

Geneva, 20 November 2013

Written statement to the second annual UN Forum on Business and Human Rights and the Working Group on the issue of human rights and transnational corporations and other business enterprises

THE GUIDING PRINCIPLES AND AUTISTIC SELF-ADVOCACY

Autistic Minority International is the first and only autism self-advocacy organization active at the global political level. The NGO, headquartered in Geneva, aims to advance the interests of autistics worldwide at and through the United Nations, World Health Organization, human rights treaty bodies, and other international organizations.

We believe that autistic self-advocacy is about more than disability rights. Autism is a distinct culture and identity. The only one we know. Regardless of where in the world we live, autistics are more like each other than like the people surrounding us. According to the most recent prevalence figures, the autistic minority is estimated to comprise seventy million people, one percent of the world's population. It includes those diagnosed with Asperger's syndrome and various other conditions on the autism spectrum as well as those children and adults who remain undiagnosed.

In 2007, the United Nations General Assembly declared 2 April World Autism Awareness Day. On that day in 2013, UN Secretary-General Ban Ki-moon wrote: "This international attention is essential to address stigma, lack of awareness and inadequate support structures. Now is the time to work for a more inclusive society, highlight the talents of affected people and ensure opportunities for them to realize their potential."

In 2012, the United Nations General Assembly unanimously adopted resolution 67/82 "Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities". In this resolution, the UN member states recognize "that the full enjoyment by persons with autism spectrum disorders [...] of their human rights and their full participation will result in significant advances in the social and economic development of societies and communities" and stress "the important contribution that non-governmental organizations and other civil society actors can make in promoting human rights for [...] all individuals with autism spectrum disorders [...] and their integration in societies". The GA voices its concern "that persons with autism spectrum disorders [...] continue to face barriers in their participation as equal members of society" and calls this "discrimination" and "a violation of the inherent dignity and worth of the human person".

Autistics struggle as much with bias and prejudice as with health and disability. Challenges and severity vary widely between individuals. In this statement we will seek to address the concerns of those autistics who depend on business enterprises to provide

professional care and support, but also remain mindful of the situation of those of us who may be working in those same or any other business enterprises, but often hide their condition for fear of repercussions. The latter is no longer tenable at a time when millions of children diagnosed with autism come of age and many more get diagnosed as adults.

The Guiding Principles on Business and Human Rights "apply to all States and to all business enterprises [...] regardless of their size, sector, location, ownership and structure", large healthcare groups as much as small and medium enterprises, such as are frequently involved in the care and support of autistics. These Guiding Principles aim to "achieve tangible results for affected individuals and communities", including autistics (general principles and principle 14). The commentary to principle 3 encourages States to provide "guidance" in the form of laws and policies "to business enterprises on respecting human rights" and to pay particular attention to vulnerable and marginalized groups, such as "minorities, children, persons with disabilities", and the commentary to principle 12 highlights the responsibility of business enterprises to respect "the human rights of individuals belonging to specific groups or populations that require particular attention" as elaborated on in "United Nations instruments [...] on the rights of [...] minorities; children; persons with disabilities".

Operational principle 18 calls on business enterprises to "identify and assess" their "actual or potential adverse human rights impacts [...]. This process should [...] [i]nvolve meaningful consultation with potentially affected groups [...] as appropriate to the size of the business enterprise and the nature and context of the operation". Too often, in the context of the professional care and support of autistics, it is wrongly assumed that we cannot or should not be consulted about potential sources of human rights violations, such as our living arrangements or medical and psychological treatment. Instead, non-autistics, among them parents, professionals, and so-called autism experts, may get a hearing. It is our conviction that rather than subjecting us to institutionalization, behaviour modification by way of degrading medical and therapeutic practices, including electric shocks and withholding of food, and teaching us how to appear less different, we should be taught self-esteem, self-confidence, and how to advocate for ourselves.

Autism is a neurological difference that is both genetic and hereditary. There is no cure, and we do not believe that a cure will ever be found. Autism awareness must lead to acceptance, recognition, and respect for autistics. Along the same lines, we call on governments to engage and consult with autism self-advocacy groups at the global, national, regional, and local level, too.

The commentary to principle 18 specifies that "assessments of human rights impacts should be undertaken at regular intervals [...] throughout the life of an activity" and "potentially affected stakeholders", specifically "individuals from groups or populations at heightened risk of vulnerability or marginalization", such as autistics, should be consulted "directly in a manner that takes into account language and other potential barriers to effective engagement". Most autistics, be they children or adults, can be consulted if barriers are removed. We encourage business enterprises to find and explore ways of consulting us directly. Even those of us who are non-verbal may, for example, be able to express themselves in writing online, as evidenced by Internet fora that unite autistics across the spectrum, from least to most severe.

Equally important is that the outcomes of such consultation are acted upon. "Potential impacts should be prevented or mitigated through the horizontal integration of findings across the business enterprise, while actual impacts – those that have already occurred – should be a subject for remediation" (commentary to principle 19). Either requires verification and tracking, drawing once more "on feedback from [...] affected stakeholders", the vulnerable and marginalized, which as before are autistics themselves, not their parents, professionals, or autism experts (principle 20 and commentary).

Principle 21 highlights the need for transparency: "In order to account for how they address their human rights impacts, business enterprises should be prepared to communicate this externally, particularly when concerns are raised by or on behalf of affected stakeholders". This principle thus also underlines the important role played by autism self-advocacy organizations such as ours in raising human rights concerns on behalf of autistics who may not be able to do so themselves. Communication with "individuals or groups who may be impacted [...] can take a variety of forms, including [...] online dialogues", which we recommend, as long as it is a real dialogue, as it lowers barriers for autistics and makes the process more accessible to us (commentary to principle 21).

In terms of remedies, the commentary to principle 26 finds that "whether through active discrimination or as the unintended consequences of the way judicial mechanisms are designed and operate, individuals from groups or populations at heightened risk of vulnerability or marginalization often face additional cultural, social, physical and financial impediments to accessing, using and benefiting from these mechanisms. Particular attention should be given to the rights and specific needs of such groups or populations at each stage of the remedial process: access, procedures and outcome". The same applies to non-judicial remedies and grievance mechanisms (commentary to principle 27). Autistics are at a particular disadvantage in seeking remedies as often we have to overcome multiple, if not all the mentioned impediments at once.

Better for "grievances to be addressed early and remediated directly" (principle 29). "Operational-level grievance mechanisms are accessible directly to individuals [...] who may be adversely impacted by a business enterprise. They are typically administered by enterprises, alone or in collaboration with others, including relevant stakeholders" (commentary to principle 29). We strongly urge business enterprises that provide care and support to autistics to set up such mechanisms and involve autistics actively in their administration.

Grievance mechanisms must be widely known and provide "adequate assistance for those who may face particular barriers to access [...] Operational-level mechanisms should also be [...] [b]ased on engagement and dialogue: consulting the stakeholder groups for whose use they are intended on their design and performance, and focusing on dialogue as the means to address and resolve grievances" (principle 31). Once more, this means consultation of and a dialogue with autistics themselves, even if it may be challenging. This dialogue is crucial, though, as "[p]oorly designed or implemented grievance mechanisms can risk compounding a sense of grievance amongst affected stakeholders by heightening their sense of disempowerment and disrespect by the process" (commentary to principle 31).

Finally, it is important to bear in mind that "[s]uch mechanisms need not require that a complaint or grievance amount to an alleged human rights abuse before it can be raised, but specifically aim to identify any legitimate concerns of those who may be adversely impacted. If those concerns are not identified and addressed, they may over time escalate into more major disputes and human rights abuses" (commentary to principle 29). And: "Grievances are frequently not framed in terms of human rights and many do not initially raise human rights concerns. Regardless, where outcomes have implications for human rights, care should be taken to ensure that they are in line with internationally recognized human rights" (commentary to principle 31).

Autistics are in a particularly vulnerable position opposite business enterprises that provide our care and support, and many of us live in a perpetual state or constant danger of abuse and violations of our basic human rights by those who are supposed to protect us. Of course, all of the aforementioned equally applies to care and support providers in the public and non-profit sector as well as other public, private, and third sector providers of services targeted not exclusively at autistics, such as educational institutions.

Business enterprises also employ autistics, particularly those of us who are independent. The Guiding Principles fully apply to the "fundamental rights set out in the International Labour Organization's Declaration on Fundamental Principles and Rights at Work" (principle 12). While many of us go unnoticed in the workforce, or at most may be thought of as weird or odd, distant or aloof, arrogant or egotistical, this comes at a heavy price. We may mimic others' behaviour in order to hide our condition and pretend to be "normal", but it never feels natural. Many of us experience a middle age burnout when the decades-long effort of keeping up a façade becomes just too much. Fear of discrimination in the workplace is the primary reason why autistics choose not to be open about their autism.

Other barriers and potential human rights concerns at work that should be addressed within the "Protect, Respect, and Remedy" framework of the Guiding Principles include an over-reliance on teamwork, overstimulating work environments, and possible repercussions due to most autistics' aversion to small talk and difficulties multitasking, which collectively mean that an ever increasing number of autistics are forced out of a job and into disability. Far from being able to realize our potential, society seems to have stopped valuing the unique contributions made by persons on the autism spectrum throughout human history.

We applaud the few business enterprises that provide jobs particularly aimed at autistics, namely in the field of information technology. We trust that these business enterprises will be cognizant of the Guiding Principles as they relate to autistics at work and apply them in full, in the process training their autistic staff in self-advocacy. Unfortunately, most autistics who are open about their condition do not have superior IT skills, and jobs for us are scarce. It is our hope that the Guiding Principles may help improve understanding between autistics and non-autistics and sensitize business enterprises beyond the providers of professional care and support and information technology companies for autistics' plight and potential alike.

Autistic Minority International welcomes contact from and is open to collaboration with UN member states, the UN system, the wider NGO community, autism charities run by

non-autistics, researchers particularly in the social sciences and international law, business enterprises, and individuals. We look forward to interacting with participants in the forum as well as other business and human rights stakeholders in the near future.

We urge the Forum on Business and Human Rights and the Working Group on the issue of human rights and transnational corporations and other business enterprises to pay increased attention to the concerns of the autistic minority as well as persons with disabilities in general.

Erich Kofmel, President
Autistic Minority International