CIVIL SOCIETY FACED WITH HEALTHCARE EXCLUSION

Defending our healthcare

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A change in the healthcare system behind society’s back

On 20th April 2012 the world of healthcare was shocked. That day the Government approved at a cabinet meeting Royal Decree-Law 16/2012 (RDL) which brought about profound changes in the Spanish healthcare model.

This reform was introduced behind society’s back by using an exceptional legislative procedure reserved for urgent situations that allowed the repeal of the measure of the previous political and social debate. Without taking into account the opinion of the professional sector or consulting the main social organisations, the Executive drastically changed the basis of the Spanish National Health System (Sistema Nacional de Salud, SNS) which gradually and by consensus had been consolidated since the General Healthcare Law of 1986 based on the principles of universality, prevention, decentralisation, and redistribution.

With a stroke of the pen the RDL eliminated decades of progress in the construction of a more inclusive and caring healthcare system. Pointing the finger at the migrant population in an irregular situation as being responsible for the alleged abuse of this system without ever providing evidence to prove this, it excluded it from the SNS, denying it the right to normalised medical attention. This group was not the only one affected. European Union citizens or elderly people involved in the process of family regrouping were also excluded. The regression of rights in question was unjustifiable and indignation arose.

Civil society was immediately mobilised with the aim of mitigating the serious infringement of human rights that was occurring. Healthcare and social organisations and citizen platforms assumed the defence of the excluded population and made use of all the means at their disposal to face up to the RDL. Thanks to them and the tireless fight they have put up throughout these five years, small windows of hope have been opening in particular in the context of the autonomous regions so that these people can receive attention. Unfortunately healthcare exclusion is still a reality in Spain that obliges us to persist in our strategies for defending the human right to health.

THE JOURNEY OF A PERSON LIVING WITH HIV

Pedro is a Colombian who has been living in Spain for 20 years. Despite being firmly established in this country after such a long period, he has not been able to obtain authorisation to live here legally. In early 2015 he fell ill and spent two months convalescent in his room until a flatmate called Doctors of the World. As he was in an irregular situation Pedro was afraid of going to the hospital.

As he was now very weak and with clear symptoms of severe malnutrition, the Doctors of the World team feared for his life and accompanied him to emergency unit. After the appropriate tests he was diagnosed as having an HIV infection (AIDS), syphilis, and hepatitis B. However, despite the fact that the internal regulations of Galicia guarantee healthcare and pharmacological cover to those suffering from diseases that are a risk to public health (regardless of whether their documentation is in order or not), at the hospital the staff were unaware of this possibility. Finally after several days of negotiations with those responsible for the Galicia Health Service (Servicio Gallego de Salud, SERGAS) cover for Pedro was obtained.

However, he was soon to suffer the consequences of the territorial differences generated by the sanitary reform of 2012. As this ruling obliged each region to design its own response to attend people who had been excluded from the healthcare system, the cover acquired thanks to the regulations of Galicia is only valid within that region. So when Pedro moved first to Valencia and then to Bilbao in search of work he lost access to anti-retroviral drugs and when he finally returned to Galicia he was informed that his right there had expired.

The situation got even worse. On initiating the procedure in order to recover the healthcare that he needed, the police confiscated his passport and he was received an expulsion order.

For someone in Pedro’s situation deportation means being left without medicine that is essential to his life, as in his country of origin its supply is not guaranteed. The intervention of Doctors of the World and the Galicia Immigration Office managed to revoke it and process an authorisation of residence on humanitarian grounds, so today Pedro has a health card. Now thanks to anti-retroviral treatment Pedro has continued to improve. He has put on weight again, has no symptoms, and his viral load is undetectable.
On 1st September 2012 this healthcare reform came into effect and as a consequence hundreds of thousands of people who on 31st August could request an appointment with their family doctor and be attended in a perfectly normal manner became invisible to the system overnight. Their health cards were deactivated and their medical records were eliminated to prevent the correct follow-up and treatment of any diseases that they might suffer from.

A large number of healthcare professionals refused to collaborate with this injustice. Flourishing the Hippocratic Oath and the code of professional ethics, they bravely took the option of civil disobedience and continued to attend those excluded. For example, the Spanish Association of Family and Community Medicine (Sociedad Española de Medicina Familiar y Comunitaria, (semFYC) organised a register of conscientious objectors that soon included more than a thousand names; to these must be added those who object without appearing on any kind of register. Running the risk of being fined for failing to comply with the regulations, these professionals dignify healthcare work by means of the weaving of a welfare network which, although it has serious limitations as it cannot guarantee the transfer from Primary Attention to Specialised Attention or include pharmaceutical benefits, gives a solution and hope to many people who would otherwise be completely excluded.

In this resistance an important role is also played by the groups of information and accompaniment that have been promoted by various social organisations and citizen platforms.

In contrast to the tremendous lack of information that dominated the setting up of the new regulation, which meant that many migrant people did not even dare to go to emergency unit, these groups take pains to explain to those affected their options for receiving attention. When despite everything this is not possible (because the staff of the health centres are often unaware of the regulations and refuse attention to those who have the right to it) the aforementioned groups accompany the excluded persons to health centres and hospitals in order to mediate and demand they be attended and even offer legal support in order to make a claim when this is possible.
The effects of healthcare exclusion were soon felt. While the Government bragged of the effectiveness of the measure, social organisations working with groups affected by economic and social exclusion began to find that their offices were overflowing with cases of people who had been refused medical attention. Given this situation, associations such as Doctors of the World or platforms such as ODUSALUD, PASUCAT, Ciudadanía Contra la Exclusión Sanitaria or Yo Sí Sanidad Universal began to document the cases of the violation of the right to health that were coming to their knowledge with the aim of reporting the health crisis that was occurring and warning of the serious risks that this entailed.

These risks turned into certainties when the RDL celebrated its first anniversary and on 24th April 2013 in Mallorca the young Senegalese Alpha Pam died of tuberculosis alone at his home. After six months of attending the emergency unit of the health centre it was recommended to him that he should go to the hospital to be X-rayed. He was twice refused emergency attention there until he was seen by a doctor who also failed to carry out the diagnosis tests that had been requested. Apart from the fact that the refusal of emergency attention infringes the RDL itself, this is a symptomatic case of the dangerous nature of the ruling. Indeed it was the lack of normalised access to Primary Attention that prevented the saving of Alpha Pam’s life.

Despite the fact that both Spanish and international legislation require the justification in a reliable manner of the adoption of exceptional measures restricting rights, the attitude of the Government concerning healthcare exclusion has been characterised by the absolute neglect of its obligations. Not only did it approve the RDL without accompanying it with a detailed economic report to prove the relationship between the use that people in an irregular situation made of the healthcare system and the alleged deficit of the latter, it also failed to carry out any kind of analysis on the impact of the measure on the health of the population as a whole and in particular on the most vulnerable sectors. On the contrary its position has been to affirm repeatedly that thanks to this ruling Spanish healthcare is more universal than ever.

Unfortunately the actual situation is far from that of this smug vision and the social organisations have played an essential part in making it visible. The various reports published by REDER and other bodies show that the RDL has tainted the Spanish national healthcare system with injustice, on leaving precisely
the most needy more unprotected. It has also been revealed thanks to sound studies by Spanish experts and European institutions that the system that was born of the reform of 2012 is less efficient from an economic and healthcare point of view. Renouncing the prevention model based on universal attention therefore, forcing part of the population to have to resort to emergency attention as the only way of achieving medical assistance is much more expensive (as it often leads to hospitalisations that could have been avoided) and involves greater health risks.  

This work of denunciation has not been restricted to the publication and presentation of reports but has also been taken to official institutions such as the various Ombudsman Offices, and has contributed to the condemnations of the RDL which have been issued by various European and international human rights organisations, such as the European Committee of Social Rights, the Committee for the Elimination of Discrimination against Women, and the Special United Nations Court Reporter on extreme poverty, together with other special United Nations court reporter posts.

In a situation of economic crisis such as that being experienced in Spain in 2012 (the effects of which are still being felt), demagogic messages with a xenophobic undertone found a fertile breeding ground. It was therefore easy for the discourse defended by the Government regarding the RDL to instil perceptions within society such as “the healthcare system is unsustainable if everyone is attended” or “immigrants abuse the health services and come to Spain to get free healthcare”.

Refuting the myth of the risk that migrants represent for the sustainability of the SNS has been one of the main battlefronts of the organisations of civil society. The link constantly established by the Executive between immigration and health tourism has made it necessary to clarify that these two concepts are radically different. Compared with the profile of the possible health tourist (an elderly European of means who comes to Spain with the main aim of having access to the quality benefits of our healthcare system), migrants are generally young people in good health who arrive in the country to work and seek a better life. This distinction is reinforced by the multiple studies indicating that the use migrants make of the healthcare system is considerably less than that of the local population.

These fallacies conceal the profound transformation of the Spanish healthcare system which has made it more regressive and less caring. Demonstrating publicly the incoherence and injustice of making migrants scapegoats for the policies of austerity that are cutting back social spending and rights has been the objective of campaigns such as #NadieDesechado (Médicos del Mundo), #YoElijoSerHumano (Red Acoge), or #5MentirasQueDuelen (REDER). These actions are designed in an original and imaginative way and pursue the aim that citizens can identify with the victims of healthcare exclusion by putting themselves in their shoes. By presenting the daily experience of thousands of migrants in Spain the idea is to generate empathy with their suffering and to arouse awareness of the pressing need for defending a public and universal SNS.


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**Boundary Case**

**Wrongful Invoicing Preventing the Detection of Cancer**

Sabrina is an Italian woman who had been living in Barcelona for six months together with her husband and three children. In late 2015 she discovered a lump on her neck that made it difficult for her to eat and she went to the health centre. Despite lacking a health card she was attended by a primary attention doctor, who given what she understood to be worrying symptoms, sent Sabrina urgently to the hospital for an X-ray and an appointment with the medical and surgical team.

When Sabrina arrived at the hospital she was told that she could only be assessed at emergency unit if she paid 250 euros, which she could not afford so she returned home. The weeks went by without the pain going away, but Sabrina did not return to casualty for fear of having to pay the bill. After two months her family doctor phoned her to ask how she was and the result of the tests. When Sabrina told her what had happened the doctor, both surprised and indignant, arranged tests for her at a national health clinic that gave the worst of results: she had a thoracic lymphoma that had spread, which could have been contained if it had been detected earlier. Sabrina had to start chemotherapy immediately.

Fortunately the treatment was successful and Sabrina has now fully recovered. However, if it had not been for the involvement of the primary attention doctor the outcome could have been much more dramatic. Now Sabrina is suing the Catalán Health Service (CatSalud) with the support of PASUCAT.
Resisting, denouncing, sensitising. These three verbs are part of the same strategy, the main objective of which is to reverse healthcare exclusion. If one thing has been made clear during these five years it is that the mobilisation of civil society is essential when promoting political action. Health and social organisations have therefore been working since the very instant of the approval of RDL 16/2012 in order to pressurise and demand a change in the law to put an end to this injustice and guarantee truly universal healthcare.

The attitude of the central Government, protected by an absolute majority in Congress that prevented any inkling of rectification, meant that the efforts of the organisations concentrated in the first instance on the context of the autonomous regions. They worked intensely with the various regional government ministries and political groups (giving information on the serious violations that the RDL was causing, reminding the autonomous governments that they also were subject to the human rights obligations, and issuing recommendations on how to comply with them) which has gradually given results. Today therefore practically all regions have some kind of ruling or regulation that seeks to guarantee assistance for those excluded from the reform of 2012.

There is no doubt that these measures represent considerable progress, which has helped to mitigate considerably what was otherwise becoming a true healthcare crisis. However they are far from constituting a definitive solution. Apart from their technical deficiencies and difficulties of application (which are under constant supervision by the organisations with the aim of demanding the pertinent corrections by the various regional governments), the limitations of competence of the autonomous regions themselves prevent the latter from recognising the persons excluded as having rights under the same conditions as the remainder of the population. To this must be added the fact that the dispersal of regulations causes territorial imbalances in the requirements and rights of those excluded that are recognised, in such a way that these vary depending on the region of residence. Moreover it is worth remembering that as several of these rulings have been appealed against by the central Government to the Constitutional Court their survival is threatened.

It is therefore essential to implement a national legislative reform to invalidate RDL 16/2012. This is precisely one of the objectives of the Pact promoted by REDER and signed on 12th September. Constituting a genuine front of civil society, the main healthcare and social organisations have called on practically all the parties of the opposition (which hold an absolute majority in Congress) to commit themselves to defend a public, universal, and quality SNS. The first of the commitments acquired is precisely the presentation of a white paper to guarantee healthcare assistance as a right of all persons living in Spain regardless of their administrative situation. Its processing and approval, which is not without difficulties as the Government may attempt to veto it, will be an essential step in order to recover the dignity and solidarity of the Spanish National Health System.

But this is not the end of the road. The RDL and the policies of austerity and privatisation that have accompanied it have revealed the threat that hangs over our healthcare model as a pillar of the Social State; ensuring the public and inclusive nature of the health system and defending its quality is now more necessary than ever. Vindicating and extending the role of civil society as the first line of defence against any infringement of the human right to health will be essential if we are to face these challenges. There, if where we will be.
The fight for autonomous change

On 25th February 2013 the Regional Parliament of Navarra approved Regional Law 8/2013 which recognised the right to healthcare of all people resident in the autonomous region. This Law (which does not include census registration as a requirement) was made possible thanks to the hard work and insistence of the Plataforma Navarra de Salud, which together with other social and health organisations persuaded members of parliament to approve this measure in spite of the opposition of the autonomous government itself. Navarra thus joined Andalusia and Asturias on the road of the rejection of healthcare exclusion in the context of autonomous regions. Some months later the Basque Country was also to swell this list, albeit with a more restrictive ruling as a year’s census registration was required.

In the remainder of the autonomous regions the lack of political will of the various regional governments forced the organisations of civil society to undertake the hard work of denouncing and political incidence. The commitment to universal healthcare promoted in March 2015 by Doctors of the World and signed by almost all parties was the prelude to the change of context that would occur after the elections of May of the same year.

The Decree of the Cabinet of the Generalitat Valenciana, in which gestation ODUSALUD played a very active role, was the spearhead followed by the instructions of Aragon, Cantabria, and Murcia which were driven by the action of the Plataforma Salud Universal, Ciudadanía contra la Exclusión Sanitaria, and the Observatorio de Exclusión Sanitaria de la Región de Murcia respectively. In Cataluña the action of civil society led by the PASUCAT achieved in the first instance the approval of a new improved instruction and subsequently its replacement by Law 9/2017 of 27th June on the universalisation of healthcare.

Thanks to all these efforts, the immense majority of autonomous regions have by now adopted some form of measure to allow some healthcare access to excluded people. This is not the case in Ceuta and Melilla or in Castilla y León where the RDL continues in force to its full extent. Galicia is a special case as it is governed by the Galicia Public Health Social Protection Programme, however its stipulations are systematically ignored despite the repeated condemnation of this situation by the Rede Galega en Defensa do Dereito á Saúde.

Updated map of Autonomous Regions

1. ARs with rules extending assistance to those excluded.
2. ARs with internal order of the regional ministry: it provides attention to those excluded but its legal insecurity is causing concern.
3. ARs with a special programme.
4. ARs with agreement between the Government and an NGO so as to provide primary assistance subject to certain requirements.
5. ARs with no ruling.

REDER Red de Denuncia y Resistencia al RDL 16/2012
REDER calls for effective respect for the human right to health through a universal public health system

In view of the situation of the serious violation of the right to health described in this report and in previous ones, REDER considers that a change in the law is essential and can be delayed no longer. Therefore and in accordance with the Pact signed on 12th September, we demand that various parliamentary groups present a white paper with no further delay that contemplates:

- The elimination of the figures of the insured and the beneficiary and the recognition of the right to healthcare assistance under equal conditions for all persons living in Spanish territory irrespective of their administrative situation.

- The incorporation of flexibility clauses to guarantee attention at all times, preventing the lack of proof of a requirement (e.g. census registration, a consular certificate, etc.) from being an insuperable barrier.

- The inclusion of means of assessment and follow-up to guarantee the effectiveness of the ruling.

REDER calls on the governments of the autonomous regions to reach the limit of their competences so as to guarantee that all persons living within their limits have access to healthcare with no discrimination of any kind. They are asked to adopt measures to make good the current deficiencies in their regulations and to collaborate with the social organisations that are fighting against healthcare exclusion. In particular we demand the implementing of full informative campaigns aimed at both healthcare personnel and the people affected. Despite our concern about the pending appeals to the Constitutional Court against the various rulings of the autonomous regions, REDER would like to remind all public authorities of their obligation to respect international legislation on human rights.

The healthcare, administrative, and management professionals of the Spanish National Health System are invited by REDER to join the conscientious objection movement with regard to the application of Royal Decree-Ley 16/2012, reminding them of the existence of the right and the duty to not collaborate with the violation of human rights.

We encourage civil society as a whole to support the mobilisations and acts of rebellion against the Royal Decree-Law.
REDER is a network of groups, movements, organisations, and people involved in the defending of universal access to health and denouncing non compliance. Currently REDER is made up of over 300 social and professional organisations such as the Spanish Association of Family and Community Medicine (Sociedad Española de Medicina de Familia y Comunitaria, SEMFYC), Doctors of the World, the Observatory of the Universal Right to Health of the Region of Valencia (Observatorio del Derecho Universal a la Salud de la Comunitat Valenciana; ODUSALUD), Andalucía Acoge, the Aragon Universal Health Platform; the Platform for Universal Healthcare in Cataluña (Plataforma per una Atenció Sanitària Universal a Catalunya, PASUCAT); the Galicia Network in Defence of the Right to Health; the Healthcare Users’ Association of the Region of Murcia; the Platform “Citizens against Health Exclusion”; the Spanish Association of Public Health and Healthcare Administration (Sociedad Española de Salud Pública y Administración Sanitaria, SESPAS), the Federation of Associations in Defence of Public Health (Federación de Asociaciones en Defensa de la Sanidad Pública, FDASP), the Peruvian Association of Refugees and Immigrants (Asociación de Refugiados e Inmigrantes de Perú, ARI-PERÚ) and the Transnational Women’s Network (NetworkWoman). For further information consult: [www.reder162012.org](http://www.reder162012.org)