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7-15-2021

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### Recommended Citation

Iyall Smith, Keri E.. 2021. "Understanding and Promoting the Human Rights of Autistic People." *Societies Without Borders* 15 (1).

Available at: <https://scholarlycommons.law.case.edu/swb/vol15/iss1/3>

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## Understanding and Promoting the Human Rights of Autistic People

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**Acknowledgements:** I would like to thank Mark Frezzo for his efforts to organize the International Sociological Association’s Thematic Group 03 session “Sociological Perspectives on Economic and Social Rights,” where this paper was first shared (Toronto 2019). I am also grateful to my fellow panelists, Anne Bryden, Brian Gran, Elaine Thais Lima, Maria Soledad Etcheverry, Marie S epulchre, Zuzana Kusa, Paula Pinto and Teresa J. Pinto, and our excellent audience, all of whom helped me to deepen my work on this paper. I am also grateful for the feedback from two anonymous reviewers. All remaining errors are mine.

**Abstract:** Rates of autism diagnosis are on the rise and autistic people are entering the public sphere in new ways, represented in theater, on television, as international experts, and more. Yet, do autistic people experience their full human rights? Experts argue that autistic people suffer discrimination and violations of their human rights, noting that more must be done to ensure the full entitlement of human rights for autistic people (Autism Society ND, Baron-Cohen 2017 and Sarrett 2012). To better understand and promote the human rights of autistic people, this paper applies theories of disability to autism, looking at the biomedical model, the social model, and the capabilities approach. The capabilities approach asserts the universality of human capabilities and the importance of protecting the human rights of all people to develop their capabilities (Lynch 2013). The capabilities approach offers the best framework to support the human rights of autistic people, which can be seen through the application of the capabilities approach to their experiences. After a brief look at the comparative research in this area, revealing a consensus on human rights for autistic people in word if not in deed, it is possible to see opportunities for autistic people to realize their human rights as autistic people.

**Keywords:** Autism, Human Rights, Disability, and Rights of Persons with Disabilities

## **Understanding and Promoting the Human Rights of Autistic People**

Autistic people have brains that function differently. The medical community refers to it as a neurological condition. One to two percent of the world's population are on the autism spectrum. Autism impacts a person's experience of the environment and how their bodies experience the social and natural worlds (Bumiller 2008). An autistic person has a unique sensory experience, with heightened or dulled sight, smell, touch, sound, and taste. Autistic people may have speech delays, impairments to communication, or they might use technology assisted means to communicate. They may have difficulties with social relationships, adjusting to change, and dealing with ambiguity. People on the autism spectrum often appreciate repetition, routines, and patterns. They may also develop a narrow range of interests. Autistic people may interpret language literally, rather than metaphorically or symbolically. Medically, this condition is defined by "an inability to understand social conventions" and the progress of autistic people towards "treatment" is measured by the extent to which they are able to acquire "normal" social skills (Bumiller 2008:976).

Autism is both a diagnosis and a lived experience (O'Dell, Rosqvist, Ortega, Brownlow, and Orsini 2016). In this article, I focus on the lived experience of autism, beginning by looking at threats to autistic people's human rights. I then look at three models of disability and consider how our understanding of disability can contribute to violations of an autistic person's human rights or affirm their human rights. The capabilities approach offers unique opportunities to support the human rights of autistic people, even those rights which are currently under threat. A brief glance at the international literature shows that the capabilities model has not yet been broadly applied to the study of autism. Given the broad consensus on the human rights of people with disabilities as expressed by support of doctrine, there is great potential to expand the human rights of autistic people by embracing a capabilities approach.

### **Threats to Autistic People's Human Rights**

The World Health Organization (2017) notes that autistic people experience stigma, discrimination, and human rights violations, such as lack of access to health care, education, and lack of access to community participation. WHO is very concerned with human rights and autistic people, particularly the impacts of their unmet health care needs. The United Nations (United Nations General Assembly 2012) also sees the importance of attending to the socioeconomic needs of autistic people and their families, adopting a resolution in the General Assembly in support of enhancing service delivery and inclusive education, collecting data and conducting research on autistic people, and working to facilitate the full and equal participation of autistic people. The UN (United Nations General Assembly 2007) earlier expressed concerns on the ability of autistic people to fully realize their human rights in the General Assembly resolution adopted in 2007 in recognition of World Autism Day. Over a decade later, World Autism Day consistently brings news of the experience of discrimination against autistic children and adults (United Nations Office of the High Commissioner of Human Rights 2015).

In a 2017 speech to the United Nations marking Autism Awareness Week, Simon Baron-Cohen (University of Cambridge 2017) identified six ways that autistic people currently experience threats to their human rights, specifically rights to dignity (Gary and Rubin 2015), education (United Nations Department of Economic and Social Affairs 2017), public services, work, protection from discrimination, and protection from the law. Gary and Rubin (2015) also note the importance of the right to a life in community as one of the rights established in the UN Convention on the Rights of Persons with Disabilities which may be precarious for people on the autism spectrum. Sarrett (2012) notes the importance of supporting negative rights as well as positive rights<sup>1</sup> for autistic people: “negative rights are integral to creating an inclusive model of human rights” (7).

Violations of the right to dignity as granted in the UN Convention on the Rights of Persons with Disabilities include victimization by care providers (University of Cambridge 2017), being excluded from public places due to their behaviors, and exposure to treatments that can cause harm, especially Applied Behavior Analysis (one of the only treatments thought to be effective in teaching children social interaction). Applied Behavioral Analysis is inspired by training for animals and in its original form includes both positive rewards for behavioral changes—being more like neurotypical people—as well as negative sanctions for neurodiverse behavior (Silberman 2016). In the first application of Applied Behavior Analysis, a child was denied rewards and this led to self-harm (Silberman 2016). While modern Applied Behavior Analysis is less sadistic than this original application, it remains controversial among the autism spectrum community. For some people, the existence of a “treatment” for autism threatens their dignity by indicating that their neurotypical traits are not diversity but disability.

Autistic children and their families struggle to obtain public education that is appropriate and inclusive, free in the public setting and with appropriate supports and accommodations (United Nations Department of Economic and Social Affairs 2017). Securing access to health care and social work can be made more challenging by autism, which can make it challenging for people to understand and navigate bureaucracy or present concerns regarding eligibility for services. There are also many undiagnosed autistic people, particularly women and girls, who go without care and support (Szalavitz 2016).

Autistic people experience high rates of unemployment, even among so-called high functioning people (University of Cambridge 2017). This is due to their communication and social challenges which can result in negative perceptions during the interview process. It may also be due to difficulties presented by the work environment and inflexibility around telework or other accommodations. This challenge to obtain employment not only threatens a person’s right to work, it also threatens a person’s right to be economically self-sufficient in adulthood (Gary and Rubin 2015). In many societies this continues into retirement, where there are barriers to income support and health insurance from public or private sources. Autistic people

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<sup>1</sup> Negative rights are freedoms from harm and positive rights are provisions to experience rights. For instance, an autistic person might enjoy freedom from discrimination (a negative right) and the right to fully participate in community (a positive right).

experience stigma and discrimination in education and employment, as well as in other social settings. Autistic people are disproportionately victimized, yet they may be reluctant to seek remedies through the criminal justice system (University of Cambridge 2017). They are also disproportionately incarcerated, sometimes via criminalization of their behaviors and other times when accomplices take advantage of them (University of Cambridge 2017).

Many of these deficits are noted by the UN Office of the High Commissioner of Human Rights (UN OHCHR) (2015)—especially lack of access to health care, education, employment, and living in a community. The UN OHCHR (2015) also critiques the medicalization of autism and harmful treatments that threaten or violate the human rights of autistic people. These rights are protected under the Universal Declaration of Human Rights, the Convention on the Rights of Persons with Disabilities and the Convention on the Rights of the Child, along with ICESCR. Constitutions of many countries also protect rights for persons with disabilities, rights to education, the right to work, the rights of children, and the right to health. Yet autistic people continue to experience bias to the extent that Autistic Minority International (No date B) says that autistic people struggle as much with bias and prejudice as with health and disability. Social institutions often serve as obstructions to social life and equity for autistic people, rather than gateways to engagement and inclusion in their communities.

### **Biomedical Model**

As with other disability studies, the biomedical and social models are competing to interpret and understand autism. Biomedical studies seek to identify the cause of autism with a focus on genetic and environmental factors. The biomedical model sees autism as either a psychiatric disorder to be treated **or** a neurological reality with a possible genetic basis which we should seek to prevent (Hens, Robeyns, and Schaubroeck 2018). While there are many reasons to critique the biomedical model from the perspective of an autistic person within the high-income countries, in the developing world the biomedical model is replacing cultural definitions of autism that, for example, see autistic children as possessed (Silverman 2008). The biomedical model gives a scientific explanation, and in so doing it helps people in developing countries to better understand autism. Perhaps they will become less likely to discriminate against autistic people and their families as a result of the biomedical rationale.

Biomedical theories attempt to explain the pathological conditions that give rise to an autism spectrum diagnosis. For instance, the inability to construct a theory of mind prevents an autistic person from taking the perspective of others (Frith 2003, as cited in Hens, Robeyns, and Schaubroeck 2018). Instead, they assume that others have the same perspective as their own. Baron-Cohen connects autism to hormones, attributing the difference to high levels of testosterone and understanding autism as an “extreme male brain” (as discussed in Bumiller 2008).<sup>2</sup> For Baron-Cohen, this explains the prevalence of autism among the male population, but

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<sup>2</sup> While this conceptualization normalizes autism, it also essentializes gender (Bumiller 2008), and therefore we must be critical of the weight given to this model.

there is growing evidence that autism is underdiagnosed in women and girls, not that it is less prevalent among them (Szalavitz 2016).

Weak Central Coherence theory suggests that the problem is an autistic person's inability to see the whole picture (Hens, Robeyns, and Schaubroeck 2018 and Solomon and Bagatell 2010). Alternatively, it may be an autistic person's Weak Executive Function skills (Hens, Robeyns, and Schaubroeck 2018 and Solomon and Bagatell 2010) that leads them to engage in restrictive or repetitive behavior patterns. Because they are unable to keep track of planning and organizing a more dynamic array of activities (Hens, Robeyns, and Schaubroeck 2018), autistic people prefer to follow a few comfortable routines. Focusing on the sensory experience of autistic people, the Intense World theory focuses on the neural pathways that cause the brain to respond differently to sensory stimuli (Markram, Rinaldi, and Markram 2007, as cited in Hens, Robeyns, and Schaubroeck 2018). Finally, High, Inflexible Precision of Prediction Errors in Autism (HIPPEA) theory looks at the ways that the brain and body respond to "deviation from expectation" leading autistic people to be less able to be flexible around these unexpected circumstances (Van de Cruys, Evers, Van der Hallen, Van Eylen, Boets, de-Wit, and Wagemans 2014 as cited in Hens, Robeyns, and Schaubroeck 2018).

There is considerable effort to identify a cure or treatment for autism. The biomedical model is dominant in advocacy, which tends to seek a cause, a cure, and awareness of autism (Bagatell 2010). There is concern that continuing to problematize autism as something to cure or eliminate, as the biomedical model does, pathologizes autistic people and the things about them which they see as who they are. By pathologizing these traits, the biomedical model creates a narrow, strict definition of treatment for autistic people and indeed sometimes the "curative" treatments may risk the human rights of autistic people.

### **Social Model**

The social model is the critique of the biomedical model, asserting that autism as a disability is a social construct. Autistic people face challenges due to barriers in society rather than due to a medical condition. The Nordic relational model of disability focuses on how a person's capabilities may not match the demands of the environment (Mallett and Runswick-Cole 2014). By pointing out the gaps between a person's abilities and the demands of the environment, this model allows for adjustments to be made in the environment to accommodate different capabilities. The goal of the Nordic relational model is normalization—meaning that disabled persons should be empowered to live normal lives (Mallett and Runswick-Cole 2014). An important component of supporting this normalization requires a critical look at the environment and how it can be more supportive of people who experience the environment in different ways. Thus, consideration should be given to the potential impact of sounds, smells, and crowding in physical spaces to avoid indirectly discriminating against autistic persons in these spaces, e.g., public transit (Baker 2006 and Owren and Stenhammer 2013).

As autism is currently managed, the burden to fit in is borne by autistic people, rather than a burden to change institutions or the environment. The growth of a social skills curriculum

for neurodiverse people is institutionalizing the expectation that autistic people and others with a similar profile carry the burden of learning to behave, rather than institutionalizing the inclusion of neurodiverse people *as they are* even if this requires shifts to our institutions (Woods 2017). This points to a failure in the application of the social model of disability to autistic people and other neurodiverse people.

Woods (2017) offers steps to improving the practice of the social model of disability to autistic people—to place the burden of change on the predominant neurotypical institutions, rather than on autistic people. First it is necessary to remove the negative language (e.g., disorder or deficit) along with subcategories (e.g., high or low functioning) attached to autism to instead bring focus to autistic potential and autistic emancipation (Woods 2017). Woods (2017) also suggests the use of policies such as the basic income to affirm the citizenship of disabled people by ensuring their financial security. By changing the language and policies, autistic people and other neurodiverse people will come to be seen as more fully human and more fully citizens, leading to the more complete implementation of current protections and laws (where they exist), and thus expanded autism emancipation (Woods 2017).

The autism rights movement has been active in calling for change, regarding neurodiversity as a minority group rather than a disability. The minority group approach rejects the focus on training autistic people to “act normal” (Bumiller 2008 and Woods 2017). Instead, autism is also a form of identity (Hens, Robeyns, and Schaubroeck 2018). Autism is another culture, similar to the deaf community, and as such should be supported as other forms of diversity are supported. Neurodiversity acknowledges the neurological variation across people and the marginalization of those with differences (McGee 2012). The concept of neurodiversity emerged as workplaces came to see “personality traits,” such as social differences or inflexibility, as problematic at the same time that technology was facilitating the development of a neurodiversity movement (McGee 2012).

To promote pride among the disabled community, regardless of their capacity to meet the requirements of social norms, the social model seeks to redefine what it means to be normal, asserting that people who are other than “normal” are simply different (Mallett and Runswick-Cole 2014). Rejecting the normal/impaired dichotomy, autism becomes “not necessarily a source of difficulties in functioning, nor does their amelioration change the constraints that arise from living with autism” (Bumiller 2008: 971). Autistic difference is just as easily framed and indeed experienced as difference, rather than a list of pathologized symptoms (Bumiller 2008). Behaviors serve a purpose for autistic people. Seeing them as deviant denies the right of autistic persons to meet their needs and make themselves comfortable in social and natural environments that are challenging to navigate (Bumiller 2008). As with other minority groups, autistic people can experience the affirmation of autism as empowering, affirming, and establishing their dignity (Bumiller 2008) This affirmation stems from their membership in a group of people who share unique traits, not because they are in “treatment” to become more like neurotypical people.



### Capabilities Model—a Human Rights Approach

Seeing weaknesses in both the biomedical and social models, Jean Lynch (2013) looks to human rights scholarship and finds the capabilities approach. According to this approach, human capabilities are universal. All people have abilities and it is important to afford all people the opportunities to develop their abilities. The freedom to develop our abilities should not be reserved for the able-bodied or neurotypical. Lynch (2013) then brings in Amartya Sen, who asserts that all people have the right to be given the chance to develop *their* capabilities. Lynch (2013) notes that the capabilities approach, with its focus on the ends rather than the means, can be used together with the social approach to achieve human rights. A capabilities approach focuses on what we are all able to do rather than the differences in *how* we do these things and by doing so embraces accommodations to expand inclusion and accessibility (Lynch 2013).

The capabilities approach also addresses a key weakness of the social model, which is the failure to include impairment (Lynch 2013). For instance, it is possible to mediate impairments to communication for autistic persons without pathologizing their different mode of communicating as the biomedical model does. Autism self-advocates and indeed all autistic people can then participate more fully and enjoy their human rights *as* autistic people. Beyond tolerance, beyond a cure, by changing our *social* understanding of autism, rejecting a medicalization of autistic people, it will be possible to focus on the capabilities of autistic people and welcome their full participation in society.

Broadening our conception of what it means to be social (Bagatell 2010) will be fruitful for welcoming the participation of neurodiverse people (O’Dell et al. 2016). A wide range of competencies can be incorporated, to include deep independence and those who benefit from supportive accommodations—affirming the choice to live with assistance as a form of capability (Silverman 2008). The 2015 World Autism Day’s theme “Employment: The Autism Advantage” focuses on the potential contribution of autistic people and exemplifies the capabilities approach (Gary and Rubin 2015). Indeed, the speech by Secretary General Ban Ki-moon (2015) highlights the capabilities approach when he states that “Recognizing the talents of persons on the autism spectrum, rather than focusing on their weaknesses, is essential to creating a society that is truly inclusive.”

Beyond the capabilities approach, the human rights critique of liberalism is also relevant. It is liberalism’s promotion of individual responsibility that can lead to an unequal distribution of resources. Liberalism also carries strong assumptions about citizenship, particularly regarding labor force participation (O’Dell et al 2016). Critical autism studies is very concerned about instances of autistic people experiencing threats or denials of their human rights, frequently with little or no outcry. If we do not broaden our understanding of humanity to include a wider range of human behavior and neurodiversity, it seems that autistic people may continue to live at the border of our definitions of humanity (O’Dell et al. 2016).

As Blau and Moncada (2009) remind us, human rights is rooted in the idea and practice that people are equal **and** different. Rather than difference causing inequality and stigma, difference can be addressed with supportive means (Lynch 2013). Institutions rooted in a human

rights philosophy and approach can acknowledge and respond to diverse needs to bring about equitable conditions (Lynch 2013). Solomon and Bagatell (2010) suggest that embracing the complexity of autism can be a fruitful path towards better understanding how autistic people experience their diagnosis. Welcoming complexity might be a way towards improved outcomes, promoting equity and full participation of all people (Solomon and Bagatell 2010).

Turner's (2006) concept of shared vulnerabilities also points to the importance of shoring up institutions to protect human rights. A human rights approach allows autistic people to advocate for services that minimize their impairment and accommodations that support their abilities. It creates space for diversity and a path to equity through strong, rights-based institutions. Sarrett (2012) notes the importance of the definition of "human" for the purposes of human rights—particularly whether this definition carries any implicit or explicit requirements regarding a person's physical or cognitive abilities, or the requirement that a person must work. If people with disabilities are not seen as fully human, then they are not seen as being entitled to human rights—and Sarrett (2012) observes that this is problematic for non-verbal autistic people as well as those who assert high levels of independence. Indeed, Woods (2017) is highly critical of language that attaches deficit or disorder to autistic individuals, as it "allows Predominant Neurotypes to treat autistic people as less than human" (1092), risking the full citizenship and personhood of autistic people. Yet when autistic people are positioned in strong institutions that recognize their entitlement to human rights as citizens and persons, they are well positioned to thrive.

### **Applying the Capabilities Model: A Human Rights Approach in Practice**

In practice, the capabilities model offers many opportunities to affirm the human rights of autistic people that were previously described as threatened (Gary and Rubin 2015, United Nations Department of Economic and Social Affairs 2017, and University of Cambridge 2017). Focusing on the abilities of people protects human dignity, brings attention to appropriate strategies for education, and allows people to participate in the workplace in meaningful ways. Education using a capabilities approach values the diverse abilities of autistic people and affords them the opportunity to develop their unique abilities, rather than mandating a strict adherence to standardized education. The capabilities model promotes equality and non-discrimination, supporting access to public services and community membership. Under the capabilities model it is possible to be attentive to the ways that autism can present legal challenges. The experience of autism evolves throughout the life course, and thus it is also important to examine capabilities as they shift (or do not) to ensure that the human rights of autistic people are realized. Enhancing the human rights of autistic people not only supports the wellbeing of autistic people—it also creates the opportunity to establish structures that are supportive of the human rights of neurotypical people as well as people with other forms of disability (Sarrett 2012).

#### *Dignity*

To affirm the humanity of all—including autistic people—it will be necessary to expand our conception of what it means to be a part of our communities, to include those who wish to express more independence (as opposed to dependence) within their communities (Sarrett 2012). Concrete ways to support independence might include opportunities for teleworking or support of independent study in school at the student’s chosen pace (Sarrett 2012). Because some autistic people require close support and are therefore highly dependent, what is really needed is an inclusive approach to supporting people who prefer a range of levels of support (Sarrett 2012). This support of a range of independence of individuals affirms their dignity.

Among the Navajo, the worldview of *hozho* sees everyone as making a distinct contribution to the community, acknowledging the range of ways that people can contribute (Kapp 2011). Families celebrate milestones when they are achieved—without judgment or concern—rather than expecting them to occur on a specific timeline (Kapp 2011). Development is more organic, flexible, and evolving, with a focus on building skills (not when or how long it takes to acquire skills). People participate in their community, making contributions that are appropriate for their skills and abilities, not necessarily based upon chronological age (Kapp 2011). Traditional Navajo teaching using storytelling that gives details and illustrates the steps of different social processes and interactions, which can be supportive of an autistic person’s needs for developing social skills as well as executive functioning (Kapp 2011). In Navajo communities “Autistic people walk in beauty and are fully accepted and participating members of society, while Western Autistic people often face rejection” (Kapp 2011:591). A model of neurodiversity that affirms the dignity of autistic people is already in existence and can be adapted to other cultures as well (Kapp 2011).

When we affirm the dignity of autistic people, health care is readily accessible and patients are able to participate in their treatments, in collaboration with providers. Recognizing the unique experiences and capabilities of autistic people, caregivers must incorporate the perspectives of the autistic service user (Owren and Stenhammer 2013). Owren and Stenhammer (2013:36) observe “the uncritical use of ‘neurotypical standards’ as guidelines...may bring staff into the territory of indirect discrimination.” When the requests of the autistic service user can be honored, regardless of the neurotypical caregiver’s perception, the rights and equality of the autistic service user are affirmed (Owren and Stenhammer 2013). In this way, the difference of the autistic person is just different, rather than disabling. Openness to the perspective of the autistic service user allows them to be independent and have control in their lives (Owren and Stenhammer 2013). Service providers and other community members support the individuality of autistic people by honoring their preferences, instead of pathologizing, labelling, or otherwise diagnosing their choices (Sarrett 2012).

### *Education*

Diverse means of education are widely available within public school settings, improving the education outcomes for all students. The Individuals with Disabilities Education Act<sup>3</sup> in the United States is currently accessible to students in the highest and lowest income brackets (Baker 2006), unlike many Autism Spectrum interventions. Creating space for individuality within our institutions, offering more programming like Individualized Education Plans to everyone destigmatizes the use of such plans at the same time that it creates supports for more people and children who may benefit from them (Sarrett 2012). Similar administration of other interventions that “deliberately engage the public sector using a broad-spectrum approach” (Baker 2006:26) expands access to supports for autistic children and persons. Generalizing personalized supports across our institutions and across society creates “widespread respect for individual needs, desires, and expressions of selfhood is a critical tenet of basic human rights” (Sarrett 2012: 13). Caregiving and supports provided in the school system must be offered in a manner that affirms the self-determination and autonomy of autistic people across the spectrum, avoiding paternalism (Hens, Robeyns, and Schaubroeck 2018).

### *Work*

Embracing the capabilities of autistic people in the workplace becomes more feasible when autistic young people are nurtured in an education system that respects their human rights. Autistic young people are then prepared to move into economic institutions and workplaces that are supportive and able to incorporate their diverse skills, interests, and needs (Hens, Robeyns, and Schaubroeck 2018). Stigma can be removed in the interview process and workplaces might welcome the alternative perspectives of autistic persons. Temple Grandin credits her autism for allowing her to conduct groundbreaking work on the humane slaughter of livestock (Grandin 2008) and employers in Silicon Valley actively seek people on the autism spectrum for their distinctive skills (Silberman 2016). Workplace environments that are supportive of diverse workers contribute to the alleviation of poverty and other social disadvantages that disabled people are more likely to face (Levitt 2017). Expanding access to work for autistic adults is a human right in itself, but it also supports the human rights to dignity and equity, protection from discrimination, and the right to participate in a life in community.

### *Equality and Non-Discrimination*

When autistic people live in communities that embrace human rights and diverse capabilities, unexpected behavior is merely surprising, rather than a reason to exclude people. A human rights approach can allow us to see past disability as a personal tragedy and think about how the social construction of the disability prevents people from full, equal participation in their community—socially, economically, and politically—with an eye towards effecting change

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<sup>3</sup> Accommodations provided under the Individuals with Disabilities Education Act are far from perfect, but their availability to all students—not just those who can afford them—is what Baker values and it is what I wish to underscore here. Many autism spectrum interventions and supports are only available to people with the financial means to pay for them out of pocket. This leaves them out of reach for many, maybe most autistic people.

(Lynch 2013). Living in a society created for and by neurotypical people can incidentally discriminate against the neurodiverse, and this discrimination is not without consequences (Runswick-Cole 2014). To ensure the provision of autistic people’s rights to equality and non-discrimination, it will be essential that autistic people participate in policy creation and the institutionalized practices that emerge. This can lead to the incorporation of diverse modes of interaction in our social lives and it will no longer be necessary for autistic people to assimilate to the neurotypical model (Bagatell 2010). A focus on equality of condition ensures the provision of supports for those who experience the disabling aspects of autism and creates inclusive space that is supportive of neurodiversity.

Moving beyond the binary of the biomedical and social models will promote policies that focus on the resulting experience of the autistic person and what they need to live their lives fully within their communities—for equality of condition. Along these lines, Sarrett (2012) is critical of language that references normality, typical, or level or degree of disability to imply vulnerability. Instead she proposes a “sphere of humanity” which considers the whole person and the range of capabilities that a person can possess *without* pathologizing some configurations of traits (Sarrett 2012). Placing everyone’s traits within a sphere allows for the expression of vulnerabilities and differences among us all—not just among some kinds of people, and it also allows us to see that “those with more obvious differences also have traits considered to be more traditionally common” (Sarrett 2012: 14). The “Sphere of Humanity” promotes a holistic view of individuality that is universally applied to all people. It allows us to acknowledge the differences among ourselves as being both individual, particular attributes to a person, and universal.

### *Legal Rights*

Within the legal system it will be important to create provisions for people with different modes of communication, for example in the accessible booklet by The British Institute of Human Rights (2017) about learning disabilities and human rights. This particular document is more widely accessible due to its use of simple language, pages that are not cluttered with extensive text and content, and the use of pictures to elaborate on the text. It will be more challenging to incorporate different ways of being and different understandings of legal institutions, but guided by a capabilities approach and autistic people, it will be possible to ensure the legal rights of autistic people and affirm their rights to dignity, equality, and non-discrimination.

### *Life Course*

The life course approach encourages policymakers to consider the impacts of autism on how a person experiences the different phases of life and the potential supports that will be needed to allow for full participation of autistic persons in all stages of life. For instance, supports in school are necessary for children and young adults need assistance with housing and workplace modifications. This will be particularly important given the large growth in the

population of autistic people in Western societies. As young people move out of school and into adulthood, attention will be required to provide supports and attend to the ways that the environment can constrain their experience of life—at each stage of life.

A person's position within the life course determines whether it is appropriate to provide support that responds to neurological disabilities, primarily for autistic children, and programming that addresses neurodiversity, primarily for autistic teenagers and adults (Baker 2006). Supports for neurological disabilities will offer guidance and socialization to autistic children so that they may be able to understand their distinctive sensory and social experiences **and** learn to navigate social life with their unique perspective. A community that embraces neurodiversity will create space for accommodations, allowing autistic persons to participate fully in their community, utilizing their strengths without discounting their contribution if they require supports to fully engage. Services and interventions that shift as an autistic person moves through the phases of life supports the dignity and human rights of autistic persons in all aspects of their lives. A life course approach to disability responds to the needs of the autistic people who experience life as neurodiverse, as well as the needs of those in the autistic community with conditions that are more disabling and require medical or other supports (Baker 2006).

### **International Comparisons**

Most research on autism is currently produced in the US, Canada, the UK, and Sweden (O'Dell et al. 2016). Comparative research examines the state of access to care for autistic people in the developing world. Frequently in low to middle income countries, autism is newly recognized and autistic people are just beginning to receive treatment (Gary and Rubin 2015 and Wallace et al. 2012). There are limited resources for diagnosis and treatment and in these countries and families and children may still experience stigma with an autism diagnosis (Gary and Rubin 2015 and Wallace et al. 2012). What is worrisome is that the drive to expand access to diagnosis and treatment of autism is a globalization of the biomedical approach to autism, resulting in the framing of autism as a disorder. Wallace et al. (2012) describe an effort by Autism Speaks to spread awareness, diagnosis, and treatment to low and middle-income countries, but it is bringing a biomedical lens to the thinking about autism—rather than incorporating a social model or a capabilities/human rights approach. It does not incorporate the perspective of autistic people within the countries where they are working to spread knowledge. Autism Speaks also (ironically) excludes the voices of autistic people from high income countries.

Chung et al. (2011) conducted comparative research across Israel, South Korea, the United Kingdom, and the United States and found very little variation across countries regarding “challenging behaviors” in children with autism spectrum disorders. The study examines children who are deemed to meet the criteria of autism spectrum disorder in the DSM and finds the least variance between the United States and Israel and the United States and South Korea. This suggests that if human rights policies and practices incorporate neurodiversity and its ideals

for inclusiveness, it will be possible to globalize these policies and practices—they will promote the same types of expansion of our understanding of humanity in different cultural contexts.

Examination of Northern Ireland’s approach to autism shows that this region of the UK, which through devolution creates their own policies and practices regarding autism, continues to fail to promote best practices to provide behavioral supports for autistic children (Dillenburger, McKerr, and Jordan 2014). Dillenburger, McKerr, and Jordan (2014) note that in the UK there is an assumption that autism will “unfold” as children grow, but there is a lack of concern for looking more closely at how the environment that children experience may “influence and promote development” (139). Without these early supports, autistic people in the UK experience high rates of dependence, have difficulty finding work or are underemployed, and those who are employed experience bullying and discrimination (Dillenburger, McKerr, and Jordan 2014).

While there is little international comparative research on autism, it is clear that this research is dominated by the biomedical model. This underscores the need to establish a capabilities approach to autism and do more overt work to promote the human rights of autistic people. The European Union offers some legal protections for autistic people within their frameworks that protect disabled persons, along with provisions for equity and non-discrimination, although specific laws pertaining to autism do not yet exist (Palmisano 2015). Rather than calling for more legislation or normative instruments that pertain to autism, Palmisano (2015) urges that European rules and principles now in existence must be properly applied by states to achieve equity and prevent discrimination.

The majority of countries today offer protections for disabled people, children, the right to work, and the right to health care in their constitutions. Given this information, it is not surprising that a majority of these countries have also frequently signed and ratified the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities.<sup>4</sup> Legal provisions exist to ensure the human rights of autistic people and there is broad consensus on these human rights *in abstract*. What is needed moving forward is intent and action to protect these human rights for autistic people in their daily lives.

## Conclusion

Some pediatricians in the US are now optimistic about the future for their autistic patients (Demer 2018). Their patients are part of the wave of people diagnosed under the new Diagnostic and Statistical Manual of Mental Disorders (2013) framework. These young autistic people have educated their peers as they experienced inclusive education and they have changed the perspectives of their service providers (Demer 2018). While there is concern for how the medical establishment will support these pediatric patients as they enter adulthood, Demer (2018) is optimistic about the ability of autistic adults to self-advocate and be a part of the process of institutionalizing acceptance *with* assistance. Because of the high rates of abuse experienced by people with disabilities, medical providers will need to be watchful of their

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<sup>4</sup> Botswana, South Sudan, Somalia, and Tajikistan have not signed the Convention. Belarus, Bhutan, Ireland, Kyrgyzstan, Libya, Lithuania, the United States, and Uzbekistan have signed but not ratified the Convention)

patients and prepared to act if or when signs of abuse appear (regression, depression, and behavior problems) (Demer 2018). This expanding awareness is creating more allies/accomplices to work in support of autistic people as they claim their human rights.

In addition to self-advocacy in the doctor's office and with other service providers, autistic people want to speak for their community within the UN structure (Autistic Minority No date A). Indeed, it is their self-advocacy movements that are pushing both our understanding of autism as well as our knowledge of current policy weaknesses and failures (Bagatell 2010). This advocacy must inform new practices and policies. Self-advocacy began in Sweden in the 1960s, moving to the US in the 1970s (Bagatell 2010). Today it is an engaged, active, and diverse process supported by the internet and technological innovations that allow inclusive forms of engagement and community (Bagatell 2010). Autistic reformers seek to improve their lived experiences as autistic people and they are expanding conceptualizations of citizenship (Bagatell 2010). By creating more inclusive forms of citizenship, it becomes possible to expand our understanding of who is entitled to the privileges of citizenship, allowing autistic people to be fully human and possess dignity and equity *as themselves*, not because they have managed to imitate others (Bumiller 2008). Calls for an intersectional approach to be folded into neurodiversity (O'Dell et al. 2016) will only create more opportunities to build inclusive communities and affirm the human rights of all people.



## References

- Australian Human Rights Commission. No date. "Autism."  
<https://www.humanrights.gov.au/quick-guide/11937> (last accessed October 12, 2017).
- Autistic Minority International. No date A. "United Nations of Autism."  
<http://www.autisticminority.org/united-nations/> (last accessed July 20, 2018).
- Autistic Minority International. No date B. "We are the one percent."  
<http://www.autisticminority.org/autism/> (last accessed July 20, 2018).
- Autism Rights Movement. 2018. *Wikipedia*.  
[https://en.wikipedia.org/wiki/Autism\\_rights\\_movement](https://en.wikipedia.org/wiki/Autism_rights_movement) (last accessed July 10, 2018).
- Bagatell, Nancy. 2010. "From Cure to Community: Transforming Notions of Autism." *Ethos*. 38(1):33-55.
- Baker, Dana Lee. 2006. "Neurodiversity, Neurological Disability and the Public Sector: Notes on the Autism Spectrum." *Disability and Society*. 21(1):15-29.
- Baron-Cohen, Simon. 2017. "Keynote Address: Toward Autonomy and Self-Determination-World Autism Awareness Day 2017."  
<http://webtv.un.org/assets/rss/video3804186128001/watch/keynote-address-toward-autonomy-and-self-determination-world-autism-awareness-day-2017/5441187189001/?term=&lan=arabic> (last accessed January 8, 2019).
- Blau, Judith and Alberto Moncada. 2009. *Human Rights: A Primer*. Boulder, CO: Paradigm Publishers.
- British Institute of Human Rights. 2017. *Learning Disability, Autism and Human Rights*.  
<https://www.bihhr.org.uk/Handlers/Download.ashx?IDMF=5867be08-7d9e-42d1-8fb5-f94770df85cf> (last accessed April 1, 2019).
- Bumiller, Kristin. 2008. "Quirky Citizens: Autism, Gender, and Reimagining Disability." *Signs*. 33(4):967-991.
- Chung, Kyong-Me, Woohyun Jung, Jae-won Yang, Esther Ben-Itzhak, Ditzza A. Zachor, Frederick Furniss, Katie Heyes, Johnny L. Matson, Alison M. Kozlowski, and Alyse A. Barker. 2011. "Cross cultural differences in challenging behaviors of children with autism spectrum disorders: An international examination between Israel, South Korea, the United Kingdom, and the United States of America." *Research in Autism Spectrum Disorders*. 6(2):881-889.
- Demer, Linda L. 2018. "The Autism Spectrum: Human Rights Perspectives." *Pediatrics*. 141(4): S369-S372.
- Dillenberger, Karola, Lyn McKerr and Julie-Ann Jordan. 2014. "Lost in Translation: Public Policies, Evidence-based Practice, and Autism Spectrum Disorder." *International Journal of Disability, Development, and Education*. 61(2):134-151.
- Gary, Juneau and Neal S. Rubin. 2015. "Global awareness of autism spectrum disorder: Impact and interventions." *Psychology International*.

- <http://www.apa.org/international/pi/2015/06/autism-spectrum.aspx> (last accessed July 10, 2018).
- Grandin, Temple. 2008. *Humane Livestock Handling: Understanding Livestock Behavior and Building Facilities for Healthier Animals*. North Adams, MA: Storey Publishing.
- Hens, Kristien, Ingrid Robeyns, and Katrien Schaubroeck. 2018. "The Ethics of Autism." *Philosophy Compass*. 14: e12559. <https://doi.org/10.1111/phc3.12559> (Last accessed January 31, 2019).
- Kapp, Steven K. 2011. "Navajo and Autism: The Beauty of Harmony." *Disability and Society* 26(5):583-595.
- Ki-moon, Ban. 2015. "Remarks on World Autism Awareness Day." <https://www.un.org/sg/en/content/sg/speeches/2015-04-02/remarks-world-autism-awareness-day> (last accessed March 1, 2019).
- Levitt, Jonathan M. 2017. "Exploring how the social model of disability can be re-invigorated: in response to Mike Oliver." *Disability and Society*. 32(4):589-594.
- Lynch, Jean M. 2013. "Chapter 11: Disability and Society." Pp. 107-117 of *The Handbook of Sociology and Human Rights* edited by David L. Brunsma, Keri E. Iyall Smith, and Brian K. Gran. Bolder, CO: Paradigm.
- Mallett, Rebecca and Katherine Runswick-Cole. 2014. *Approaching Disability: Critical Issues and Perspectives*. London: Routledge.
- McGee, Micki. 2012. "Neurodiversity." *Contexts*. 11(3):12-13.
- Ministries of Health and Education. 2016. *New Zealand Autism Spectrum Disorder Guideline* (2<sup>nd</sup> edn). Wellington: Ministry of Health.
- O'Dell, Lindsay, Hanna Bertilsdotter Rosqvist, Francisco Ortega, Charlotte Brownlow, and Michael Orsini. 2016. "Critical autism studies: exploring epistemic dialogues and intersections, challenging dominant understandings of autism." *Disability and Society*. 31(2):166-179.
- Office of the United Nations High Commissioner for Human Rights. 2015. "Discrimination against autistic persons, the rule rather than the exception – UN rights experts." <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15787> (last accessed July 10, 2018).
- Owren, Thomas and Trude Stenhammer. 2013. "Neurodiversity: Accepting Autistic Difference." *Learning Disability Practice*. 16(4):32-37.
- Palmisano, Guiseppe. 2015. "The Protection of People with Autism in the Framework of the Council of Europe and the European Union." Pp. 11-23 in *Protecting the Rights of People with Autism in the Fields of Education and Employment*. Institute for International Legal Studies, National Research Council, Rome, Italy. [http://link.springer.com/chapter/10.1007/978-3-319-13791-9\\_2/fulltext.html](http://link.springer.com/chapter/10.1007/978-3-319-13791-9_2/fulltext.html) (last accessed October 12, 2017).
- Runswick-Cole, Katherine. 2014. "'Us' and 'Them': The Limits and Possibilities of a 'Politics of Neurodiversity' in Neoliberal Times." *Disability and Society*. 29:7. Pp. 1117-1129.

- Sarrett, Jennifer C. 2012. "Autistic Human Rights: A Proposal." *Disability Studies Quarterly*. 32:4. <http://dsq-sds.org/article/view/3247> (last accessed January 8, 2019).
- Silberman, Steve. 2016. *Neurotribes: The Legacy of Autism and the Future of Neurodiversity*. New York: Penguin Random House.
- Silverman, Chloe. 2008. "Fieldwork on Another Planet: Social Science Perspectives on the Autism Spectrum." *BioSocieties*. 3(3):325-341.
- Solomon, Olga, Nancy Bagatell. 2010. "Introduction. Autism: Rethinking the Possibilities." *Ethos*. 38(1):1-7.
- Szalavitz, Maia. 2016. "Autism—It's Different in Girls." *Scientific American*. <https://www.scientificamerican.com/article/autism-it-s-different-in-girls/> (last accessed February 26, 2021).
- Turner, Bryan Stanley. 2006. *Vulnerability and Human Rights*. University Park, PA: Pennsylvania State University Press.
- United Nations. Convention on the Rights of Persons with Disabilities and Optional Protocol.
- United Nations. General Assembly. 2008. "World Autism Awareness Day." A/RES/62/139.
- United Nations. General Assembly. 2012. "Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities." A/RES/67/82.
- United Nations Department of Economic and Social Affairs. 2017. "UN calls for recognizing the rights of people with autism to make their own decisions." <https://www.un.org/development/desa/en/news/social/autism-day-2017.html> (last accessed July 10, 2018).
- University of Cambridge. 2017. "Human rights of people with autism not being met, leading expert tells United Nations." <http://www.cam.ac.uk/research/news/human-rights-of-people-with-autism-not-being-met-leading-expert-tells-united-nations> (last accessed January 8, 2019).
- Wallace, Simon, Deborah Fein, Michael Rosanoff, Geraldine Dawson, Saima Hossain, Lynn Brennan, Ariel Como, and Andy Shih. 2012. "A Global Public Health Strategy for Autism Spectrum Disorders." *Autism Research* 5(3):211-217.
- Woods, Richard. 2017. "Exploring how the social model of disability can be re-invigorated for autism: in response to Jonathan Levitt." *Disability and Society*. 37:2. Pp.1090-1095.
- World Health Organization. 2017. "Autism Spectrum Disorders." <http://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders> (last accessed July 10, 2018).