Editorial

Promoting personal independence and the social protection of dependence: challenges and opportunities

Dependence, as an emerging phenomenon, is revolutionizing the social and human landscape in countries with the highest levels of economic development. Our streets and towns are not what they were thirty years ago and great change is yet to come: we are getting older and, should things continue much as they are today, the future will offer us the chance to experience dependence intensely and democratically.

As yet, we have only seen the very beginnings of this sociodemographic transformation that is set to continue well into the twenty-first century. Although it will provide excellent opportunities to make progress in terms of rights and quality of life, it will also entail a collective challenge on many fronts: social, environmental, economic, scientific, technological and ethical.

Dependence, in brief, is a complex reality that we will experience in the personal sphere – nobody will manage to escape it in their own or their family's lives – and in all aspects of our social life: in our occupation, in coexistence with others and as citizens. It is not then an issue that we can either ignore or leave up to merely political decision making, but one of the chief responsibilities we shall have to take on, with greater awareness and a new, profound ethical approach.

We already recognize some of the most direct causes of this complex phenomenon. The most well-known of these is greater life expectancy, as proof of the success - to my mind the relative success – of our social and healthcare organization capabilities. Yet this dramatic longevity, these 'extra life-years' that we have achieved, do not always mean 'extra life'. Perhaps we should be asking ourselves why we have only attained half of the target that the WHO (World Health Organization) set for the year 2000 over thirty years ago. Perhaps the answers might force us to rethink the way we promote health and treat disease: not only, or primarily, from a public health perspective but in tune with the old 'bio-psycho-social' principle of health.

All of this brings to light the challenge of setting a new paradigm for action across our many social protection systems – health care, social services, education, employment, housing, pensions and so forth. Moreover, this new paradigm must be positive and proactive. It must be able to function in future society as a new vision of health which focuses on the quality of people's lives and their living environment. In the scientific sphere, one of the reference points for such a paradigm could be the new International Classification of Functioning, Disability and Health (ICF) which was endorsed by the WHO in 2001.

Europe is taking a care-focused approach to this major challenge, in both the public health and social spheres. The reference document is Council of Europe Recommendation (98) 9 of the Committee of Ministers to the member States on dependence. Although this recommendation is of some use, it requires significant revision to match up to the ICF and the EU's burgeoning legal experience in equal opportunities and non-discrimination against people with disabilities.

In this context, the Spanish government is drawing up a prematurely superannuated bill on the promotion of personal independence and care for dependent persons. It is unarguably a positive, necessary initiative, but it is founded upon outdated thinking on dependence, focused on individuals and care.

Among other reasons, the bill has come under fire for failing to respond sufficiently or adequately to the needs of dependent persons and, in particular, the needs of people with disabilities and their families. Worse still, it provides no guarantees that people who require support for personal independence within the community will be included in the forthcoming State System for the Protection of Dependence. This could result in severe discrimination against people with intellectual disabilities, mental illness or senile dementia, which must all be included in scoring and assessment systems for dependence. Likewise, the welfare system must be adapted to encompass the services that these people need in order to have their support requirements met adequately.

Notwithstanding, this is a vital initiative that should provide the springboard for a more ambitious project: guaranteeing high-quality social and social-health services throughout Spain. The importance of this becomes even more marked when we consider the fragile state of social services in this country: Spain only earmarks 0.32% of its GDP for public spending on social care services for dependent persons (compared to 1.5% in Central European countries and 3% in Nordic countries). Spain's autonomous communities must therefore undertake to bring this system in line with the standards that are already guaranteed in health care and education, and in line with other more advanced European countries. Among other priorities, this requires that future regional legislation on social services safeguard the following fundamental points:

Guarantee: a subjective and enforceable right to social services must be guaranteed.

Universalization: social services must ensure optimum access and proximity for all those in need of them.

Quality: social services "portfolios" should be in place, as reference models, to regulate the technical and functional conditions of all types of benefits and services aimed at all target groups, providing an effective and adequate response to the specific social needs of each group.

Costlessness: bringing these services in line with the rest of the welfare state requires that all types of benefit offered by the public social services network be free of charge to their beneficiaries.

Development, recognition and guaranteed participation and cooperation with third-sector (social-enterprise) bodies.

In view of all of these points, when this law is passed with the improvements that will come out of parliamentary debate, we shall be facing a major opportunity to move towards attaining a regulatory framework and contributing to the effectiveness of social and social-health service systems that truly ensure full integration and participation in all aspects of life for people with disabilities and their families, with wholly equal opportunities. To this end it is necessary that:

– The state and the regions ("autonomous communities") pledge to create social and social-health service systems that secure the support needed by people with disabilities to a sufficiently high standard.

– Third-Sector bodies and organizations foster the creation of citizen platforms for awareness raising and rights advocacy.

- Health and welfare workers share and refresh their scientific and technological skills in the context of a new health and disability paradigm geared towards quality of life and equal opportunities for all.

– Society as a whole holds an in-depth ethical and political debate on the type of society we wish to build.

It is my belief that such a society will only be viable and desirable if we can find a way of respecting and promoting the rights of each and every person in it, free from all forms of discrimination or exclusion. This would give us a shared space to create, grow and enjoy full freedom.

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