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In this issue:

- Featured article: **A Patient's Advocate's Journey in Search of Social Justice**
- **ICSW speaks up on the issue of rethinking and strengthening social development in the contemporary world**
- **The rights of persons with disabilities must be fully included in the new development framework – UN experts**
- **Useful resources and links**

In December 2014, ICSW, in cooperation with DIDA (DIRECCIÓN DE INFORMACIÓN Y DEFENSA DE LOS AFILIADOS A LA SEGURIDAD SOCIAL) convened a forum in Santo Domingo, Dominican Republic, aimed at exploring ways and means to enhance the visibility and effectiveness of social protection in the region. One of the issues discussed at the forum was the role played by independent public representatives, such as ombudsmen and public advocates, in protecting vulnerable groups and society at large. We asked Dr. Carlos R. Mellado López from Puerto Rico to write about his personal experience as a Patient's Advocate, highlighting some lessons learned and obstacles encountered. The Editor

- Featured article: **A Patient's Advocate's Journey in Search of Social Justice**
By Carlos R. Mellado López
Puerto Rico's Patient Advocate



The Forum convened by ICSW and DIDA was an important and well-focused meeting; I participated in this meeting for the first time, but I am sure it won't be my last, if it becomes a regular event. This opportunity has allowed me to reflect on my current position as Patient's Advocate and on the situations that patients face every day in the Island regarding gaps in health care, including their lacking access to high-quality health-care services. In these notes I will discuss briefly the history and laws related to the Patient's Advocate Office, the political and public policy determinants in Puerto Rico that affect the health system, and pertinent issues like sustainable development, which is linked to public health.

The history behind the creation of the Patient's Advocate's Office.

Since the Universal Declaration of Human Rights (UDHR) was adopted by the UN General Assembly on December 10, 1948, human rights have surged to the forefront of global political debates and policy discussions. Along with the UDHR, the key legal tools adopted in the 1960s, first of all the International Covenant on Civil and Political Rights, and the International Covenant on Economic, Social and Cultural Rights, were aimed at upholding all human rights for all people, creating internationally agreed human-rights standards that governments have legal obligations to respect and protect. The promise made by the international community to address systemic issues like inequality and discrimination has been combined with the quest for socio-economic development, including improvements in health, education, nutrition, water and sanitation within a human-rights framework. The UDHR, in Article 25, includes as a human right, "the right to an adequate standard of living for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control." Unfortunately, when Puerto Rico adopted the Constitution of the Commonwealth of Puerto Rico in 1952, it incorporated all the fundamental rights acknowledged by the UDHR, with exception of Article 25. Nevertheless, it incorporated the Legislative Assembly's duty to create laws seeking to ensure the right to health for every citizen in the Island. One of the laws that was enacted for this purpose was the Act 194 of 2000, known as the Patients' Rights and Responsibilities Act ("Act 194").

Act 194 recognizes certain rights that every patient in Puerto Rico has regarding the health services they receive. These rights include: access to high-quality health services; access to services and facilities during an emergency; access to complete and accurate information regarding their health; participation in all health decisions; the right to be treated with respect; the right to choose their health services providers; the right to continue a treatment with a provider during a transition period if the provider's contract is cancelled or terminated; the right to present a complaint against a health services provider; and the right to have their medical information and medical records kept strictly confidential.

The Patients' Advocacy Office of Puerto Rico (PAO) was created in 2001 as a state agency designed to ensure compliance with Act 194. The goal of the PAO is to ensure that patients

in Puerto Rico have access to high-quality health services, and the Office strives to fulfill this role in various ways. First, the Office has a duty to provide guidance to all patients of their rights and the availability of the benefits provided by the Act. The patient may place a complaint at the Office, or the PAO may initiate an investigation on its own. The Office coordinates, addresses and solves problems, needs and claims in the area by identifying fast and effective solutions. The PAO works to promote excellence in Puerto Rico's health system so that every patient has his or her needs met and feels protected. Overall, the PAO advocates and promotes patient's rights in order to increase confidence in our health system.

Our objective is to monitor complaint patterns and corrective action plans; expand the reach of the National Association of Patients, which is trained to understand patients' rights so as to take care of the specific needs of the groups they represent; increase Call Center capacity so as to better serve, assist and counsel patients; establish a continuous education plan aimed at retraining 100% of the Claim Officers on the processes related to complaint management; audit the quality of the health services of institutions under the Bankruptcy Court in accordance with the Law; conduct on-site inspections at all health-service centers in the island, and directly examine any violations of the Patient's Bill of Rights and Responsibilities.

Once violations have been identified, the PAO undertakes specific targeted actions. For example, we conduct field investigations to provide an efficient self-improvement tool for health-service providers and insurers; conduct unannounced visits to Primary Doctors Groups (PDG) and mental health clinics to ensure compliance with patients' rights; continue the systematic monitoring of complaint patterns and corrective action plans; place at the public's disposal complaint information organized by providers and insurers, so that it serves as the basis for selecting an insurance company or health provider; train patient organizations, health professionals, insurance companies and education centers about the Rules of the Patient's Bill of Rights and Responsibilities through annual educational activities. We also offer legal advice to the various adjudicative and legal forums in order to provide assistance in the solution of cases and provide recommendations for public policy regarding the protection of patients' rights; and continue to encourage a pro-service mentality in employees.

In 2011 various Advocacy Offices in Puerto Rico were reorganized under Act 1 of 2011. The PAO benefited from this reorganization to the extent that its jurisdiction was extended to Medicare programs and other state health-care providers that originally were not under our

supervisory power. The Office was renamed as the Health Care Ombudsman Office. In July 2011, I was appointed the Health Care Ombudsman of Puerto Rico for a term of ten years. However, on July 24, 2013, the Office underwent a drastic reorganization. Under Act 77 of 2013, the PAO could only ensure the rights of patients who were the beneficiaries of certain programs (such as Medicaid and the State Health Insurance Plan known as MI Salud). The position of Health Care Ombudsman was also eliminated. Before Act 77 of 2013 was enacted the PAO received approximately ten thousand complaints a year.

In my view the reorganization went too far, and I was determined to fight the obvious legal inconsistency and injustice. On September 2013 I presented a legal complaint in the Puerto Rico State Court. Among my claims I included (1) that the Act 77 of 2013 discriminated against the rest of the patients on the Island; (2) that the agency's independence was being threatened by the Legislative Assembly when it removed an officer appointed by the Governor of Puerto Rico and confirmed by the Puerto Rico Senate for a ten year term. I won but not completely: the court determined that I could return to the Office and continue as the Patient's Advocate, but it also determined that the legislative branch had the power to reorganize state agencies and, as part of this reorganization, limit jurisdiction, even if the reorganization resulted in the fact that more than half (55%) of the patients in Puerto Rico no longer having a state agency that worked to ensure their health rights.

While this jurisdiction limitation is still alive and remains, in my view, a major obstacle to the work of the Advocate's Office, we continue working every day for the benefit of the population that we represent, looking for new ideas and alternatives that would empower the patients of the Puerto Rico. The option of giving up has never been on my agenda. Better than ever, I realized now that patients do need representation and support in the face of various bureaucratic hurdles, and that my background as a medical doctor facilitates my activities. Despite the huge workload and constant stress the personal satisfaction resulting from an opportunity to change the life of people for the better is enormous. Gradually, our Office has become the driving force for equality and the protection of the rights of patients, upholding the rights of the patients to high-quality health care.

Certainly the road may sometimes seem hard and bumpy, but there is a recognition that our efforts are appreciated by the people, who encourage us to continue our efforts for the benefit of all. After all, aren't we all patients?

Some lessons learned

According to our observations and information, patients in Puerto Rico may, when receiving health-care services, often face a number of negative factors. These include, first of all, excessively high prices for medications and the denial of referrals to see specialists not for medical but for economic reasons (mainly when the provider works within the remits of a Health Management Organizations - HMO). Other complaints include a lack of respect for patients on the part of providers, lack of coverage for expensive medications, and the inability to get other treatments that are medically necessary. We investigate these complaints and take actions.

There are some difficulties in our work, stemming from the prevalent approaches to medical practice, including the existing gaps in preventive practices. The comparison of the US-type of the provision of medical services, which is predominant in Puerto Rico-- aimed at the treatment of current diseases over the prevention of future diseases—to European-style prevention (which Latin American countries also adopt) demonstrate that the former, i.e. a cure (or treatment) approach is more costly to individuals and society alike. In my view we should consider solutions that combine high-quality medical outcomes and lower costs. And of course, people should be taught and become aware that they must take preventive care of themselves and think seriously about their own well- being.

Another lesson that I learned doing my job is one of a political nature. Every four years newly elected politicians come with new ideas and often start making changes to health-care schemes that were well-functioning and efficient. Actions like the reorganization cannot but affect the services and the quality of the services already being provided. So in the end, should political interests come before the best interest of the citizens? The answer is obvious- - no.

And what about the cost of medications? Why are they so expensive? Why do the same drugs cost more in the US (and Puerto Rico) compared to other countries, sometimes more than twice the cost in nearby countries? Why, if Americans spend billions of dollars a year on health care, are so many people sick? Shouldn't there be a correlation between the money spent and the health of a society? These are questions that we need to ask.

As Patient's Advocate I have been asking these questions, trying to find better options for the citizens of Puerto Rico. I have represented the interests of many patients at state courts. I am determined to continue the fight, trying to ensure that everyone in need of health-care

services has access to better choices and that they know their rights as patients—a very important point. Many people don't.

Another part of my responsibilities as Patient's Advocate is to submit draft bills to the Legislative Assembly, as well as provide comments and analysis illustrating my opinion regarding other bills that have been submitted. Health-related themes that have been attended to by our Office are: improving mental health care; reviewing food labeling and improving the way food is produced, in ways that do not pose a threat to human health; lifestyle-related health determinants; matters relating to the environment; respect for cultural diversity; improving the supervision of the financial resources spent on ensuring better outcomes for patients; the regulation of services included and excluded by health-care plans; among others. Our position is always the same – put the interests of people first.

Without a doubt I have grown as a professional with the opportunities provided by my work, but I have also become a different human being. I have learned during my years as Patients' Advocate that in order to really make a difference and improve the health system of a country and the health of its citizens, all politicians need to act in a multidimensional and comprehensive manner, taking into consideration the environment, the economy and specific social aspects of society. These dimensions should be approached as part of a whole. For example, when such aspects as sanitation and hygiene, nutrition, family life, work and justice are in harmony, we have a healthier population. We may not be able to guarantee the health of the people, that's a tall order, but we should strive to ensure access to health services. We can also work hard to improve our environment—that is an important factor that helps people to live healthier.

Sustainable development and health care.

Another important aspect that we need to continue working on is raising a young generation that is environmentally conscious. As people of Puerto Rico-- and also citizens of the world-- we have to think of the future of our children, and we need to make sure that the critical role of sustainable development is firmly recognized in society. This aspect has direct relevance to the health of people, and this is also part of my agenda and activities. We cannot compromise the ability of future generations to meet their needs. Safeguarding the earth's capacity to support life in all its diversity, protecting the environment, minimizing pollution, working to break the link between economic growth and environment degradations, and

doing it mostly through legislation, is a step towards enhancing the health of our citizens. And everyone has to do his or her part—only then we achieve success.

The opinions expressed in this article are those of the author and may not necessarily reflect the position of the ICSW Management Committee

- **ICSW speaks out on the issue of rethinking and strengthening social development in the contemporary world.**

Statement made at the 53rd session of the Commission for Social Development, 4-13 February, New York

Priority theme: Rethinking and strengthening social development in the contemporary world.

Established more than 86 years ago, the International Council on Social Welfare is one of the oldest international non-governmental organizations dealing with a wide range of social development issues, including the promotion of social justice and human welfare. True to our mandate, and taking advantage of our extensive collective experience, we wholeheartedly support the work of the Commission for Social Development and hope that the fifty-third session will lead to important and practical outcomes, which are essential for strengthening the transformative elements in the design and future implementation of social policies at the national level.

Our organization is deeply concerned by the visible weakening in social cohesion in some countries and regions and by the adverse situation of vulnerable social groups and numerous individuals facing inequality, insecurities and multiple deprivations. Deeply entrenched inequalities within and among nations represent enormous challenges for development and for all of us, diminishing the productive potential of people and harming human prospects in a profound way.

That is a systemic issue and must be addressed systematically and in a comprehensive manner by Governments and the international community at large.

Important research completed recently by the United Nations Development Programme, the Department of Economic and Social Affairs, the United Nations Research Institute for Social Development, the Economic Commission for Latin America and the Caribbean and

other international bodies has clearly demonstrated the importance and detrimental impact of inequalities on economic and social development. Vulnerability to environmental degradation exacerbates existing inequalities.

The voices of people with disabilities, frail older persons, women who are excluded, indigenous communities and other social groups who face discrimination and marginalization for various reasons deserve to be heard, and their concerns must be addressed. We strongly support the inclusion of a stand-alone goal on inequalities in the post-2015 development framework. We would like to draw the attention of the Commission to the fact that support for a stand-alone goal on inequalities was reflected in the outcome declaration of the Joint World Conference on Social Work, Education and Social Development, convened in July 2014 by the International Council on Social Welfare together with our partners, the International Association of Schools of Social Work and the International Federation of Social Workers.

Strengthening social protection is not only one of the best ways to reduce insecurity and deprivation in the world, but also an effective means to reinvigorate the development agenda and come up with new solutions to a range of old and new social ills. Addressing the issues of inequality and poverty reduction in a comprehensive manner and linking human rights and social security obligations facilitates a cross-cutting approach, moving towards mainstreaming human rights throughout the United Nations system. Our organization consistently and fully supports the recommendation of the International Labour Organization (ILO) concerning national floors of social protection (recommendation No. 202), which was unanimously adopted by ILO members in 2012.

In its recommendation, the ILO recommendation defines social protection floors in terms of four essential social-security guarantees ensuring a minimum level of income security during childhood, adult life and old age, as well as access to essential health care for all. It stipulates: "The guarantees should ensure at a minimum that, over the life cycle, all in need have access to essential health care and to basic income security, which together secure effective access to goods and services defined as necessary at the national level". The issue of social protection floors is thus a key element of a coherent, comprehensive and rights-based social development strategy aimed at protecting women, men and children from risks and vulnerabilities, helping to sustain their well-being throughout the life cycle, combating poverty, reducing inequalities and enhancing the social and economic inclusiveness of societies.

The International Council on Social Welfare has been a strong supporter of the social protection floors initiative of the United Nations since 2009. We have made the promotion of social protection floors the cornerstone of our global strategy. The International Council is a founding member of the Global Coalition for Social Protection Floors, a group of more than 80 non-governmental and international trade-union organizations that plays an increasingly important role in shaping the debate, raising awareness and achieving national consensus on strategies on social protection floors. On the strength of its global political acceptance and legitimacy, the concept of social protection floors should be included in all future national and global development strategies.

Social protection floors are mentioned in the proposal of the Open Working Group on Sustainable Development Goals (see goal 1, on ending poverty in all its forms everywhere, target 1.3). Other core elements of income and health-security guarantees are included in other proposed goals, i.e. those on food security and on access to health-care, education, water and sanitation and energy. We still hope that social protection floors will play an even more prominent and more visible role in the final formulation of the goals that will succeed the Millennium Development Goals. Already about a year ago the Global Coalition for Social Protection Floors demanded a stand-alone goal on social protection floors.

In that context, we would like to draw the attention of the Commission to the statement and report delivered, on 24 October 2014, to the General Assembly by the new Special Rapporteur on extreme poverty and human rights. The Special Rapporteur urged Governments to embrace the social protection floors initiative, which aims to guarantee basic income security and access to essential social services for all. The Rapporteur placed particular emphasis on the relevance of the initiative to the post-2015 development agenda and presented the implementation of the right to social protection through the adoption by all States of social protection floors as “by far the most promising human rights-inspired approach to the global elimination of extreme poverty”.

The year 2015 also marks the twentieth anniversary of the World Summit for Social Development, held in Copenhagen in 1995. The lessons of the Summit and its impact should be carefully studied, if we wish to enhance the effectiveness of social policy formulation for the post-2015 era. The Summit was instrumental in charting new paths to improving the human condition and putting human beings at the centre of development. The three interrelated core issues of the Summit (poverty eradication, employment promotion and social integration, supported by an enabling environment based on a framework of equity

and equality), along with its 10 commitments, exemplify a still valid, inclusive and holistic vision of social development. The norms set out in the outcome documents of the Summit reflected values and principles of key United Nations documents, such as the Universal Declaration of Human Rights and the International Covenant on Economic, Social and Cultural Rights, as well as a set of agreements achieved at several prior international conferences and summits.

One of the lessons learned in the past 20 years, and clearly applicable in the ongoing elaboration of the post -2015 development agenda, is the need to retain and enhance a comprehensive vision of development as advocated at the Summit, without reducing it exclusively to an economic perspective. Despite its undeniable importance, economic growth is a means to development, not an end in itself. The economic perspective is just one of the perspectives and should be seen in conjunction with political, environmental, ethical and spiritual considerations, while human dignity and equality should never be overlooked. In both economic and social terms, as clearly affirmed in the Copenhagen Declaration, the most productive policies and investments have been those that empower people to maximize their capacities, resources and opportunities. As proven by the experience of many countries, economic growth and human development reinforce each other. The majority of the most efficient and successful economies are still operated for and by the world's most equal, socially secure and inclusive societies.

Social policy can achieve better outcomes when it is conceived and implemented as part of broader national development strategies. While economic tools may be essential for addressing some underlying causes of such social ills as persistent poverty or long-term structural unemployment, a reduction in vulnerability and insecurity, particularly given the new threats associated with climate change and environmental degradation, can occur much faster when economic, social and environmental policies are conceived and implemented in an integrated manner. Moreover, intergenerational equity and the strengthening of economic and social ties between generations are important considerations that should not be overlooked in the emerging social agenda of a rapidly ageing world.

Social issues are, by definition, political issues. The implementation of a social agenda usually involves the redistribution of the national output, and it is inevitable that social policies in a democratic society represent a compromise among various political forces and actors. Establishing and protecting fiscal space for expenditures on social services, including welfare and social protection, should become an indispensable element when national

budgets are prepared and the corresponding priorities are established. This also implies that efficiency issues pertinent to social interventions should be a vital part of the picture, while the deployment of the most effective management resources to achieve social ends is always one of the public priorities in the implementation of the national budget.

Finding an integrated way of looking at socioeconomic development, and making development sustainable and equitable, is a challenge, but that challenge needs to be met for the sake of present and future generations. One way of charting out that integrated way is to build a comprehensive set of global governance tools, consisting of development goals that are periodically reviewed and a body of rights-based, legally binding United Nations instruments that codify and specify the non-alienable social rights of global citizens in their national and global economic environment.

One such tool is the United Nations Convention on the Rights of Persons with Disabilities, adopted in December 2006, which is successfully changing the lives of many people with disabilities for the better, as it begins to exercise a normative influence on national law and practice. We urge Member States to complete the ongoing consultations on a similar international convention on the rights of older persons and enter into the legal formulation process as expeditiously as possible.

Using the opportunity to engage in the process of “rethinking and strengthening social development in the contemporary world”, as proposed by the Commission for Social Development, we call for the elaboration and adoption of a new United Nations social policy instrument, one that would strengthen the impact of ILO recommendation No. 202, providing tangible content to the human right to social security and the right to an adequate standard of living. A comprehensive international instrument on social protection floors, open to ratification by Member States, would enhance the political impact and weight of the concept of social protection floors, provide visibly joint ownership of the concept by the entire United Nations system and ensure its genuine mainstreaming in national and international social policy debates. While such an instrument could take the form of a convention or an optional protocol to the International Covenant on Economic, Social and Cultural Rights, it would be of pivotal importance that the instrument be legally binding and that it exercise direct impact on national law. It is hardly possible to overestimate the importance of such an instrument for the 75 per cent of the global population who still lack adequate social security and the 35 per cent among them who still live in abject poverty.

The elaboration and adoption of a pertinent Economic and Social Council resolution would be a logical first step on the road to the new international instrument on social protection floors and a concrete first result of the process of rethinking social development.

➤ **Rights of persons with disabilities must be fully included in the new development framework – UN experts**

“One billion people – 15 per cent of the world’s population – are persons with disabilities, and their rights cannot be ignored,” a group of United Nations human-rights experts has warned the international community at the end of February 2015. Their call was made when the Second Session of International Negotiations on the Post-2015 Development Agenda came to a close in New York.

“No one should be left behind if we want to ensure a fully inclusive society for all,” they said, urging international negotiators and all UN Member States to firmly include the human rights of persons with disabilities in the new development framework.

The 17 new post-2015 Sustainable Development Goals (SDGs), to be adopted in September 2015, will replace and expand the Millennium Development Goals (MDGs), and will frame agendas and policies for the next 15 years. The Outcome Document of the Third International Conference on Financing for Development, which will take place in July 2015 in Addis Ababa, is an agreement on policies and financing. It will be key in the implementation of the post-2015 agenda.

“The inclusion of persons with disabilities in the SDGs is fundamental if we are to achieve sustainable development that is genuinely rights-based. This commitment must also be reflected in the Financing for Development Outcome Document,” said the new UN Special Rapporteur on the rights of persons with disabilities, Catalina Devandas Aguilar.

“Whereas people with disabilities were invisible within the MDGs, we have seen promising advances in ensuring that the new development framework is sustainable, inclusive and accessible,” Ms. Devandas Aguilar said.

The expert noted that, “as we enter the critical final stages of negotiations on the new SDGs, it is imperative that we maintain the important achievements already attained and that the global community fulfils its promise to guarantee human rights and development for all on an equal basis, including for persons with disabilities.”

A key issue for many people with disabilities is food security. Worldwide, an estimated 805 million people are chronically undernourished. Since many persons with disabilities live in absolute poverty, these two large populations overlap to a considerable extent, making food security of utmost importance.

“We know that nutrition and disability are closely linked. Both children and adults are often discriminated against, due to social stigma and negative cultural norms,” the UN Special Rapporteur on the right to food, Hilal Elver, said.

States are particularly responsible for making sure that vulnerable and marginalised people, including those with disabilities, are able to access adequate and nutritious food, she said.

“Food must be physically and economically accessible,” Ms Elver added. “To achieve this, States must ensure that a disability perspective is taken fully into account in nutrition policy and programming, maternal and child health policy, and broader health initiatives.”

The new UN Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte, called on Member States to give particular attention to the situation of older persons with disabilities in the current negotiations.

“Although disability should not be associated with ageing, it is frequent in old age and thus requires resources to ensure access to different services, including education, health-care and social protection and poverty reduction programmes”, she pointed out.

“An age-sensitive approach should be incorporated in the new development framework to enable all persons with disabilities, including older persons, to fully enjoy all human rights and fundamental freedoms”, Ms. Kornfeld-Matte emphasized.

“The scope of the post-2105 development goals and the Financing for Development Outcome Document provides a unique opportunity to ensure persons with disabilities are not just more visible, but are also active participants in the global agenda, and it is an opportunity that should not be missed,” the three experts concluded.

(*) The experts: Catalina Devandas Aguilar, Special Rapporteur on the rights of persons with disabilities; Hilal Elver, Special Rapporteur on the right to food; and Rosa Kornfeld-Matte, Independent Expert on the enjoyment of all human rights by older persons.

➤ **Useful resources and links.**

The Global Age Watch Index 2014 released by HelpAge International presents a snapshot of the situation of older persons in 96 countries of the world today. It highlights which countries are doing best for their older populations and how this links with policies towards pensions, health, education, employment and the social environment in which older people live. For more details please go to: <http://www.duchodova-komise.cz/wp-content/uploads/2014/10/Global-AgeWatch-Index-2014.pdf>

Adapting development. Improving services for the poor. ODI, London, 2015.

The report, prepared by the Overseas Development Institute draws attention to the possibility that the international campaign around the SDGs will reproduce some key limitations of the MDGs experience. To avoid this, the report advocates an approach to the SDGs grounded in history and experience, and calls for the international community—and developing country governments in particular—to help shift the post-2015 debate towards implementation and delivery rather than concentrating simply on goals and targets.

For additional details please go to: <http://www.odi.org/sites/odi.org.uk/files/odi-assets/publications-opinion-files/9438.pdf>

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Newsletter Editor: Sergei Zelenev, Executive Director
Address: ICSW, 5700 Arlington Ave., Bronx, New York, 10471 (US Office)
Phone: +1 347-526- 4893,
E-mail: szelenev@icsw.org, icsw@icsw.org
Website www.icsw.org;

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