While the understanding of autism as a diagnosable disorder is now over 60 years old, in the past 20 years there has been the steady development of an alternative understanding, that we ought to see autism as difference, not disorder. In the late 1990's Singer (1999) advocated that autistic people such as Simon ought to be understood as neurologically different in the same way that we understand people as culturally or ethnically different. Autism can be seen as part of the vast variation of the human

condition, to be appreciated and celebrated, not a fault or an anomaly to be diagnosed and corrected.

Twitter and social media have given a platform for many autistic people to have a voice, and alongside the emergence of the neurodiversity movement, autism can be seen as something to identify with and to celebrate. Autistic adults are able to advocate for autistic children, sharing their lived experience, strengths and challenges. However, the increase in autism advocates in the media and social media has led to some resistance from those who feel we ought to see a difference between autistic adults and autistic children, especially those who have more difficulties communicating and/or additional learning and physical needs. In our attempts to highlight the strengths and benefits of a neurodiverse population, it is also important to ensure that we do not silence the voices of those who need to express their difficulties with neurodiversity. We should celebrate neurodiversity, but we ought to make sure we do not silence people when they need to talk about the obstacles and challenges they face within their daily lives.

In June this year, my children and I attended our local autistic pride event. An event run by autistic people, for autistic people and their families. Autistic Pride Day, which started in 2005, is the antithesis to autism awareness events. Rather than saying people ought to be aware of this “disorder,” its message is that we ought to understand and celebrate difference. Yes, autism has many challenges but these can be, at least in part, due to external social demands, the modern-day environment, the education system, and a lack of understanding about difference.

In science, autistic people are involved in research as advisors, reviewers, or as the researchers themselves. The message being that you ought to include autistic people in research about autism, or “nothing about us without us” (Charlton, 1998). Autistic people ought to be seen as the experts in their own lived experience, moving the research community from an about-ness position to a with-ness position. Gillespie-Lynch, (2017) highlight that “autistic people should be considered autism experts as they often build upon insights derived from the lived experience of being autistic (p. 11). In conferences in the UK, there is an increase in autistic people talking about their experience of being autistic, or their

own practice and research, rather than just a focus on non-autistic professionals talking about their “expertise.” After much debate, there is also an increased agreement that they ought to be remunerated equally for doing so.

## A Final Thought

Autism is made up of layers of oughtism (Simon, Evans, et al., 2020). Oughtisms are powerful, co-created narratives and beliefs that inform how we feel and how we act, and how we think we ought to feel, and how we think we ought to act. They dominate medical and social discourse, they exist in relationships both personal and professional, and they are perpetuated in our actions, in medical journals and in the media.

It is my hope that by raising awareness of oughtism, you are now more aware of the oughtisms that inform your life and the lives of your loved ones and those you work with, and that you will then in turn be free from some of the restraints that oughtisms can have on our lives. Perhaps you can create new oughtisms that work better for you and your family. Oughtisms such as “you ought to do what makes you happy,” “you ought to learn to embrace diversity and celebrate difference,” and “you ought to give autistic people a voice.” Re-authoring some of the oughtisms that surround autism will not make life easy, but it can potentially stop making it harder. It is not for me to tell you what your own oughtisms should be, that in itself would be oughtistic. What I hope is that by drawing the dominant narratives of oughtisms to your attention I may have enabled you to challenge and be free of them, just like Rebecca.

**Mairi Evans** is a systemic family therapist, supervisor, and social worker with experience across a number of settings within the UK. She is currently studying for a Professional Doctorate in Systemic Practice at Bedfordshire University, where she researches the maternal experience of diagnosis for autistic girls. Mairi’s writing is informed by her practice, her research and her experience as a member of a neurodiverse family.



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