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## Enabling law on disabilities: does “utter dependence” benefit all?

Sitting in joint session on 9 December 2021, the Chamber of Deputies unanimously approved a bill delegating the Government to review existing legislation on the subject of disabilities. The long-awaited bill is expected to integrate various policies concerning persons with disabilities (so far provided for in a variety of separate fields - healthcare, socio-sanitary, social, active labour market policies, education, etc.). At the same time, it aims at defining the statutory and ethical framework for the implementation of a reform under the National Recovery and Resilience Plan. In particular, it deals with a specific section of Mission 5 “Cohesion and social inclusion”, termed “Social infrastructures, families, communities and the not-for-profit sector”, financed with resources under the new Fund for Disabilities and non-self-sufficiency, for the purpose of ensuring the full implementation of the principles set out in the UN Convention on the Rights of Persons with Disabilities, ratified by Italy in 2009, pursuant to the EU Charter of Rights and the recent “Strategy for the Rights of Persons with Disabilities 2021-2030.” *It thus marks a high degree of attention on the part of the Italian Government, besides constituting a significant effort to lay the foundations for simplifying sensitive matters relating to the quality of life of persons with disabilities, such as access to services, disability assessment procedures and, more importantly, instruments for the development of a Life-long Project, which is to be the cornerstone, enabling the harmonisation of all measures within a sensible framework tailored to individual needs.* Therefore, while due credit must be given to this extraordinary initiative, it is equally necessary to highlight a number of critical aspects, which can and should be discussed as part of the process that, in the Government's intentions, will culminate in the adoption of one or more legislative decrees within the next twenty months, thereby completing the reorganisation and integration of the regulatory framework. These critical aspects include an underlying ambiguity in the inspiring principles. In fact, on the one hand, the extensive Quality of Life perspective is finally being acknowledged in all its facets, calling for a wide range of services and benefits, identified through a multidimensional assessment, combined with an evaluation process that reconciles the person's wishes, expectations and choices with the opportunities offered by the local context, carefully monitoring the presence of barriers and facilitators. On the other hand, starting with the name of the bill (Regulations for ensuring the independent living of persons with disabilities) an imbalance in favour of one of the aspects of Quality of Life, namely Independence (as is also the case in the aforementioned UN Convention), is immediately noticeable. While the fact of being independent undeniably promotes full self-expression, other equally decisive aspects, such as Wellbeing and Participation, should likewise be taken into account, prioritising each of these aspects on a case-by-case basis within the Life-long Project, without adopting an ideological approach, but rather a practical and truly personalised one. In fact,

**paradoxically, a condition of total Independence could for some people jeopardise both their well-being (physical, psychological and spiritual) and their communal and social sense of belonging.**

The methodological implications of this imbalance can also be seen in the explicit reference to so-called de-institutionalisation (also found in the NRRP). What is meant by this term? If it is understood as an affirmation of the right to life in contexts offering a wealth of opportunities and respect for rights and self-determination, then it would be only a matter of greater clarity. However, if it implies that all persons with disabilities should live alone, or in small numbers, in the context of residential flats, then there is a risk of disregarding the wide range of needs, requiring an equally wide range of housing solutions. *While it cannot be denied that, for many persons with disabilities, living in a flat or in an Adult Family Home offers the most appropriate form of support for their own Life-long Project, it seems equally evident that, for others, greater protective solutions are needed, in community contexts which, precisely because of their scale, provide a wide range of opportunities for*

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*relationships and wellbeing, hardly achievable within individual housing units. So maybe, instead of "de-institutionalisation" - a term that suggests some sort of combative distinctiveness - the term "appropriateness" could be used instead, since it is more consistent with the rationale of the Personalised Project, and equally capable of inspiring the necessary reforms. The legislative decree(s) that will ensue will surely serve to overcome the generic and potentially generalising aspects. It is hoped that the Government will launch a more extensive debate, involving not only voluntary organisations but also those long-standing institutions that have responded to the needs of persons with disabilities, even when welfare systems were not yet in place. Constructive dialogue will also make it possible to tackle authorisation and accreditation mechanisms that resulted in overly standardised care for persons with disabilities, thereby running the risk of depleting the rich diversity of generative charisms. Could this be the key to so-called de-institutionalisation? (\*)*Professor of Pedagogy at the Catholic University of the Sacred Heart and Head of the Development and Formation Area of Opera Don Orione

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