The Models of Disability and the Effect of a Child with Autism on the Family

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In this paper, I begin by discussing the medical and social models of disability, and recent arguments to combine or move beyond these models, and define autism. I use the literature on the effects of a child with autism on the family to demonstrate that neither the medical nor the social model of disability could encompass the effects of autism on the family. Although parents discuss social constructions that are disabling to people with autism, such as society's lack of understanding, they also talk about impairments, such as aggressive behaviours.

Models of Disability

The model of disability has changed, grown, and branched out over the past 30 years. It began with the medical or individual model of disability, which was overtaken by the social model of disability. The social model is based on the concept that the medical model looked at impairment, while the social model looks at how society disables people with impairments. As the social model of disability also began to be critiqued, theorists tried to combine or move beyond the medical and the social models of disability. There is currently no dominant model of disability that combines or moves beyond the medical or social models of disability.

Before the 1980s, the medical model was the dominant model of disability.[1] As Siebers points out, "disability has been a medical matter for as long as human beings have sought to escape the stigma of death, disease, and injury".[2] Siebers defines the medical model of disability as "an individual defect lodged in the person, a defect that must be cured or eliminated if the person is to achieve full capacity as a human being".[3] Wendell gives the United Nations definition of impairment as "any loss or abnormality of psychological, physiological, or anatomical structure or function".[4] In summary, the medical model only looks at the effect of an impairment on a person, not the social effects leading to disability. It treats the impairment as the cause of the problems the impaired person faces, and it looks for solutions that cure the impaired person's impairment.

Siebers defines the social model, as opposed to the medical model, by defining disability relative to the social and built environment, arguing that "disabling environments produce disability in bodies and require interventions at the level of social justice".[5] The social model of disability "does not treat disease or disability, hoping to cure or avoid them; it studies the social meaning, symbols, and stigmas attached to disability identity and asks how they relate to enforced systems of exclusion and oppression".[6] Thomas claims that now that disability is defined by social barriers, "the term 'disability' now refers to a type of social oppression, and disablism enters the vocabulary alongside sexism, racism,

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[1]Colin Barnes, Mike Oliver, and Len Barton, "Introduction," in *Disability Studies Today* (Malden: Polity Press, 2002), p. 3.
[2]Tobin Siebers, *Disability Theory* (Michigan: University of Michigan Press, 2008), p. 3.
[3]*Idem*
[4]Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability,* (New York: Routledge, 1996), p. 13.
[5]Tobin Siebers, *Disability Theory* (Michigan: University of Michigan Press, 2008), p. 25.
[6]*Ibid*., p. 3

and other discriminatory practices".[7] In summary, the social model looks at the social world as the only cause of disability, and it looks for solutions in changing the social world.

Combined Models of Disability

Neither the medical nor the social model of disability adequately represents the lived experiences of people with disabilities when taken separately. Barnes, Oliver, and Barton claim that "concerns have been expressed regarding the social model's apparent neglect of the experience of impairment, the body, and questions of difference".[8] The social model has been questioned by various theorists, including Allan.[9] Other theorists have attempted to combine the social/medical models, or impairment/disability, to create a blended model based on this dualism. There is not one generally accepted model of disability that goes beyond the social/medical models.

Wendell (1996) argues that we need a balance between thinking about impairment as uncontrollable, and thinking of disability as so socially constructed that it is controllable by human action and thought. She acknowledges that social justice can eliminate some disability, but that there is some impairment that cultural change cannot solve.[10] She gives a concrete example of the need to look beyond socially created aspects of disability when she talked about her own experiences getting sick:

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[7]Carol Thomas, "Disability Theory: Key Ideas, Issues and Thinkers," in *Disability Studies Today,* ed. C. Barnes, M. Oliver and L. Barton (Malden: Polity Press, 2002), p. 38.

[8]Colin Barnes, Mike Oliver, and Len Barton, "Introduction," in *Disability Studies Today* (Malden: Polity Press, 2002), p. 9.

[9]Julie Allan, "The Sociology of Disability and the Struggle for Inclusive Education," in *British Journal of Sociology of Education,* vol. 31, no. 5 (2010), p. 603-619.

[10]Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996), p. 45.

> "I felt taken over and betrayed by a profound bodily vulnerability.... This experience was not the result of any change of cultural "reading" of the body or of technological incursions into the body. I was infected by a virus, with debilitating physical and psychological consequences. Of course, my illness occurred in a social and cultural context, which profoundly affected my experience of it, but a major aspect of my experience was precisely that of being forced to acknowledge and learn to live with *bodily*, not cultural, limitations".[11]

She had to come to terms with both her disability and her impairment, and finds the experiences of the body relevant.

McClimens criticizes the social model of disability in light of people with intellectual disabilities. He points out that many people with intellectual disabilities feel excluded from a model of disability designed around people with physical disabilities. He claims that the social model could be oppressive to certain sections of people with disabilities. He starts a discussion on thinking of disability on a continuum. He asks "is there some middle position that allows for the experience of intellectual disability to be understood as an amalgam of both?".[12] He believes that impairment belongs in the definition of disability. He claims that impairment forces us to consider how some conditions cannot be changed through changes in the environment or society's view of people with impairments.[13]

Anastasiou and Kauffman also criticize the social model of disability. They claim that social constructionists only replace the biological determinism of the medical model of disability with cultural determinism, and that the social model is unable to encompass each and every

[11] *Ibid.*, p. 169
[12] Alex McClimens, "The Organization of Difference: People with Intellectual Disabilities and the Social Model of Disability," in *Mental Retardation,* vol. 41, no. 1 (2003), p. 43.
[13] *Ibid.*, p. 37

one of many disabilities.[14] Like McClimmins, they criticize social constructionists for applying a disability model and movement of people with physical disabilities to other disabilities such as intellectual disabilities, autism, sensory disabilities, and emotional and behavioural disorders. They argue that there is more to be gained from recognizing an impairment than by denying it as a social construction. They claim that "it is difficult to see what social barriers should be removed to accommodate the needs of people with autism".[15]

When Clare discusses not being able to make it to the top of Mount Adams, he claims that he "decided that turning around before reaching the summit was more about impairment than disability. But even as [he] formed the thought, [he] could feel [his] resistance to it. To neatly divide disability from impairment doesn't feel right".[16] He goes on to point out that his "frustration knows no neat theoretical divide between disability and impairment. Neither does disappointment or embarrassment".[17] Clare wants to talk about disability and impairment, but he realizes that there is something else besides a social disability and a medical impairment. The duality no longer works in his story.

Paterson and Hughes agree that "the social model has to be reworked to incorporate all the complexities of being disabled".[18] The complexities of being disabled include more than just the social constructions of disability and the biological or medical problems of impairment.

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[14]Dimitris Anastasiou and James Kauffman, "A Social Constructionist Approach to Disability: Implications for Special Education," in *Exceptional Children,* vol. 77, no. 3 (2011), p. 376.
[15]*Ibid.*, p. 378
[16]Eli Clare, *Exile and Pride: Disability, Queerness, and Liberation* (Cambridge: South End Press, 2009), p. 7.
[17]*Ibid.*, p. 8
[18]Kevin Paterson and Bill Hughes, "Disability Studies and Phenomenology: the Carnal Politics of Everyday Life," in *Disability and Society,* vol. 14, no. 5 (1999), p. 602.

They claim that "the problem with this dualistic position is that it requires the social model to embrace a disembodied view of disability and an asocial view of impairment".[19] They also define active social disability as disabling barriers, and passive social disability as "attitudes and emotions that came from experiences of discrimination".[20]

Hughes continues to talk about embodiment when he tries to bring the sociology of impairment into disability theory. Unlike the social model of disability, the sociology of impairment looks at the body without separating it from society, as the site of human experience. He looks at disability as embodied, and this can bring up issues that are not addressed by either the social or the medical model of disability, such as emotions that result from pain.[21]

Siebers' complex embodiment includes conditions such as chronic pain, secondary health effects, and ageing. He does not consider these defects, but calls them 'resistant to change', and claims that they must be considered along with the social forces.[22] Siebers claims that some disabilities can be approached with changes to perception or the environment, or some can be treated through medical care. Other disabilities cannot be approached by either.

Thomas' social-relational model acknowledges "pain, discomfort, fatigue, limited functioning, and other impairment effects"[23] by including

[19] *Ibid*., p. 599
[20] *Ibid*, p. 600.
[21] Bill Hughes, "Disability and the Body," in *Disability Studies Today,* ed. C. Barnes, M. Oliver, and L. Barton (Malden: Polity Press, 2002), p. 58-76.
[22] Tobin Siebers, *Disability Theory* (Michigan: University of Michigan Press, 2008), p. 25.
[23] Lorella Terzi, "The Social Model of Disability: A Philosophical Critique," in *Journal of Applied Philosophy,* vol. 21, no. 2 (2004), p. 150.

'impairment effects' in her model of impairment and disability, along with 'barriers to doing' and 'barriers to being'.[24]

Shakespeare and Watson agree that the priority of a model of disability should be social change and barrier removal, not medical research, but they support appropriate action and prevention on impairment. They argue that people are disabled both by social barriers and by their bodies.[25] They also point out that "removing environmental obstacles for someone with one impairment may well generate obstacles for someone with another impairment".[26]

Silverman, in his review of social science research on autism, addresses disability theory when he claims that

> "specialists in disability studies distinguish between the social model and the medical model of disabilities. The most successful studies are those that refuse to situate their claims firmly within one model or the other, but instead pay attention to the strategic uses of different models by various interest group".[27]

Although no one model of disability that combines or moves beyond the medical or social models has been clearly established, there are many arguments to move in this direction.

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[24]Bill Hughes, "Being Disabled: Towards a Critical Social Ontology for Disabled Studies," *Disability and Society*, vol. 22, no. 7 (2007), p. 675.

[25]Tom Shakespeare and Nicholas Watson, "The Social Model of Disability: An Outdated Ideology?" in *Researching in Social Science and Disability,* vol. 2 (2001), p. 17.

[26]*Ibid.*, p. 18

[27]Chloe Silverman, "Critical Review: Fieldwork on Another Planet: Social Science Perspectives on the Autism Spectrum," in *BioSocieties,* vol. 3 (2008), p. 336.

Autism

Autism is defined in the DSM-IV as impairments in social interaction, communication, and stereotypic behaviour. [28] Children with autism also commonly experience hyper- and hypo- sensitivities to multiple senses[29], seizures, behaviour difficulties, motor difficulties, self-care difficulties[30], educational development delays[31], and atypical physical, psychological, and perceptual difficulties.[32] Autism Spectrum Disorder is a spectrum of disorders, with a spectrum of severity.[33] Jensen and Spannagel used a two dimensional graph to create a chart with levels of autism symptoms (autism severity) on the x axis and level of cognitive impairment (deficit) on the y axis to attempt to encompass the full range of the autism spectrum.[34]

Effect of a Child with Autism on the Family

The Educational Resources Information Center (ERIC), Sociological Abstracts, and Psyc INFO databases were searched for articles with "autism," "family," and effects such as "stress" in the titles since Pisula's

[28]American Psychiatric Association, *Diagnostic and Statistical Manual for Mental Disorders,* 4th Ed. (Washington: APA, 1994), p. 75.
[29]Joyce Davidson, "'It Cuts Both Ways': A Relational Approach to Access and Accommodation for Autism," in *Social Science and Medicine,* vol. 70 (2010), p. 307.
[30]National Research Council, *Educating Children with Autism* (Washington: National Academy Press, 2001). Pamela Norton and Clifford Drew, "Autism and Potential Family Stressors," in *American Journal of Family Therapy*, vol. 22, no. 1 (1994), p. 67-76.
[31]Ministry of Education, *Special Education: A Guide for Educators* (Ontario, 2001), p. A18.
[32]Kristin Bumiller, "Quirky Citizens: Autism, Gender, and Reimagining Disability," in *Signs: Journal of Women in Culture and Society,* vol. 33, no. 4 (2008), p. 973.
[33]American Psychiatric Association, *DSM-5 Development Website* (2011), ‹www.dsm5.org/Pages/Default.aspx›.
[34]Vanessa Jensen and Sarah Cain Spannagel, "The Spectrum of Autism Spectrum Disorder: A Spectrum of Needs, Services, and Challenges," in *Journal of Contemporary Psychology,* vol. 41 (2011), p. 3.

2003 review of the literature on parents of children with autism. Bibliographies of significant articles were searched. Articles that were about dealing with the initial diagnosis of autism, adult children with autism, coping strategies, or the effects of external factors on parent stress such as parent traits were not included. Articles on the variety of Pervasive Developmental Disorders were included, as Mugno, Ruta, D'Arrigo and Mazzone found no statistically significant difference between parents of children across the range.[35]

The literature on the effect of a child with autism on the family included positive aspects of having a child with autism, such as enrichment[36], a positive learning experience, finding true friendships, strengthened marriages and families, increased spirituality, becoming more patient, compassionate, humble, and accepting (Altiere & Von Kluge, 2009)[37], greater selflessness, more compassion, a feeling of peace during uncertain times[38], a new understanding of disability, being glad for child's uniqueness, enriched lives, positive emotions, appreciation of little things, marriage enrichment, positive family adjustment, positive effect on siblings, and spiritual enrichment (Myers, Mackintosh, &

[35]Diego Mugno, Liliana Ruta, Valentina Genitori D'Arrigo, and Luigi Mazzone, "Impairment of Quality of Life in Parents of Children and Adolescents with Pervasive Developmental Disorder," in *Health and Quality of Life Outcomes,* vol. 5 (2007), p. 22.

[36]Kenneth Phelps, Susan McCammon, Karl Wuensch, and Jeannie Golden, "Enrichment, Stress, and Growth from Parenting an Individual with an Autism Spectrum Disorder," in Journal of Intellectual and Developmental Disability, vol. 34, no. 2 (2009), p. 133-141.

[37]Matthew Altiere and Silvia von Kluge, "Searching for Acceptance: Challenges Encountered while Raising a Child with Autism," in *Journal of Intellectual and Developmental Disability*, vol 34, no. 2 (2009), 142-152.

[38]Kenneth Phelps, Jennifer Hodgson, Susan McCammon, and Angela Lamson, "Caring for an Individual with Autism Disorder: A Qualitative Analysis," in *Journal of Intellectual and Developmental Disability*, vol. 34, no. 1 (2009), p. 27-35.

Goin-Kochel, 2009)[39], but this analysis of the literature will focus on the negative aspects because it attempts to apply models of disability to the literature, and positive aspects are not considered impairments or disabilities.

Parents of children on the autism spectrum had more depression[40], anxiety[41], daily hassles[42], and hopelessness[43] and less family adaptability and cohesion[44], relationship satisfaction[45], sleep quality and quantity[46], quality of life[47], physical activity and health, social

[39]Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, "'My Greatest Joy and my Greatest Heartache:' Parents' own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families' Lives," in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 670-684.

[40]Paul Benson, "The Impact of Child Symptom Severity on Depressed Mood among Parents of Children with ASD: The Mediating Role of Stress Proliferation," in *Journal of Autism and Developmental Disorders,* vol. 36 (2006), p. 685-695.

[41]Gloria Lee, "Parents of Children with High Functioning Autism: How Well do they Cope and Adjust?" in *Journal of Developmental and Physical Disabilities*, vol. 21 (2009), p. 93-114.

[42]Nicole Quintero and Laura Lee McIntyre, "Sibling Adjustment and Maternal Well-Being: An Examination of Families with and without a Child with an Autism Spectrum Disorder," in *Focus on Autism and Other Developmental Disabilities*, vol. 25, no. 1 (2010), p. 37-46.

[43]Ewa Pisula, "Parents of Children with Autism - Review of Current Research," in *Archives of Psychiatry and Psychotherapy*, vol. 5, no. 4 (2003), p. 51-63.

[44]Daryl Higgins, Susan Bailey, and Julian Pearce, "Factors Associated with Functioning Style and Coping Strategies of Families with a Child with Autism Spectrum Disorder," in *Autism*, vol. 9, no. 2 (2005), p. 125-137.

[45]Jennifer Brobst, James Clopton, and Susan Hendrick, "Parenting Children with Autism Spectrum Disorders: The Couple's Relationship," in *Focus on Autism and Other Developmental Disabilities*, vol. 24, no. 1 (2009), p. 38-49.

[46]Lisa Meltzer, "Brief Report: Sleep in Parents of Children with Autism Spectrum Disorders," in *Journal of Pediatric Psychology Special Issue: Sleep in Pediatric Medical Populations*, vol. 33, no. 4 (2008), p. 380-386.

[47]Gloria Lee, Christoper Lopata, Martin Volker, Marcus Thomeer, Robert Nida, Jennifer Toomey, Sabrina Chow, and Audrey Smerbeck, "Health-related Quality of Life of Parents of Children with High-Functioning Autism Spectrum Disorders," in *Focus on Autism and Other Developmental Disabilities*, vol. 24, no. 4 (2009), p. 227-239.

relationships[48], and sense of coherence, or confidence that a situation is manageable and engagement is meaningful[49] than parents of children without disabilities.

Mothers of children on the autism spectrum had more depression[50], more emotional disorder[51], more fatigue, more negative emotions[52], and lower sense of self-efficacy[53] than mothers with typically developing children and less positive perceptions of their child than mothers of children with other disabilities.[54]

Stress is the most common and most commonly researched effect of having a child with autism on the family. The National Research Council

[48]Diego Mugno, Liliana Ruta, Valentina Genitori D'Arrigo, and Luigi Mazzone, "Impairment of Quality of Life in Parents of Children and Adolescents with Pervasive Developmental Disorder," in *Health and Quality of Life Outcomes,* vol. 5 (2007), p. 22-31.

[49]Ewa Pisula and Zuzanna Kossakowska, "Sense of Coherence and Coping with Stress among Mothers and Fathers of Children with Autism," in *Journal of Autism and Developmental Disorders*, vol. 40, no. 12 (2010), p. 1485-1494.

[50]Leonard Abbeduto, Marsha Mailick Seltzer, Paul Shattuck, Marty Wyngaarden Krauss, Gael Orsmond, and Melissa Murphy, "Psychological Well-Being and Coping in Mothers of Youths with Autism, Down Syndrome, or Fragile X Syndrome," in *American Journal on Mental Retardation*, vol. 109, no. 3 (2004), p. 237-254.

[51]Vasiliki Totsika, Richard Hastings, Eric Emerson, Gillian Lancaster, and Damon Berridge, "A Population-Based Investigation of Behavioural and Emotional Problems and Maternal Mental Health: Associations with Autism Spectrum Disorder and Intellectual Disability," in *Journal of Child Psychology and Psychiatry,* vol. 52, no. 1 (2011), p. 91-99.

[52]Leann Smith, Jinkuk Hong, Marsha Mailick Seltzer, Jan Greenberg, David Almeida, and Somer Bishop, "Daily Experiences among Mothers of Adolescents and Adults with Autism Spectrum Disorder," in *Journal of Autism and Developmental Disorders*, vol. 40, no. 2 (2010), p. 167-178.

[53]Mieke Meirsschaut, Herbert Roeyers, and Petra Warreyn, "Parenting in Families with a Child with Autism Spectrum Disorder and a Typically Developing Child: Mothers' Experiences and Cognitions," in *Research in Autism Spectrum Disorders*, vol. 4, no. 4 (2010), p. 661-669.

[54]Gemma Griffith, Richard Hastings, Susie Nash, and Christoper Hill, "Using Matched Groups to Explore Child Behaviour Problems and Maternal Well-being in Children with Down Syndrome and Autism," in *Journal of Autism and Developmental Disorders*, vol. 40, no. 5 (2010), p. 610-619.

stated that the parents of children with autism may experience sadness, anger, or disappointment about their child's disability and how it affects their lives, and that although many families cope well, some experience "very substantial stress".[55] Thirty eight percent of parents of high functioning children with autism showed a clinically significant total stress score on the Parenting Stress Index – short form and, emotional difficulty, including stress, was a theme in their attached qualitative content analysis.[56] In Myers, MacKintosh, and Goin-Kochel's qualitative questionnaire, they found that "stress was the most frequent theme that arose in parents' accounts of how their child in the spectrum affected them and their families".[57] It also arose as a theme in the content analysis of other qualitative papers on parents of children with autism, such as Papageorgion & Kalyva.[58] Similarly, Hutton and Caron found that "the overwhelming majority of parents used the word 'stressful' to describe their experience of having a child with autism".[59]

Parents of children on the autism spectrum had more stress than parents of children without disabilities[60] and children with other disorders,

[55]National Research Council, *Educating Children with Autism,* (Washington: National Academy Press, 2001), p. 32.

[56]Myra Beth Bundy and Linda Kunce, "Parenting Stress and High Functioning Children with Autism," in *International Journal on Disability and Human Development*, vol. 8, no. 4 (2009), p. 404.

[57]Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, "'My Greatest Joy and my Greatest Heartache:' Parents' own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families' Lives," in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 674.

[58]Vaya Papagergiou and Efrosini Kalyva, "Self-Reported Needs and Expectations of Parents of Children with Autism Spectrum Disorders who Participate in Support Groups," in *Research in Autism Spectrum Disorders,* vol. 4 (2010), p. 653-660.

[59]Adam Hutton and Sandra Caron, "Experiences of Families with Children with Autism in Rural New England," in *Focus on Autism and Other Developmental Disabilities*, vol. 20, no. 3 (2005), p. 186.

[60]Brooke Ingersoll and David Hambrick, "The Relationship between the Broader Autism Phenotype, Child Severity, and Stress and Depression in Parents of Children with Autism Spectrum Disorders," in *Research in Autism Spectrum Disorders*, vol. 5, no. 1 (2011), p. 337-344.

such as Down Syndrome.[61] Mothers of children on the autism spectrum have more stress than mothers with typically developing children[62] and with other developmental disabilities without autism[63] and chronic physical illness.[64] Smith et al. found that mothers of children with autism had more stressful daily events than mothers with typically developing children.[65]

The question must be raised, why is raising a child with autism stressful? The quantitative data gives us an idea of the impact of both social and child variables on stress (but not how parents of children with autism view these variables).

Social and Child Variables

When toddler aged children with autism received childcare interventions, mothers showed significant reductions in child-related

[61]A. Dabrowska and E. Pisula, "Parenting Stress and Coping Styles in Mothers and Fathers of Pre-School Children with Autism and Down Syndrome," in *Journal of Intellectual Disability Research,* vol. 54 (2010), p. 266-280.

[62]Charles Hoffman, Dwight Sweeney, Danelle Hodge, Muriel Lopez-Wagner, and Lisa Looney, "Parenting Stress and Closeness: Mothers of Typically Developing Children and Mothers of Children with Autism," in *Focus on Autism and Other Developmental Disabilities*, vol. 24, no. 3 (2009), p. 178-187.

[63]Annette Estes, Jeffery Munson, Geraldine Dawson, Elizabeth Koehler, Xiao-Hua Zhou, and Robert Abbott, "Parenting Stress and Psychological Functioning among Mothers of Preschool Children with Autism and Developmental Delay," in *Autism*, vol. 13, no. 4 (2009), p. 375-387.

[64]Ewa Pisula, "Parents of Children with Autism - Review of Current Research," in *Archives of Psychiatry and Psychotherapy*, vol. 5, no. 4 (2003), p. 51-63.

[65]Leann Smith, Jinkuk Hong, Marsha Mailick Seltzer, Jan Greenberg, David Almeida, and Somer Bishop, "Daily Experiences among Mothers of Adolescents and Adults with Autism Spectrum Disorder," in *Journal of Autism and Developmental Disorders*, vol. 40, no. 2 (2010), p. 167-178.

stress.[66] Also, when a grown child with autism moved out of the family home, maternal anxiety was reduced.[67] These two results demonstrate that when there is support in the form of care for the person with autism, stress and anxiety is reduced. An increase in family, social, emotional, and informal support was found to lead to decreased maternal stress[68], while a decrease in support has been found to lead to more maternal stress.[69] Hutton and Caron found that most parents said services greatly reduced their stress, although some found them more stressful due to the work involved.[70] Norton and Drew believe that respite care is crucial for the well being of parents with autism.[71] Meadan, Halle, and Ebata claimed that although there is limited research on the effect of respite care on families of children with autism, they believe that respite would reduce stress based on stress being caused by things such as time demands.[72]

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[66]Mary Baker-Ericzén, Lauren Brookman-Frazee, and Aubyn Stahmer, "Stress Levels and Adaptability in Parents of Toddlers with and without Autism Spectrum Disorders," in *Research and Practice for Persons with Severe Disabilities*, vol. 30, no. 4 (2005), p. 194-204.

[67]Erin Barker, Sigan Hartley, Marsha Mailick Seltzer, Frank Floyd, Jan Greenberg, and Gael Orsmond, "Trajectories of Emotional Well-being in Mothers of Adolescents and Adults with Autism," in *Developmental Psychology*, vol. 47, no. 2 (2011), p. 551-561.

[68]Naomi Ekas, Diane Lickenbrock, and Thomas Whitman, "Optimism, Social Support, and Well-Being in Mothers of Children with Autism Spectrum Disorder," in *Journal of Autism and Developmental Disorders*, vol. 40, no. 10 (2010), p. 1274-1284.

[69]Jo Bromley, Dougal Julian Hare, Kerry Davison, and Eric Emerson, "Mothers Supporting Children with Autistic Spectrum Disorders: Social support, mental health status, and satisfaction with services," in *Autism,* vol. 8, no. 4, (2004), p. 409-423.

[70]Adam Hutton and Sandra Caron, "Experiences of Families with Children with Autism in Rural New England," in *Focus on Autism and Other Developmental Disabilities*, vol. 20, no. 3 (2005), p. 185-186.

[71]Pamela Norton and Clifford Drew, "Autism and Potential Family Stressors," in *American Journal of Family Therapy*, vol. 22, no. 1 (1994), p. 71.

[72]Hedda Meadan, James Halle, and Aaron Ebata, "Families with Children who have Autism Spectrum Disorders: Stress and Support," in *Exceptional Children,* vol. 77, no. 1 (2010), p. 27.

A child's behaviour or emotional problems have an effect on maternal stress[73] and stress.[74] Lecavalier, Leone, and Wiltz found that behaviour problems were more associated with stress than child adaptive behaviour or parent familiarity with applied behaviour analysis (a method of teaching children with autism) and autism spectrum disorders.[75] Herring et al. found that child emotional and behaviour problems contributed more to maternal stress than diagnosis or delay.[76] A qualitative study found that "the parents [of children with autism] who were the most distressed were those whose children were aggressive and/or severely obsessive.[77] Ninety percent of parents reported that they were sometimes unable to deal effectively with their child's behaviour, and felt stretched beyond their limits.[78]

[73]Richard Hastings, Hanna Kovshoff, Nicholas Ward, Francesca degli Espinosa, Tony Brown, and Bob Remington, "Systems Analysis of Stress and Positive Perceptions in Mothers and Fathers of Pre-School Children with Autism," in *Journal of Autism and Developmental Disorders*, vol. 35, no. 5 (2005), p. 635-644.

[74]Supapak Phetrasuwan and Margaret Shandor Miles, "Parenting Stress in Mothers of Children with Autism Spectrum Disorders," in *Journal for Specialists in Pediatric Nursing*, vol. 14, no. 3 (2009), p. 157-165.

[75]L. Lecavalier, S. Leone, and J. Wiltz, "The Impact of Behaviour Problems on Caregiver Stress in Young People with Autism Spectrum Disorders," in *Journal of Intellectual Disability Research*, vol. 50, no. 3 (2006), p. 172-183.

[76]S. Herring, K. Gray, J. Taffe, B. Tonge, D. Sweeney, and S. Einfeld, "Behaviour and Emotional Problems in Toddlers with Pervasive Developmental Disorders and Developmental Delay: Associations with Parental Mental Health and Family Functioning," in *Journal of Intellectual Disability Research,* vol. 50 (2006), p. 874-882.

[77]David Gray, "Ten Years On: A Longitudinal Study of Families of Children with Autism," in *Journal of Intellectual and Developmental Disability*, vol. 27, no. 3 (2002), p. 218.

[78]Vicki Bitsika and Christopher Sharpley, "Stress, Anxiety and Depression among Parents of Children with Autism Spectrum Disorder," in *Australian Journal of Guidance & Counselling*, vol. 14, no. 2 (2005), p. 155.

A Model of Disability for Parents of Children with Autism

The question now is how families with children with autism view these variables, whether they are based on social or medical / individual views of disability. Baker researched how the public, through newspaper articles, defined autism. She found that discussions about autism focused on health care policy, not rights[79], so public opinion, represented by the news, used the medical model of disability. My interest is the model of disability used by families of children with autism, through a literature review on the effect of a child with autism on the family. The model of disability used by parents of children with autism is primarily and overwhelmingly social, so much so that the literature review could nearly be called "the effect of society on families of children with autism".

Looking at the qualitative research on parents of children with autism, the most common theme content coded was society's lack of understanding and acceptance.[80] The theme of a lack of understanding in Myers, MacKintosh, & Goin-Kochel was actually called "bad treatment by strangers".[81] Woodgate, Ateah, & Seccon claimed that parents felt that society valued their children with autism less than other children.[82]

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[79]Dana Lee Baker, "Defining Autism in Canada: Unfolding the Public Aspects of Neurological Disability," in *The Social Science Journal* vol. 44 (2007), p. 687-697.

[80]Mieke Meirsschaut, Herbert Roeyers, and Petra Warreyn, "Parenting in Families with a Child with Autism Spectrum Disorder and a Typically Developing Child: Mothers' Experiences and Cognitions," in *Research in Autism Spectrum Disorders*, vol. 4, no. 4 (2010), p. 661-669.

[81]Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, "'My Greatest Joy and my Greatest Heartache:' Parents' own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families' Lives," in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 681.

[82]Roberta Woodgate, Christine Ateah, and Loretta Secco, "Living in a World of our Own: The Experience of Parents who have a Child with Autism," in *Qualitative Health Research*, vol. 18, no. 8 (2008), p. 1078.

This lack of understanding went well beyond society as a whole, and included strained family relationships[83], difficulty with the church community[84], and lost friendships.[85] Altiere & Von Kluge point out that, "as they experience difficult incidents with the public, friends, and extended family members, parents learn that most people are ignorant of the issues associated with raising children with autism".[86] For example, it is common for parents to talk of this lack of acceptance, such as saying "People do not welcome us into their homes," and "I get angry and depressed about the way that strangers stare at her some-times in public".[87] One can understand why although parents want to improve services, their main goal is "to gain acceptance and recognition from others".[88] Acceptance by schools and other services was also specifically addressed by parents of children with autism.[89]

[83]Heather Hall and Carolyn Graff, "Parenting Challenges in Families of Children with Autism: A Pilot Study," in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 195.

[84]Kenneth Phelps, Jennifer Hodgson, Susan McCammon, and Angela Lamson, "Caring for an Individual with Autism Disorder: A Qualitative Analysis," in *Journal of Intellectual and Developmental Disability*, vol. 34, no. 1 (2009), p. 30-31.

[85]Vaya Papagergiou and Efrosini Kalyva, "Self-Reported Needs and Expectations of Parents of Children with Autism Spectrum Disorders who Participate in Support Groups," in *Research in Autism Spectrum Disorders,* vol. 4 (2010), p. 655.

[86]Matthew Altiere and Silvia von Kluge, "Searching for Acceptance: Challenges Encountered while Raising a Child with Autism," in *Journal of Intellectual and Developmental Disability*, vol 34, no. 2 (2009), p. 150.

[87]Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, "'My Greatest Joy and my Greatest Heartache:' Parents' own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families' Lives," in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 681.

[88]Matthew Altiere and Silvia von Kluge, "Searching for Acceptance: Challenges Encountered while Raising a Child with Autism," in *Journal of Intellectual and Developmental Disability*, vol 34, no. 2 (2009), p. 151.

[89]Myra Beth Bundy and Linda Kunce, "Parenting Stress and High Functioning Children with Autism," in *International Journal on Disability and Human Development*, vol. 8, no. 4 (2009), p. 406.

Phelps, Hodgson, Mc Cammon, & Lamson claim that "a clearer understanding of autism by informal and formal supports would alleviate strain for caregivers".[90]

I have witnessed this lack of understanding in my professional practice when bringing students into the community. When students engage in harmless self-stimulatory behaviours (e.g., Hand flapping or rocking), they have experienced stares or even comments under people's breaths. This is not to say that this is the norm, but even once could be painful to a child with autism or a family member who loves the child.

The next most common theme content coded in the qualitative literature on parents of children with autism was the need for support and services. The system was considered unsupportive and "inaccessible"[91], services such as education and medicine were found to be lacking in knowledge, and parents suggested that educators and medical professionals were educated.[92] Woodgate, Ateah, & Seccon agree that "professionals, family, friends, and others in the system who lack an understanding of the impact that autism has on children and parents need to be educated".[93] The financial cost of having a child with autism, including employment

[90]Kenneth Phelps, Jennifer Hodgson, Susan McCammon, and Angela Lamson, "Caring for an Individual with Autism Disorder: A Qualitative Analysis," in *Journal of Intellectual and Developmental Disability*, vol. 34, no. 1 (2009), p. 27-35.
[91]Mieke Meirsschaut, Herbert Roeyers, and Petra Warreyn, "Parenting in Families with a Child with Autism Spectrum Disorder and a Typically Developing Child: Mothers' Experiences and Cognitions," in *Research in Autism Spectrum Disorders*, vol. 4, no. 4 (2010), p. 665.
[92]Heather Hall and Carolyn Graff, "Parenting Challenges in Families of Children with Autism: A Pilot Study," in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 194.
[93]Roberta Woodgate, Christine Ateah, and Loretta Secco, "Living in a World of our Own: The Experience of Parents who have a Child with Autism," in *Qualitative Health Research*, vol. 18, no. 8 (2008), p. 1075-1083.

effects[94], shows a clear need for support for parents. [95] Even themes such as time demands, pervasiveness of autism in life, sleep problems and exhaustion, missed activities, neglected siblings, and marital strain[96] can be seen as a need for support in the form of relief. Although there was some individual model language, the need for support in the form of relief was primary. One parent, when discussing marital strain, said she needed respite care.[97] Another parents, talking about living in a world her own, felt like she had to "go it alone".[98] Parents advocated for other parents so that the system would not "rip them off[99]," and felt like they needed to fight to get services.[100]

Again, I have witnessed this lack of support in my own professional practice, attempting to advocate for respite services for parents. The paperwork and meetings involved would be far too overwhelming for

[94]Matthew Altiere and Silvia von Kluge, "Searching for Acceptance: Challenges Encountered while Raising a Child with Autism," in *Journal of Intellectual and Developmental Disability*, vol 34, no. 2 (2009), p. 142-152.

[95]Vaya Papagergiou and Efrosini Kalyva, "Self-Reported Needs and Expectations of Parents of Children with Autism Spectrum Disorders who Participate in Support Groups," in *Research in Autism Spectrum Disorders,* vol. 4 (2010), p. 655; Kenneth Phelps, Jennifer Hodgson, Susan McCammon, and Angela Lamson, "Caring for an Individual with Autism Disorder: A Qualitative Analysis," in *Journal of Intellectual and Developmental Disability*, vol. 34, no. 1 (2009), p. 32.

[96]Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, "'My Greatest Joy and my Greatest Heartache:' Parents' own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families' Lives," in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 670-684.

[97]*Idem*

[98]Roberta Woodgate, Christine Ateah, and Loretta Secco, "Living in a World of our Own: The Experience of Parents who have a Child with Autism," in *Qualitative Health Research*, vol. 18, no. 8 (2008), p. 1075-1083.

[99]*Idem*

[100]Matthew Altiere and Silvia von Kluge, "Searching for Acceptance: Challenges Encountered while Raising a Child with Autism," in *Journal of Intellectual and Developmental Disability*, vol 34, no. 2 (2009), p. 142-152.

many people to follow through on an application. I could understand why parents feel like they jump through hoops for very little gain.

When parents specifically addressed a lack of understanding and acceptance or a need for support and services as above, they are clearly working from a social model of disability. There are other issues, such as child variables, that are not so clear until the language of the parents is considered. For example, maladaptive behaviour is the most common child variable theme content coded (also called disruptive and inappropriate behaviour). Parents see this as both an impairment and a socially constructed disability. Parents list behaviours including aggression, fecal smearing, extended screaming[101], "tormenting" siblings, violence with police involvement, physically assaulting a child under five years old several times, aggression requiring hospitalization, living in fear of child taking own life or losing it to poor judgment[102], obsessive and perseverative behaviours, and tantrums.[103] From the language used to describe the behaviours above, it is clear that these behaviours are impairments for parents, and are a medical issue. On the other hand, parents claim that "it hurts when people are looking at your child like he is an alien" when he acts up in public[104] and "when we go out, strangers

[101]Heather Hall and Carolyn Graff, "Parenting Challenges in Families of Children with Autism: A Pilot Study," in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 187-204.
[102]Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, "'My Greatest Joy and my Greatest Heartache:' Parents' own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families' Lives," in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 670-684.
[103]Myra Beth Bundy and Linda Kunce, "Parenting Stress and High Functioning Children with Autism," in *International Journal on Disability and Human Development*, vol. 8, no. 4 (2009), p. 401-410.
[104]Heather Hall and Carolyn Graff, "Parenting Challenges in Families of Children with Autism: A Pilot Study," in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 194.

blame us for the temper tantrums that our child throws".[105] Hall & Graft points out that child maladaptive behaviours contribute to the social isolation of parents, but that this is related to limited respite and support.[106] Therefore, it is not only the behaviour as an impairment that creates isolation, but the society that disables the child by not understanding and accepting their behaviours in public. This is reinforced by Gray when he claims that "parents of aggressive children were more likely to experience stigma than the parents of passive children".[107] Boyd also reinforces this when he claims that "behavioural issues may present more of a challenge than cognitive one because of the potential public scrutiny parents face from society, and perhaps from family and friends as well".[108]

As a teacher, I experience many of these same conflicting opinions and emotions about problem behaviours. It is difficult as a teacher to choose which behaviours to make educational goals for in the Individual Education Plan, and which ones should be acceptable. Sometimes this decision is simple. For example, self-abusive or aggressive behaviour is usual treated as medical and programs are written to reduce these behaviours, but for most of my students, I do not write programs to reduce self-stimulation such as hand flapping. (I say most, because there are students who want to stop this behaviour in public.) This is

[105]Vaya Papagergiou and Efrosini Kalyva, "Self-Reported Needs and Expectations of Parents of Children with Autism Spectrum Disorders who Participate in Support Groups," in *Research in Autism Spectrum Disorders,* vol. 4 (2010), p. 655.
[106]Heather Hall and Carolyn Graff, "Parenting Challenges in Families of Children with Autism: A Pilot Study," in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 198.
[107]David Gray, "Ten Years On: A Longitudinal Study of Families of Children with Autism," in *Journal of Intellectual and Developmental Disability*, vol. 27, no. 3 (2002), p. 218.
[108]Brian Boyd, "Examining the Relationship between Stress and Lack of Social Support in Mothers of Children with Autism," in *Focus on Autism and Other Developmental Disabilities*, vol. 17, no. 4, (2002), p. 213.

difficult as a teacher because even if I believe that a certain behaviour is not a medical issue and should be accepted by society, it is not, and therefore a decision has to be made based on what is best for the student. Not all behaviours are so easily categorized.

Many of the other student variables are neutral to parents, without hinting as to whether it is the impairment or society's lack of understanding and support that causes the stress around them, such as difficulties with self help, motor difficulties, difficulties with social skills, and worry about the child's future.[109] Educational concerns that were based on the child's ability to learn at school used some individual language such as "parents had various concerns about the child's ability to understand the rigours of education"[110], but this was not brought up frequently, accommodation to assist with learning was brought up, and all of these issues were also not shown to cause as much stress in the qualitative literature as a lack of support and behaviour.

Finally, there were two themes in the qualitative literature on families of children with autism that were talked about from the perspective of a medical or individual model, and they were emotional well being and communication.[111] The emotional difficulties were fear, anxiety, uncontrollable rage, emotional well being[112], and panic

[109]Myra Beth Bundy and Linda Kunce, "Parenting Stress and High Functioning Children with Autism," in *International Journal on Disability and Human Development*, vol. 8, no. 4 (2009), p. 401-410.
[110]*Ibid.,* p. 406
[111]Vaya Papagergiou and Efrosini Kalyva, "Self-Reported Needs and Expectations of Parents of Children with Autism Spectrum Disorders who Participate in Support Groups," in *Research in Autism Spectrum Disorders,* vol. 4 (2010), p. 653-660.
[112]Myra Beth Bundy and Linda Kunce, "Parenting Stress and High Functioning Children with Autism," in *International Journal on Disability and Human Development*, vol. 8, no. 4 (2009), p. 406.

attacks.[113] It is understandable that parents would talk about these emotional difficulty as medical, because it would be difficult to consider how society could prevent these difficulties through understanding and support. Bundy & Kunce point out that emotional ups and downs could be the underlying cause of disruptive behaviour.[114] It is more surprising that communication is seen as a medical/individual issue, because there are many supports that can be put into place to assist children with autism with communication such as picture communication, sign language, or gestures. Although there are times when communication is a medical issue because no amount of effort could break the communication barrier, there are many communication strategies that can be attempted first. Myers, MacKintosh, & Goin-Kochel included the fact that a child didn't speak in with behaviours[115], and Hall & Graft quote a parent as saying that her child looks at her like he wants to tell her something, but he doesn't have the words.[116]

When asked what I found surprising about what parents found stressful and what model they used to interpret these stressors, I was surprised that sensory issues were not discussed by parents as being more stressful, because they can be a cause of great pain to children with autism, and have been a source of stress for myself in my professional

[113]Heather Hall and Carolyn Graff, "Parenting Challenges in Families of Children with Autism: A Pilot Study," in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 194.
[114]Myra Beth Bundy and Linda Kunce, "Parenting Stress and High Functioning Children with Autism," in *International Journal on Disability and Human Development*, vol. 8, no. 4 (2009), p. 406.
[115]Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, "'My Greatest Joy and my Greatest Heartache: Parents' own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families' Lives," in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 675.
[116]Heather Hall and Carolyn Graff, "Parenting Challenges in Families of Children with Autism: A Pilot Study," in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 194.

practice as a teacher of students with severe autism. I had expected parents to discuss sensory issues from a social point of view because many sensory issues can be compensated for in the environment, even though it could be seen as a medical issue when the environment can't be changed, or two children with opposite sensory issues (e.g., A hypersensitivity and a hypsensitivity to sound) share the same space.

Although the literature used some medical language while talking about the effect of a child with autism on the family, such as wishing for or missing a "normal" child or life[117], wanting a "cure"[118], wanting to "fix" the child's problems[119], claiming there is something "wrong" with the child[120], and asking about etiology[121], and although there were some aspects of autism that were seen as medical, such as some behaviours, emotional difficulties, and communication, this was outweighed by the desire for understanding, acceptance, support, and services by parents of children with autism.

[117]Roberta Woodgate, Christine Ateah, and Loretta Secco, "Living in a World of our Own: The Experience of Parents who have a Child with Autism," in *Qualitative Health Research*, vol. 18, no. 8 (2008), p. 1078.

[118]Myra Beth Bundy and Linda Kunce, "Parenting Stress and High Functioning Children with Autism," in *International Journal on Disability and Human Development*, vol. 8, no. 4 (2009), p. 405.

[119]Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, "'My Greatest Joy and my Greatest Heartache:' Parents' own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families' Lives," in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 681.

[120]Matthew Altiere and Silvia von Kluge, "Searching for Acceptance: Challenges Encountered while Raising a Child with Autism," in *Journal of Intellectual and Developmental Disability*, vol. 34, no. 2 (2009), 145.

[121]Heather Hall and Carolyn Graff, "Parenting Challenges in Families of Children with Autism: A Pilot Study," in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 194.

Conclusion

Autism is a complex disability that includes both impairments and social constructions. Taking autism into account would require a model of disability to include the experience of impairment as well as the social construction of disability. There are two distinct forms of social construction recognized by parents, called here lack of understanding and acceptance and lack of support and services, and also aspects of autism that are recognized as based on impairment. A model for parents that puts more weight on the social construction of autism would be most accurate. Thomas calls the lack of understanding and acceptance a "barrier to being" and a lack of support and services a "barrier to doing".[122] Patterson and Hughes talk about passive social disability, which would come from the lack of understand and acceptance, and active social disability, which would come from a lack of support and services.[123] Both Thomas and Patterson and Hughes include what Thomas calls "impairment effects" in their models.[124] These models would be most reflective of the way parents view autism, but this does not speak for the people with autism themselves.

[122]Bill Hughes, "Being Disabled: Towards a Critical Social Ontology for Disabled Studies," *Disability and Society*, vol. 22, no. 7 (2007), p. 675.
[123]Kevin Paterson and Bill Hughes, "Disability Studies and Phenomenology: the Carnal Politics of Everyday Life," in *Disability and Society,* vol. 14, no. 5 (1999), p. 597-610.
[124]Lorella Terzi, "The Social Model of Disability: A Philosophical Critique," in *Journal of Applied Philosophy,* vol. 21, no. 2 (2004), p. 150.