Reflections on the right to health

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Book Chapter

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All human beings have a right to health, but what that means is vague. According to the World Health Organization, ‘health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity’ (WHO 1946). The former UN Special Rapporteur on the right to health, Paul Hunt, defines it as access to an effective and integrated health system. Also included in the definition are underlying determinants of health that might influence a person’s ability to live a healthy life (Hunt 2006).

The right to health is of central importance, of course, and we define it as having access to healthcare as well as aspects of everyday life of importance for a healthy life.¹ The latter means such things as friendship, support networks, and access to educational institutions. These were identified as central to our research because they are determinants of health, in the sense that the young people participating in our study referred to them as important. Furthermore, previous research shows that these are important aspects of coping and struggling in everyday life for children who are in a marginalized position (Andersson et al. 2010). Regarding healthcare, this is also an area that has recently been subject to a progressive political or legal development in Sweden and its third largest city, Malmö.

The undocumented youths in this study are those children and young people who have been forced to emigrate from their countries of permanent residence because of individual persecution, armed conflict or a massive denial of economic, social, and cultural rights, and who lack Swedish residence permits. There are several terms to describe people in this position—overstayers, refugees in hiding, clandestine refugees, irregular migrants—but we use the term ‘undoc-
umented’ migrants, since it reflects the terminology used by young people themselves, being papperslös, literally without papers. The term youths or children in this text refers to children aged between 15 and 18 and in a few cases young adults between 18 and 20. The UN Convention on the Rights of the Child (CRC) states that children are persons below the age of 18 (Article 1); however, since it is often unclear to everyone involved in the situation of individual undocumented migrants exactly how old they are, people slightly over 18 have been included in this study. All the participants in the study were also subject to the Dublin II Regulation, requiring that every person seeking refuge should do so by filing an application in the first country of arrival.

Taking the experiences of undocumented, unaccompanied youths, this essay aims to analyse the human right to health as it has played out in the city arena of Malmö. Specifically, we describe discrepancies between the right to health in policy and in practice, and explore the tensions between human rights regulations on the one hand and migration control on the ground in Malmö on the other. We argue that the experiences of undocumented youths illustrate fundamental dimensions to these tensions. Neither convincing legislation at the national level, nor clear policies in the city or region, are a guarantee for access to one’s rights. What is crucial, we would argue, are rather the strategies to cope with everyday hardships used by the undocumented persons themselves and their support networks, and a knowledge of human rights on the part of the service providers in their everyday work. The conclusion here is that practices of human rights in the city can contest state-level migration control policies.

Our analysis is based on empirical fieldwork carried out using participant observations in Malmö in January to December 2012, including ten in-depth interviews with undocumented youths. The interviews, which we conducted together, lasted one and a half to two and a half hours. We used a flexible interview guide to frame the conversation, structured in a manner where the interviewee was first asked to describe a normal day, followed by broad themes such as school, resources, health, and access to healthcare. We did two interviews in English and two interviews with interpreters (not offi-
cial interpreters but a friend of ours in one case and a friend of the interviewee in the other case). They interpreted from Dari and Somali to Swedish. The rest of our interviews were conducted in Swedish.

Theoretical framework

In the terminology of the political philosopher Hannah Arendt, being excluded from the protection of nation-states also leaves a person excluded from the right to have rights. Having herself experienced statelessness in the aftermath of the Second World War, Arendt famously concluded that human beings, when losing political status such as citizenship, were also excluded from human rights (1951, 300). Starting from the situation of the stateless people of her day, Arendt claimed that there is one right necessary to get access to all other rights—the right to have rights. Without this, a person was nothing but a human being stripped of all rights, and the world found ‘nothing sacred in the abstract nakedness of being human’ (Arendt 1968, 299). In other words, when a person is merely human, he or she paradoxically loses all human rights.

The relationship between citizenship and rights brought up by Arendt is not as evident today. Various human rights documents, as well as expert committees within the UN, have gradually expanded the interpretation of who is included within the scope of human rights (Benhabib 2006). Yet even so, undocumented persons still do not have unconditional access to the inalienable human rights that supposedly afford much-needed protection. Legal scholars describe this in terms of an unstable relationship between entitlements and humanity (Noll 2010) or as a site of contestation for the meaning of the right to have rights (Kesby 2012, ch. 5). One aspect of the problem is the law, since, as Lindahl (2010) argues, it is the law that determines the concept of humanity for legal purposes and the legal order is therefore by definition exclusionary.

On a practical level, claims to human rights can be used as an instrument for inclusion in the regulatory frameworks of the nation-state. An example of this is when claims are made from organizations and other actors that people who lack residence permits should nevertheless be covered by the welfare system. At a theoretical
level, the problem is more complex than this simple inclusion of all those who are formally excluded would imply. This has to do with the point made by Lindahl that inclusion always requires exclusion, and this is situated in the legal design. Specifically, this means that rights must be determined by someone, and this process of defining who is entitled to what human rights implies of necessity various forms of sorting and categorization: they may take different forms depending on the level of regulation.

What does it mean then to be categorized as an undocumented person? In several ways, yes, it is about losing those rights that every human being is entitled to. Yet it is also about losing the mastery of the language in which to claim rights. As an undocumented migrant, one does not have a voice that counts in the same way as a citizen’s would, and this despite the multiple instruments adopted by the world community, the Universal Declaration of Human Rights and the European Convention on Human Rights being perhaps the best known. In these human rights instruments, each and every member of humanity is entitled to the protection of the law and should be subject to the principle of equality. To claim that everyone is entitled to equality before the law and access to basic human rights is thus uncontroversial—the rights are explicitly inalienable for all members of the human family—which makes them self-evident. However, to treat everyone as equal, independent of their legal status, seems to be a contradiction in terms. The widespread problems with racism and the marginalization and criminalization of migrants in the contemporary world are well-known illustrations of this (CRC Committee 2012). While the rights belong to one group, it is another actor that has the mandate to implement them. We will return to the problem of exclusion as part of legal design; our point here is that human rights legislation is embedded in superiority and dependency, in stark contrast to the idea of equality.

Inspired by Arendt and others, and applying the perspectives of rights-holders themselves, we understand human rights mainly as a political enactment (Ingram 2008; Squire & Darling 2013). In this sense, the invention and reinvention of human rights is a question of coming together in plurality and granting each other reciprocal conditions (Kesby 2012, 67)—rights are not a status but
an activity. Such an activity (claims to rights), wherever it takes place, is a demonstration of how rights might occur (Ingram 2008, 413).

Furthermore, we draw on Kesby’s argument (2012) that human rights have a double function in the position of undocumented persons: they provide for entitlements to rights, and they also ‘realign national citizenship’ with international norms (ibid. 369). It is relevant to explore how this might develop in the city, as the city is one social space for rights realization (Oomen & Baumgärtel 2012).

Thus undocumented persons constitute an anomaly to that full legal, political, and social presence within a state that a residence permit represents. This makes it relevant to explore the exercise of human rights from their standpoint, in local contexts, which, in combination with an investigation of different levels of regulation, we would argue is a suitable beginning when exploring the disputed meaning of human rights today.

**A spectacle in Malmö**

Over the years, youths arriving on their own to seek refuge in Sweden have greatly increased in number, from fewer than 500 in 2005 to more than 2,000 every year since 2009. At time of writing they constitute some 10 per cent of the total number of asylum seekers. In 2013, almost 4,000 unaccompanied children applied for asylum in Sweden—the highest number in Europe (Migrationsinfo 2013). The majority are boys from Afghanistan aged between 15 and 17, who have been forced to escape because of a massive denial of their human rights or direct threats from the Taliban (Migration Board 2011). Approximately 45 per cent of the children concerned arrive in Malmö, Sweden’s third largest city with 300,000 inhabitants, situated near the Danish border. By the end of 2013 there were approximately 265 youths being sought in Malmö for deportation: youths whose asylum applications had been referred to another European state or who had had their claims for refuge rejected, in other words (Malmö Police Department 2013).

In the Malmö context, we are concerned with everyday life as an undocumented person and the role of international human rights at the city level. As noted by Jonathan Darling (2010), cities have a
strong role in the realization of human rights, and this brings to the fore tensions between different levels of regulation—a point at which the invention and reinvention of human rights can be studied. It is no longer clear that human rights are a matter of state obligations towards the individual, or the individual’s claims on the state. A recent development is the direct engagement of local communities in international human rights. Malmö, for example, has increasingly taken the initiative on human rights issues (Platform 2010–2014). This might also imply that human rights have a greater impact in terms of actual access for undocumented migrants to welfare services, as these are provided at the municipal level (Darling 2010).

In Malmö, as in other European cities, the idea of non-discrimination of irregular migrants has become one of the most politicized of our time and has called for increased attention in public debate. Gradually, the city has expanded the target groups of its welfare services to include undocumented children, partly due to initiatives by the Green Party and a vocal, broad-based refugee rights network in the city. There was controversy in Malmö about the dangers facing undocumented youths in Sweden, such as the risk of deportation when attempting to attend school. Despite national legislative changes intended to enshrine the right to an education for all living in Sweden (Skollag 2010:800), there was nothing to stop the police searching schools or the immediate area for persons they were to deport. Furthermore, in 2012 a EU-funded project was started in collaboration by the police, the Migration Board, and the Swedish Prison and Probation Service to promote ‘Legally secure and efficient enforcement work’ (REVA). This project made the situation for children and young people living in Sweden without residence permits even more insecure. The project started as a pilot in Malmö where the police adopted an intensified approach to searches. This lead to loud protests and much public debate about violent migration control (Sveriges Television 2013). The resultant demonstrations, media reports, and other local initiatives in Malmö serve to exemplify the attempts to rework and contest boundaries between ‘us and them’. Rather than the question of who should be included, it was the city as a spatial unit that was the focus. A central and recurring question is what sort of city people want.
The tension between state migration control and the policymakers in Malmö was brought up by City Councillor Katrin Stjernfeldt Jammeh when she was asked to comment on the REVA project in Malmö (the Councillor had not been informed in advance by the police about their new tactics):

If children in Malmö don’t dare to go to school or seek medical care because they are afraid the police will take them, we won’t reach the city’s goal of all children having access to school. (Stjernfeldt Jammeh interview 2013)

At the heart of the Malmö context is an ongoing negotiation between the city, trying to provide for its inhabitants’ interests and needs, and the nation-state’s interest in upholding an effective migration control. Human rights are increasingly used in the struggle within institutions to counter the sorting of people based on legal status. This was the case when it was decided that undocumented children had a right to support from social services. It was clearly stated that social workers should treat all children equally, regardless of their legal status (Malmö stad 2013).

The children, and thus also the youths, we met in our study are afforded strong protection under the policies on human rights while they are particularly vulnerable because of their position as undocumented residents. There are several reasons for this. There are the tensions between the circulation of persons and the increased control of persons, and between their inclusion in welfare systems and the workings of streamlined migration management on the part of the state. These tensions may be understood as a spectacle, or, as De Genova describes it, a ‘vertiginous spiral of inequalities that are deeply imbricated within the fabric of citizenship itself’ (2013, 1194). Drawing on Balibar’s proposition that the management of borders ‘establish and maintain “a world apartheid”, which institutes a “color bar”’, De Genova argues that this ‘runs through all societies’ (ibid. 1192). In our study, there is the spectacle of youths excluded from much of the welfare state, and at the same time completely dependent on the kindness of these institutions to get access to those rights they are entitled to under international law.
They are subject to a conditional inclusion in a process where they have severely limited scope of influence.

Nevertheless, undocumented persons cannot hope to engage ‘a state’s welfare jurisdiction’ without also ‘triggering its immigration jurisdiction’ (Noll 2010), or as Kesby puts it,

Even though a person may be physically present, they are to be socially and legally absent through the denial of key rights or formal and practical impediments to their enjoyment—not least detection by the authorities and subsequent expulsion. (Kesby 2012, 110)

This brings us to the question of rights claims in what is, after all, an irregular context at the local level (see Strange & Lundberg 2014). What are rights claimants’ strategies to cope with everyday life in Malmö?

The example of the right to healthcare

The right to healthcare for children without a residence permit is an absolute human right in policy, and there are clear guidelines stating that all children resident in Sweden should have full access to healthcare on equal terms. Referring to an agreement in June 2012 between the Green Party (which was in opposition at the time) and the Swedish government, undocumented children were included under the heading of people entitled to access to full healthcare and dental care. At the time of our field study, children whose application for asylum had been turned down were included in the regulations at the national level. However, until 2013, undocumented children who had not yet had their asylum claims assessed in a formal process were excluded from the right to healthcare. In Skåne County Council (in which Malmö is the largest city), the right to healthcare has extended to both children and adults since 2008; however, for adults, payment for care is still an issue, while by contrast all undocumented children receive subsidized care. The extension of the right to healthcare in Skåne predated the national level. Furthermore, according to Skåne County Council policy from 2011 on non-citizens and undocumented migrants, ‘the medical care,
as with other patient groups, shall be the first priority and ability to pay comes second’ (Region Skåne 2011). A complementary policy states that whatever their legal status, migrants and refugees should be treated professionally and with respect, and with a certain understanding for their special living conditions and experiences (Region Skåne 2011). However, despite the formal obligations, it is still the case that undocumented people cannot access welfare services without also triggering the system of migration control (Noll 2010).

The fear of control and detection severely limited access to healthcare services among the youths in our study. As one of them puts it:

Now I’m really scared, I hope I don’t get sick. [Why?] I get scared because you never know if the police come and get you, or if a racist doctor may call the police. (Erfan)

Clearly, in practice the experience of access to rights is conditional—here, in the meeting with the individual doctor who should provide care, but where the young man is frightened that he might be confronted with a racist doctor. Naturally, worrying about being confronted by racism is not dependent on a lack of legal status, but evidently Erfan’s situation as an undocumented person adds to the perceived insecurity. Even though the regulations do not require healthcare providers to inform the police of their patients’ presence, the possibility that someone might call the police, for example due to lack of knowledge or racism, cannot be completely ruled out.

In our fieldwork we found among receptionists and other healthcare personnel that a lack of knowledge of undocumented persons’ right to healthcare was indeed an obstacle to access to healthcare. On one occasion we accompanied 17-year-old Mohammad, who had violent stomach pains, to accident and emergency. We had a long argument with the receptionists before they would let us in to see the doctors. We were also billed EUR 350 instead of the usual highly subsidized sum. The issue of having to argue with medical receptionists for one’s right to healthcare was a common theme in our informants’ experiences. Receiving care, they emphasized, was dependent on someone helping them get access. In Arendt’s words, the youths were stripped of all rights by dint of not being catego-
thesized as a member of the nation-state. However, our findings show that the meaning of the right to have rights is indeed contested. It seems that the right to have rights is connected to being recognized, and when it comes to access to welfare services this is not limited to being recognized by the state. Access to the right to healthcare is connected not only to formal regulations, but also to being recognized by the receptionist, doctor, or other staff as a person belonging to the community of rights-holders.

Turning to the underlying determinants of health, in our study a lack of legal status is also directly connected to a lack of other resources. All our respondents knew what it was to be poor, and in school and elsewhere were treated differently to their peers who had residence permits. This affected their sense of being part of the community in which they lived. Ostensibly ‘small’ things such as not being able to participate in school activities—going on trips, appearing in school photographs, or having a library card—all contributed to the feeling of subordination due to their lack of legal status. They were not fully part of the community, but had conditional access to it. In this situation, developing a sense of belonging and being recognized appeared as an example of the how the relation between entitlement and humanity is unstable.

It should also be emphasized that all our respondents suffered from severe health problems due to their insecure situation and earlier experiences of flight and abuse. Faced with poor physical and mental health, their friends and a sense of community were central to how they coped with everyday struggles. The youths described how their network of friends, helped by activists in the local refugee rights network, was not only crucial for accessing their rights in practice, but also for creating a sense of belonging and what Arendt called a ‘place in the world’. Hence Alireza talked about the difference in the treatment he experienced in school due to his lack of legal status, and how this affected him not only practically but also emotionally:

I did not get so good self-esteem. But my friends said you are very good. You are good at Swedish. I got the energy to continue. Otherwise it would have been difficult to go to school. (Alireza)
The recognition he was given by his friends transcended the label of undocumented person that the state had burdened him with, and this promoted his well-being. Relationships and recognition thus appear important when trying to understand accessing rights to health in a broad sense, as a state of ‘complete physical, mental and social wellbeing’ (WHO 1946). In the end, as our study indicates, human rights as formal commitments are precisely that—formal commitments devoid of all practical content. As long as the risk of deportation remains and no sanctuary is to be found in the city, the rights claims go no further than being a plea for compassion. Practical access to your rights requires your recognition by someone else—in other words, human rights are relational.

Concluding remarks

Every aspect of our interviewees’ lives was permeated by their position as undocumented immigrants. Their fear of being deported, the structural discrimination that characterizes life as ‘unfree’, poor health—all cuts away at what it means to be human enough to be a rights-holder. Our study illustrates that having networks of friends and activists indeed can facilitate a conditional access to welfare services. Yet even so, the gap between human rights on paper and human rights in practice is a bleak reality as long as deportation is an alternative. This is an inevitable consequence of the nation-states’ migration management, and as we have highlighted, in Malmö it most definitely makes a spectacle of people’s lives.

Arendt raised the question of the risk of being stripped of all those categories that make a human sufficiently human to be considered a rights-holder, arguing that human rights are groundless in the sense that when a person is a mere human, he paradoxically loses his right to have rights. The phenomenon of undocumentedness thus illustrates a contradiction inherent in the very idea of human rights. The fact that none of the people we met and spent time with chose to express their claims in terms of rights also points in this direction.

Nonetheless, although undocumented status permeates the life of the youths in our study, there is more to it than that. The exclusion of migrants under contemporary migration policy also offers a basis...
for solidarity. We saw in the study that the young stick together—they have not had any other choice. In coping with everyday life, there is also an underlying reinvention of human rights as being a member of a political community. Their activities and strategies in collaboration with activists make it clear that, despite their subordination, they claim personhood in the sense of having a place in the world. To be viewed as a unique individual and not as someone who is merely undocumented can only strengthen one’s self-esteem. Participation in social networks is a way to appear a person, someone who should be included in local contexts such as school, healthcare systems, and the like, despite still being excluded at a state level.

Despite being deprived of legal personhood, the youths we have talked to are very much active members of the city’s population. In certain areas they are also under the eye of the public authorities. Access to the rights envisaged in official policy is always under contest; it does not end because there is an institution formally granting rights. Aware of their subordination, a conditional inclusion is reproduced over and over again, beyond and regardless of formal entitlements. In response to Arendt’s injunction to think of the potentiality of the city as a ‘nation-state without nationalism’, a legal order that ‘is open to all who happen to live on its territory’, our study shows that a legal order with inclusive regulations at the city level alone is not enough.

Notes

1 This essay is based on the findings of a research project conducted in 2012, Irregular=Rightsless? An Investigation of Unaccompanied Undocumented Refugee Children’s Entitlement and Access to Health in Malmö, with support from the research programme ‘Challenges of Migration’ [Migrationens utmaningar] and the Swedish Research Council.

References


